

1 July 2022

LEARNING FROM THE IMPACT OF COVID 19 TO BETTER PROMOTE THE RIGHTS AND DIGNITY OF OLDER PEOPLE



*Areas of concern
and the future
direction of work
promoting the
rights and dignity
of older people*

MOTIVATION



In the Summer of 2020 as the first major lockdown was beginning to ease, representatives of the Older People's Advocacy Alliance (OPAAL) and the National Coalition of Advocacy Schemes (C.A. Coalition) met online. The two organisations share a commitment to supporting a range of advocacy responses that are directed by local communities. They also share a concern about the impact of the Covid 19 pandemic and the restrictions that came about as a response to it. It was felt that the interests, dignity, and rights of older people had been given very little priority. This had impacted seriously on people's lives generally, but specifically on informal community advocacy and other supports. There was a particular concern around those living in care homes and the staff that supported them. It was agreed that the two organisations should collaborate on a short piece of research that would look at how older people across the country had been dealt with. Over the period when this research was being carried out, there were many changes in the restrictions and guidance from government. It was hoped that we could identify the main areas of concern and subsequently use that information to guide the future direction of the two organisations' work in promoting the rights and dignity of older people. Further information about OPAAL and C.A. Coalition can be found in the appendices to this document.

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PURPOSE

The purpose of this research was to assess the impact on older people and their advocates of the Covid 19 (Coronavirus) pandemic and the restrictions that came about as a response to it. There was concern as to how the crisis had impacted on people's lives generally, but specifically on informal community advocacy and other supports. From the outset, it was clear that people needed to talk about their experiences as part of a cathartic process. For many, the research interviews and questionnaires presented an opportunity to express their feelings of frustration, anger, loss as well as of those that they care about. As will be obvious from the main body of the report, these went far beyond advocacy. For this summary, we want to highlight some of the main points that we feel that advocates need to address in the years ahead. We also wish to take forward some of the positive factors that emerged from this unique period of crisis.

Ø The issue that aroused almost universal anger was the early recommendation that everyone over seventy should stay home during the pandemic. Most respondents considered the assumption that anyone in this age group was vulnerable was ageist. It ignored the important contributions that many people over seventy make to society. It was felt that there was a total disregard for the rights of individuals to self-determine and direct the course of their lives.

Ø In some cases, families had insisted that their elders isolate, and visiting was effectively suspended even in situations where it was possible within the restrictions prevailing at the time. This raised what has always been an issue in advocacy of the potential for people to unwittingly deprive others of choice out of genuine concern. This relates not just to the Coronavirus, but to many areas of life where there is a potential for conflict between 'best interests' and personal choice.

Ø For others, the absence of family is a permanent disadvantage, and this was felt keenly during the lockdowns. Many people rely on their peers for informal support and not being able to meet denied some people of an opportunity to see their friends or to assist them with tasks. Friendships do not receive the same recognition as blood relationships when it comes to being given information. This is particularly the case when concerned friends and informal advocates are treated as being of little importance when compared to relatives, even when the latter has little contact with the individual or knowledge of their wishes. In addition, those people without children or other family members are too often placed in particularly unacceptable situations without someone to fight their corner.

Ø Being unable to be with loved ones in their final days and hours had left a great deal of pain and, for some, a sense of guilt that had compounded their bereavement. The restrictions around funerals had meant that the usual mourning process was not allowed. This had a particularly profound impact on communities where there are important traditions around mourning.

Ø The importance of people's spirituality was also largely ignored with the suspension of visits to care homes stopping pastoral care visits. This has always been a largely neglected support at the best of times, but largely disappeared. People were also unable to worship in the community. Some people were able, if they had the means, to join worship online. However, for many older people the fellowship that is present in places of worship was not possible. A great deal of natural advocacy occurs in those environments, and this was not possible, leading to people becoming more isolated.

Ø The closure of community rooms in sheltered accommodation settings and the suspension of lunch clubs and other group activities also inhibited the potential of informal advocacy support. This has been felt particularly strongly within the Deaf community, in which communication and group solidarity are important issues.

Ø The initial evidence since the resumption of community activities seems to indicate that many people have lost confidence in mixing and, in some cases, leaving home at all. Many have lost mobility that was already precarious before the crisis and others are struggling with their mental health. Others are dealing with health issues that went undiagnosed during the lockdowns.

Ø At least one of the care homes involved in the research has subsequently closed due to financial and staffing issues. This meant that the people living there were forced to move to other settings after not being allowed out for most of the crisis.

Ø The whole issue of 'confidentiality' has thrown up many questions around the rights of older people. Staff are not allowed to disclose where people have been moved to when a home closes, or somebody is transferred from hospital to another setting. This means that it can be impossible for friends, neighbours, fellow worshippers to continue contact unless they have been named as next of kin. Another issue is the presumption that family members acting as interpreters have a conflict of interest can lead to people's needs not being understood or addressed.

Ø There was a strong sense of there being an absence of choice and a process of disempowerment in some care homes and health settings.

For the purpose of this research, informal advocacy is regarded as being an activity that is built on a community-based relationship and that is defined by the two people involved. Community could be either a locality or a community of shared interest, culture etc. The expression was introduced to distinguish this type of advocacy from both statutory and other more formal models of advocacy. Informal advocacy is about supporting people in being heard and treated with dignity and respect. It is a natural element of most of our lives. Informal advocacy relationships include the following:

- a) Citizen advocacy partnerships matched and developed by a Co-ordinator because of the partner being particularly isolated and at risk of discrimination and/or abuse.
- b) Relationships that have evolved through friendship, family and neighbourly connections.
- c) Relationships that evolve through caring responsibilities and where no conflict of interest is present.
- d) Relationships that evolve through peer support, self-advocacy and group advocacy.
- e) Informal advocacy that deals with an issue, but at a pace that is determined by individual need rather than a service model.

METHODOLOGY

The research was undertaken between December 2020 and June 2021. Evidence was gathered from 18 completed questionnaires and one focus event held via Zoom. 80% of those taking part in the survey were older people. Additional evidence was obtained via telephone by 2 activity coordinators working in different areas of the country.

Their work with older people is undertaken in a range of different venues including halls, extra care homes and community rooms in sheltered housing schemes. This allowed for some level of participation in the survey by 40 people. Two of the responses were submitted by other people due to access reasons. Three of the questionnaires were completed via telephone interviews.

The first issue that respondents were asked to comment on was how they felt about the blanket recommendation that everyone over 70 should stay at home during the pandemic. Several people expressed the view that this said a lot about perceptions of age, vulnerability, and the ability to make one's own choices. Most respondents considered the assumption that anyone aged seventy or over was vulnerable was ageist. It was pointed out that there are many people in their 70s who are working in both paid and unpaid capacities and making a big contribution to their local community and to society in general. Furthermore, many of them were physically fitter than some younger people. It was felt that there was a total disregard of the rights of individuals to self-determine and direct the course of their own lives. Several respondents felt that what had been a huge infringement of human rights that had gone largely unquestioned

Many respondents felt that the blanket approach had caused some of our most vulnerable and isolated people in society to become even more isolated. There was a feeling that the impact on mental health through people not having their usual social interaction was yet to be fully measured. Some of those participating in the research in its later stages commented on the fact that the lockdowns and restrictions had created fear in many people and when life is back to normal a lot of people will still be too scared to get back involved in their communities.

Several respondents explained how their role as carers for their grandchildren had been abruptly suspended in the original restrictions. This had caused great sadness in addition to presenting a challenge to the family's childcare arrangements. Although these restrictions were modified later, it still wasn't possible to see family members who were not in one's 'bubble'. Even when the restrictions eased, many people remained wary of visiting grandparents in case they transmitted the virus. Many respondents described how isolating and depressing they found the absence of direct contact with family members. One person described their feelings at that time as a type of bereavement. The impact of that separation was felt not just by individuals, but by their families too.

There was a general feeling of confusion as to exactly what people were 'allowed' to do, which persisted throughout the various stages of lockdown. One respondent living alone explained how they were worried and lonely, and this wasn't helped by the inaccessibility of information. The person is Deaf with BSL as a first language, and a lot of the Government TV appearances didn't have an interpreter. One respondent explained how, in the early stages, food had been a major worry because their GP had failed to put them on a priority list for food delivery. However, rescue was at hand thanks to the intervention of a younger neighbour. Some respondents detailed the confusion they felt about appointments at surgeries and hospitals and what help was available.

One respondent living in a care home explained how they were not in a position to question the decision and were prevented from meeting other people in the community lounge. Very specific issues were raised by respondents living in a sheltered housing scheme. There was a general feeling of frustration expressed and a feeling of being disempowered and deprived of choice. There was sadness at the loss of friendship and the company of neighbours. One respondent explained how a number of residents with memory problems had not been able to remember that they could not meet and continued to sit together outside. Several respondents expressed the view that, at the beginning of the pandemic, with so many unknowns, they felt that the recommendation was reasonable to try and protect as many people as possible. They recalled that at that stage, age was deemed to be a factor in the severity of the virus and its effects. However, they had not expected the lockdowns to last for as long as they had. As time went on, they began to question whether it was proportionate and effective. However, with hindsight, it was generally felt that an adult with mental capacity, who can understand and weigh up the risk should be able to make their own decisions.

IMPACT ON ABILITY TO SUPPORT OTHERS

The second issue that respondents addressed was that of whether the recommendation had prevented or inhibited them in any way from playing positive roles in caring for others in their community?

One person, living in a sheltered housing scheme, explained how she was prevented from assisting her neighbour, who had mobility problems, with small tasks and how they had been deprived of each other's company and mutual emotional support. Others explained how they would normally strive to help and support others in their scheme. This would include shopping and organising social events, and not being able to do this had made them feel anxious as they knew how it was even more important in these difficult times. The restrictions effectively prevented direct contact, and this had presented significant difficulty for those working with care homes. Telephone contact was possible, but many people did not have their own telephone and were dependent on staff taking a phone to their room. This was almost impossible when the residents were isolating in their rooms. In both care homes and housing schemes, it had not been possible to use Zoom on any significant scale as few people had smart phones. It might have been possible in some circumstances if staff had been able to provide technical help. However, they were already under greater pressure on their time than usual. In some housing schemes, the community rooms were all closed and locked and people were forbidden from going into each other's flats. This had made mutual support other than by telephone

almost impossible. Sadly, in some settings tensions were created due to different views on what the restrictions meant in reality and differing levels of compliance.

Many of the respondents said that their lives had changed overnight as they were forced to stay at home and unable, and in some cases afraid, to mix with others. Some advocates explained how their visits to people with learning disabilities and people with dementia living in care homes were cancelled. Their role had become almost impossible in the absence of face-to-face contact. Some advocates had been able, due to the nature of their working environment, to continue their work. However, it wasn't just one-to-one advocacy that was affected. Several respondents explained how group activities had to stop too and the organic mutual support that was obtained from these was brought to a halt. Others explained how they would normally strive to help and support others in their scheme. This would include shopping and organising social events, and not being able to do this had made them feel anxious as they knew how it was even more important in these difficult times.

An informal advocate explained that the main reason for their visits to care homes is to support peer quality assurance checks. They felt that the cancellation of visits meant that residents would have no contact with anyone other than members of staff and therefore would have no one to raise any issues of concern with if they were unhappy or even being treated in a way that was not appropriate.

One person detailed how they had been prevented from attending a friend's funeral and supporting the bereaved family during that difficult time. Similar experiences were recalled by numerous respondents. Another respondent explained that a regular source of mutual support comes from attending weekly worship at which most worshippers were over 70. Although some services were held on zoom and Youtube, it wasn't the same and many people can't access those services. Some people had gone into hospital during lockdown, with some ending up in care homes. It had not been possible to visit them or, in at least one case, even find which home they had been sent to. In 'normal' times, this information would have been shared after worship.

One respondent explained that they had been prevented from taking the Eucharist to people both in a local care home and to people's houses. Three of the six people that usually received the Eucharist had died, without the comfort of that spiritual support. In one area, a Memory Singers group for people with dementia and their carers had also been suspended. The fortnightly sessions were important for carers and cared for alike and provided an important opportunity for social interaction. Several members of the group had passed away without any opportunity to mark their passing. There was a sense that those making the restrictions had little understanding of the importance of support during the bereavement process or indeed of the spiritual needs of people generally.

On a more positive note, several respondents explained that they had been forced to develop new communication skills. It was felt that these could be utilised in the future to enhance the effectiveness of their role.

WORKING AROUND THE RESTRICTIONS

Respondents were next asked if they had been able to work around the absence of direct contact and, if so, how. Many of the respondents explained how important things such as Zoom, WhatsApp, Face Time and video calls had been. For most of them, these were very new and had been used reluctantly. However, in many circumstances they had at least enabled some degree of support for people and were described by some as an essential 'lifeline'. Some people had used them extensively, but others not at all. Some of those working in advocacy explained that many of the people that they would usually visit are non verbal and unable to use these methods. Having to use these with people who struggle with communication was very difficult and not everyone has the skills or equipment to be able to. Some respondents had greater success with facilitating meetings and services via Zoom and some in joining in events via YouTube. Again though, they were aware that they had not been able to reach everyone that they would in normal circumstances. Some groups had increased the number of mailings they sent out. However, in the early stages of the first lockdown there had been some wariness about this. The most common form of communication during the various lockdowns had been the telephone. Many respondents described how they had used common sense when it came to maintaining essential contact. The most vital of these had been getting shopping to family members and friends and neighbours who were required to stay at home. Most commonly, people would deliver shopping to either the garden gate or the main door of apartment blocks. In most circumstances, conversations were held at a safe distance. However, it was clear that this was easier in urban areas where there was better transport and a wider range of shops. One respondent living in a rural area explained the difficulties they experienced there. They had relied on somebody local to get them bits of food and somebody in the next village to go to the doctor's surgery and collect their prescriptions. Because they had to order food deliveries from the bigger supermarket chains, which were more expensive than the ones that they would normally use. Even then, they had to make a case to be put on a priority delivery list. They had to make up the difference in costs from their heating budget. They felt that some supermarkets had wasted no time in putting up prices of goods. They felt that they owed their survival to the kindness of the two people who had gone to their aid.

Another example of creativity came from a sheltered housing scheme where the community room had been closed in compliance with the restrictions. The self-employed chef, who had provided a midday meal for twenty plus residents as a private enterprise for many years continued to provide a substantial two course lunch. He arranged for the meals to be taken on trolleys by lift and delivered to outside residents' rooms.

DENIAL OF DIRECT CONTACT

The next area that the survey looked at was people's experience of either directly being prevented from visiting loved ones in residential care, supported living, hospital and other settings, or of witnessing others being prevented?

This was the aspect of the survey that aroused the most passionate response. It was pointed out that it was highly unlikely that people were given any choice as to whether they would prefer the risk posed by Covid to not being allowed to see their families. For those with dementia the choice had been completely denied them. One respondent explained how he was not allowed to visit their partner whom they had previously visited daily. This care home resident had subsequently forgotten who their partner was and the mental health of them both had suffered. Another respondent described how they were suddenly transported from being an active person looking after grandchildren to this old person who had to be protected from seeing them. It was felt that people get little choice as it is, but what little there was had been taken away. One person explained how they couldn't visit their deaf friend in a care home. The person didn't have access to Facetime or any device to keep in touch other than text message with her friends. There was the additional problem that the staff couldn't use British Sign Language (BSL).

Several respondents recounted situations of people dying alone in hospitals and nursing homes. Many, but by no means all of them had dementia. Being in hospital can be traumatic at the best of times, but having visitors makes a huge difference as to how people cope. One advocate explained how they were the main support for somebody in their eighties who has learning difficulties. The person had been in hospital for most of last year due to various health conditions, and during the lockdowns the advocate was not able to go in and visit. This caused the person to become very distressed, which in turn caused issues with their health care because there was nobody to help them understand what the medical professionals were telling them. It also led to the label of 'challenging behaviour' being applied as the staff did not know the best ways to support and communicate with them.

Another respondent described how a relative had a catastrophic fall at home in August 2020 and was eventually hospitalised four days later after several traumatic days of paramedics being called out etc. The family had no choice but to leave personal belongings such as clean clothing, toiletries etc with security at the front door of the hospital. When they realised that discharge was imminent, they prepared a lengthy report on behalf of family inform any discharge planning and handed it to ward staff at the hospital entrance. The family appreciated that they would not be able to attend assessments but wanted to ensure that they could do as much as they could to advocate for their relative and explain the background to their care needs. However, they were never even asked to attend a virtual assessment. The relative was disorientated and very confused following the fall and any mobile phone conversations were unpredictable. Consequently, it was impossible to get a clear picture of what the situation was, and this was compounded by the fact that there was a lot of repetition with a different member of staff was on duty each time the family rang the ward.

Many of the respondents referred to the fact that the distress did not end when people had died. There were so many other restrictions that prevented the grieving process from taking its usual course. There were long delays in sorting funerals and then rigid limits on the number of people allowed to attend ceremonies and wakes left many feeling that they had let their loved ones down. The bereaved were unable to meet to console one another and restrictions to travel compounded these difficulties. In many cases, the 'bubbles' concept had caused division in some families by preventing visits from other relatives. Once again, there was a feeling that some of the restrictions had been drawn up by people with little understanding of these issues.

Many of the respondents expressed amazement that the issue of visitors to homes was so far down the list of those to be addressed. It was felt that ensuring that visits could be resumed safely with the right precautions and equipment should have been prioritised for care homes. As the restrictions eased in late Spring of 2021, some group activities began to resume, and this was possible through adherence to Covid safe practice including social distancing. Visits to care homes became possible through the use of 'pods'. However, many people found that both those and window visits could be more distressing for relatives who were confused and couldn't understand why they couldn't touch. Some people thought that these arrangements were worse than not visiting at all. One respondent expressed something that has been heard a lot in the past nearly eighteen months. They explained how their parent had spent the last year of their life in nursing home after a severe stroke before dying in October 2019. They were relieved that they had died before COVID as they would not have understood why the family couldn't visit and would have been traumatised and felt abandoned by his loved ones, most especially by their partner who used to visit every day.

For those living in their own homes, the most contact that they could have with loved ones was from the bottom of a path or a 'safe' distance from the front door as shopping was dropped off. It was not possible for them to go in and perform household tasks that they would have done before Covid 19. Several advocates explained how their role had changed enormously. Two-thirds of communication is non-verbal, and not being able to see the person prevents this, making the advocate's role very difficult if not impossible.

THE IMPACT OF THE ABSENCE OF LOVED ONES ON MENTAL AND/OR PHYSICAL WELLBEING

The research then looked at the impact the absence of loved ones had, or is having, on mental health and/or physical wellbeing? Some respondents commented on the impact on basic social skills and confidence with people deprived of basic interaction and conversation. Some described the frustration of not being able to sit down with loved ones with a cup of tea or to eat a meal together. The closure of day services had created a great deal of loneliness, as mixing at these would normally be therapeutic. In many sheltered housing schemes, the closure of communal rooms prevented any opportunity for social interactions. The closest that many people got to the latter was exchanging greetings from their windows during the Thursday evening applause for the NHS.

A source of distress for many was not being able to see children and grandchildren and particularly missing key stages in their lives such as first words and walking. More than one respondent expressed the feeling that the absence of family and friends had left them feeling so unhappy not seeing family and friends that they would rather have taken the risk of catching the virus. One person related the story of a friend who had cancer receiving their letter defining them as vulnerable. This had caused confusion in the first instance and then distress at the thought of not seeing close family members again.

One of the most eloquent responses to this aspect of the research came from a conversation with a Care Home manager. They explained that the impact on residents' physical and mental well-being had been substantial with a massive deterioration in health. People's moods changed in the absence of loved ones, and this had an impact on their desire to eat and drink. This led in some cases to weight loss and associated skin problems through not wanting to take fluids. It was necessary to have the input of Dieticians and the Community Mental Health Team. One resident had been very well before lockdown with regular family visits and trips out. These suddenly had to stop, and it was felt that this led to

a sharp decline in their physical and mental well-being and subsequent death. It was pointed out that Covid 19 had an impact far beyond just contracting the virus.

One respondent explained how they had been prevented from visiting their friend in a care home due to a combination of having to shield themselves and visiting restrictions. The friend has dementia, and the condition will have deteriorated significantly since March 2020, and it was feared that their relationship will have been forgotten. Others pointed out that a lot of residents don't get many visitors even when there isn't a virus, and so the impact wasn't as great on them. One respondent thought that their partner had improved due to the staff giving more one-to-one support. However, residents were also not allowed to go out and so it hadn't been possible to take them out on trips or to get fresh air.

There was the general consensus that the ban on visitors had been very damaging. Of course, the degree varied between individuals and specific circumstances. An example was given of a relative who prior to the first lockdown was able, with mobility aids, to use public transport to visit a friend, go shopping and attend church. Once the first lockdown was announced, family members stopped entering their home. It was felt that this had a profound effect, physically and psychologically in terms of them welcoming visitors into their home, seeing grandchildren and great grandchildren, going out into the community etc. From September 2020, following a fall at home, subsequent hospitalisation and discharge with formal care in place, the family decided that key individuals would continue to go into their home to provide support and much needed contact and company. This was agreed with full consent of the person involved, who is now much more dependent than they were previously. It was felt that this was a judgement about risk versus mental health and well-being. Several respondents referred to how people had routine hospital appointments cancelled and not been able to see their GPs. Some have also been too afraid to go to their doctors or hospital in case they caught covid there. It was felt by many that the most vulnerable in society were once again feeling forgotten about.

A number of respondents explained how greatly they had missed physical contact. This ranged from the exchange of a smile or giving somebody a hug up to taking them out for the day for a change of scenery. The loss of the ability to worship and sing in services and ceremonies had really impacted on those for whom this was a regular source of comfort and emotional support. The impact of this was both physical and mental. For people with loved ones with dementia, the impact on mental health and cognitive abilities had been devastating in many cases. However, the impact on mobility due to lack of activity and exercise had taken its toll also. This applied almost as much to informal advocates

and carers as it did those whom they would normally support. Concern was expressed by many that some people that had struggled with their mobility prior to the lockdowns would possibly never regain the confidence to leave their homes. Even people not living alone found the effects of not seeing family and friends particularly difficult over the winter months. Many people had experienced personal loss during the lockdowns and had been prevented from going through the normal bereavement process and closure and this had affected them greatly. It was felt that all these factors had led to a loss of independence, dignity, choice and control. Several respondents expressed the view that their motivation, stamina and confidence had been affected. For some of those living with partners, the lockdowns had brought other tensions, and particularly where one or both were living with long term physical and mental health issues. There had been little opportunity for time alone which, in some cases, had made some worries and concerns seem worse.

As the research was being undertaken, several changes were made to the restrictions affecting older people in general and those in residential care in particular. Window and pod visits were allowed which was a great relief to many. However, people were unable to touch and had to stay behind a screen. This could be distressing for both parties. Some relatives had preferred not to visit in these circumstances as they felt that they were doing more harm than good. Another issue was that people have to schedule a visit and vacancies on the visiting rotas often don't fit in with work shifts, caring responsibilities etc. One respondent residing in a nursing home explained how people who would normally have visited phoned initially, but that soon stopped. People had drifted off and subsequently lost contact, the gap in time made resuming contact difficult. They felt that the procedures currently in place made people more reluctant to visit.

Two respondents explained how there were additional barriers for Deaf people. Not being able to use mobile phones limits what they can do. Although many in the Deaf community are able to keep in touch using technology, it was not the same as personal contact. However, many people are not able to use the internet and others don't hear very well on the telephone, and so a lack of face-to-face socialising has been particularly negative for them. One person described the distress sometimes caused if a call was missed because they were out of the room.

Respondents were then asked if they felt that there was, and/or subsequently has been, any effort to provide care homes with the support and equipment that would make visiting safe. Responses indicated that the picture had varied across the country and this variation equally applied to the most recent changes with easing of restrictions. Several respondents expressed the view that the issue of the right of homes to prevent visits had not been seriously challenged in earlier situations when other viruses had affected homes. It was felt that the idea of providing personal protective equipment had not been addressed years ago. It was felt by many that there was a latent disregard for the rights of people in care, with a prevalent culture of avoiding risk and consequently blame or litigation rather than an emphasis on rights and dignity.

Several respondents reported that although some sort of support was available from local authorities, it was not provided quickly enough. One home manager felt that the guidance for a grant from the Council was quite straightforward unlike that for the Department of Health. They felt that the guidance from the latter was unclear and didn't seem to reflect the differences of building types when it came to the construction of pods. It was pointed out that although many larger care homes were of relatively modern construction, others were adapted Edwardian and Victorian buildings. There was a feeling from some respondents that care homes had been left to do their own thing. Even for bigger organisations the additional costs of extra cleaning etc presented challenges.

One respondent explained how there was a comprehensive Local Council report for Care Homes in their area which stated there that there was funding for extra support and equipment, however their website stated (Care Home Implementation Status) that there was a shortage of specialist equipment. e.g., specialist mattresses and beds, testing equipment as well as an understaffing problem.

Most respondents accepted that the nature of the Covid crisis presented unique challenges and so it was generally accepted that nobody could have made all the right decisions. However, it was largely felt that even when the situation had begun to improve, care homes and the rights of people living in them seemed to be of very low priority. Many respondents felt that the attitudes that led to the initial failures had long term effects of attitude, and this applied, for instance, to the availability of tests. Some respondents felt that that care homes have all the necessary equipment to keep staff and residents safe. There was also a general acceptance that nowhere would be totally safe, an acknowledgment that urgent decisions about safety would sometimes need to be made. However, it was felt that these should reflect respect for the rights and dignity of the people affected.

It was here that there was a feeling that nobody had asked care home staff what they thought about the way forward. If they had, things might have been done better. Although the NHS received the acclamation, there was little recognition of how hard care staff were working, and continued to work, to keep people safe.

INVOLVING FAMILY AND FRIENDS

Next, respondents were asked what efforts care homes had made, and were making, to involve families and friends as much as possible during the lockdowns and restrictions. One care home manager explained that they had tried to be as flexible and safe as possible within the specified restrictions. During the period when visits were not possible, staff utilised their personal phones and iPads to facilitate such things as facetime and WhatsApp to keep in contact with families. Window visits were arranged when the guidance allowed these. The home had been able to update its communications thanks to a grant from the local authority that allowed it to purchase an iPad. This meant that a regular sing song could be held via Zoom with neighbours joining in. However, this was not the experience everywhere. One respondent felt that little had been done to assist the care homes, with some unable to facilitate any type of video calls due to lack of appropriate devices. There were several examples quoted from across the country of staff using their own mobile phones to facilitate contact. Many respondents felt that at the beginning of the pandemic family members were really excluded from communicating with their loved ones, and that it took a long time for things such as window visits to be set up. Even then it was a struggle with a lot of the care staff being off sick or isolating. The availability of staff was a major factor in how easy or otherwise it was to communicate.

Several respondents provided details of other lines of communication that were used. These include family members being involved via telephone calls to update them and linking via such things as WhatsApp to share photographs, for example from activities like birthday teas etc in care homes. One respondent explained how the care home that his partner was in have kept in touch by email in addition to weekly zoom conferences to discuss the care programme. One respondent felt that although families were informed, residents weren't. When the staff had tried to inform them what was happening, they didn't do it very sensitively. One Deaf respondent explained how impossible they had found it to keep in touch.

Overall, it was felt that the response varied from home to home, with some making greater effort than others. Several respondents felt that friends and informal advocates had greater difficulty keeping in touch than family members did. It was suggested that the guidance from Government was very poor.

This was not helped by constant revisions to the restrictions and guidance. The pace at which such things as window and pod visits resumed varied from home to home. As referred to earlier in this report, even where these exist, they are not always felt to be suitable or widely used.

A number of respondents living in sheltered accommodation explained how their community rooms, kitchens and activities had been closed or suspended at the beginning of the first lockdown. Some of these have still not been re-opened at the time of writing this report. There is some concern that the Covid crisis is being used to conceal reductions in services.

DO NOT ATTEMPT RESUSCITATION ORDERS

Respondents were asked if loved ones been affected by Do Not Attempt Resuscitation (DNAR) orders on residents at some care homes and/or restrictions on access to hospital. One care home manager explained that this had not been a problem for them, as they had spoken to families to help ascertain people's wishes. Other people were able to clearly state their wishes for themselves. In addition, there had been input from a Geriatrician. One person who had power of attorney had successfully had a DNAR removed from the person's care plan before the epidemic. Two informal advocates reported that they had successfully challenged a total of five DNARs, one of these being on a person with learning difficulties who clearly hadn't been consulted. Another advocate explained how a person with learning difficulties that they knew was put on a DNAR along with other people when there was a Covid outbreak in the hospital ward. Others reported that the ban on visitors had prevented them from raising these issues on behalf of any residents due to the no visitor restriction.

One respondent described how a relative who had lived in a care home for many years had become unwell and subsequently passed away in the home in spring 2020. Medication had been prescribed over the telephone without the GP visiting the patient. The respondent felt that everyone has the right to be seen by a clinician when they are unwell.

The next area that respondents were asked to comment on was the suspension of regular oversight procedures for care homes by the statutory regulating body, the Care Quality Commission (CQC), and the Local Government and Social Care Ombudsman. The response to this was mixed with one care home manager explaining that in their area although physical visits ceased, the monitoring still went on virtually. They felt that this was right approach in the early uncertain days of the pandemic. The Manager went on to report that they had received help from CQC with interpreting the guidance which had helped in training the staff team. Respondents In some areas reported that, as time went on, some visits did take place in certain circumstances. One respondent expressed the view that it was right in the circumstances prevailing at the time of the first lockdown then suspend visits. However, they thought that when the situation improved there should be thorough investigations and inspections along with the strengthening of the oversight bodies. They also felt that a separate body should look at why homes have closed in recent years.

One advocate explained how on one occasion they had felt the need to report concerns to CQC about the treatment of residents. A telephone interview was carried out by them with the home manager, but they felt that without face-to-face contact it would have been difficult to discuss the issues that had been reported without contact with other staff members and residents. More than a third of respondents were very unhappy with the decision to suspend visits at such a crucial time. There was a feeling that with families and friends no longer able to visit and provide the informal ears and eyes they do every time they visit, these statutory interventions were even more vital. One Advocacy Worker explained their organisation's role in visiting care providers on behalf of the local authority to complete quality assurance questionnaires with both residents and providers. The information is fed back to the contracts and monitoring section to help inform their reports. In March 2020, all activities had been suspended. An offer to continue this role remotely was not taken up. However, following discussions, the service did resume in January 2021 using different ways contact people i.e., by post, digitally and by telephone. Most respondents were not aware whether oversight procedures had been resumed.

The research next looked at the ways in which the roles of care staff both in residential care and in-home care had changed since the crisis began. There were different views expressed with the majority reflecting positively on care staff. However, more than one person expressed some notes of caution about staff confusing their roles. They felt that the belief that care workers could become 'families' was admirable but was in fact badly mistaken and could in some cases be insensitive and inappropriate. They felt that although Care staff can be companions and friends, they were not family. As with advocacy, the individual's choice was of key importance. It was also felt that care staff had had insufficient time to fulfil their own roles without trying to take on others. One person living in a nursing home observed that one or two staff have been promoted because of less competition for jobs. They felt that some staff had been working harder throughout the crisis and missing food breaks to help out. Several respondents felt that it was hard to generalise about this as some care staff had been seriously concerned about the lack of any outside contact for the residents and gone above and beyond their duty by contacting them directly to tell them what is happening in the homes. Others just did as the management told them and did not appear to be really bothered about the damage that isolation was doing to residents. Although some staff and shown great sympathy for excluded family others seemed to see them purely as potential infection sources. Some respondents felt that having been unable to visit made it difficult to say how roles had changed but felt that a lot was expected of staff considering how little they were paid. The downside to carers' roles having become so diverse was the lack of one-to-one time they had to give to residents. Most respondents expressed their appreciation of the role of care workers during the crisis. Many had used skills they had not been part of their job description. One person described how a carer who used to be a hairdresser had done residents hair during the lockdowns and isolation. There was appreciation of the fact that they had not been given the right PPE but were still expected to go into work putting themselves and their loved ones at home in danger. Several respondents described how in some cases staff had stayed in the care home in order to reduce risk to either their family or residents. In the worst circumstances, workers had to see people they had been close to pass away in the absence of their family members. They were required to take on a role that would ideally have been undertaken by their loved ones. A poem on the wall of a visitors' pod in a care home in Liverpool written by the twelve-year-old child of the manager expressed the feelings of many workers and their families:

Even without the blood,
We will act as a family should,
We will be here for you,
And do what families do.

One care home manager explained how the crisis had affected their small, family-run home. The workload had inevitably increased significantly, with staff having to undertake some tasks that were not previously considered to be part of their role. Job roles were subject to constant change and bringing with it added pressures during a stressful period. The staff worked as a team and took on extra shifts to help avoid engaging agency staff. They were lucky to have owners that recognised the importance of supporting staff and offering incentives and bonuses. They felt that the bonds between staff and residents had grown stronger with staff taking on some of the roles that family members and other visitors would normally and ideally. There was a sense of shared experience and solidarity that they felt augured well for the future. People living in the same street as the home had also rallied around and began to take an interest in the home and the lives of the people living and working in it. Strong links had long existed with the local community advocacy project, and this facilitated their support. The weekly Thursday evening applause was focussed on the home, with neighbours standing either outside the home or at their garden gates. Several other initiatives were undertaken that provided practical help and a sense of solidarity.

There was a strong feeling expressed by almost all respondents that both residential and domiciliary care staff had huge responsibility above and beyond their job descriptions. They have never really received the recognition that they deserve in training, pay and conditions. They faced increased anxieties regarding their health, that of the people they care for and their own families together with their job security and being paid if having to self-isolate or take sick leave. It was hoped that the work of many of these people might be properly recognised in the future.

[i] Poem by Riley Vickerstaffe, aged 12

Respondents were asked what was the personal impact of knowing that their and/or others loved ones were experiencing end of life alone in hospitals or care homes? Several expressed gratitude for the care from nursing and physiotherapy staff in the care home which had ensured that their loved ones were not totally alone. A few people were able to link via Zoom and one person described how a virtual visit was made memorable for their partner by the staff feeding chocolate to them at their prompting. Some respondents referred to some of the fear that was around at the beginning of the crisis and how this had affected people. Many had been frightened about visiting their loved ones in case they inadvertently passed on the virus. This inevitably impacted on the quality of any visits that were possible.

The loss was not one sided and was not all about death. One resident explained how one member of staff at the home had not been around for two months and had a particularly bad case of Covid. They had been sorely missed but nobody had explained where they were, this had led to a sense of loss among some of the residents. One Deaf respondent detailed their experiences during a hospital appointment when they needed urgent surgery in the latter stages of the crisis. The BSL interpreter didn't turn up, so the hospital wanted to cancel the procedure. They wouldn't consider an alternative such as reading the consent form and it was a very difficult time. This led to the person reflecting on how it must feel like to be a Deaf person on a Covid ward with everyone wearing masks and unable to communicate.

Most respondents knew somebody that had died in either hospital or a care home. The fact that they were not, at some stages of the crisis, to have anyone with them other than staff had left a strong feeling of guilt and loss. The rules around the burial and cremation of people that had died of Covid were very rigid and so funeral arrangements had been extremely restrictive. Even when people had died of other illnesses and conditions, the restrictions were very tight. Consequently, the sense of loss was heightened by not being able to say goodbye properly. In many cases of larger families, not all immediate family were able to attend leading to some difficult decisions and tensions. There was an almost unanimous view that the impact of these factors on people's mental health and well-being was still impossible to fully quantify. There was a sense that compassion and an understanding of the impact on people's mental health were not uppermost in the minds of people making the rules and guidance.

It was clear from the research that there are several key areas that we can be focussed on in the future. The learning gained from these past two years needs to be used to improve the future for all of us.

Ø The experiences referred to above have helped us to identify some of the things that really matter to people and to the quality of their lives. This will help to focus the work of advocates in the years ahead.

Ø The sense of anger felt by many older people needs to be harnessed to campaign for better future.

Ø Irrespective of Covid 19, there should always have been Personal Protective Equipment (PPE) available for staff and visitors to care homes and other settings. It is not unusual for viruses to hit care settings and for visits to be suspended and this not right. We need to ensure that this should only ever happen after a process of consultation with those involved.

Ø Now that external oversight has been resumed, it is important that the vital role that friends, family and informal advocates can play be recognised. This can only benefit those processes and make them more effective.

Ø The role that both residential and domiciliary care staff can play in identifying advocacy needs and facilitating access to appropriate support groups should be recognised. Although care staff can have a conflict of interest in some circumstances, this does not mean that they cannot contribute to the advocacy process.

Ø There were some wonderful examples of people in the local community relating for the first time to the people living and working in care homes during the crisis. This goodwill could be built on in the future to encourage people to contribute as volunteer advocates and visitors.

Ø Some of the engagement with neighbours that emerged during the crisis broke boundaries between generations. This process needs to be carried forward and facilitated to greater mutual awareness and willingness to engage on each other's behalf across the generations. It can help to protect and promote the rights and dignity of people, and especially of those without children or other close family.

Ø Some new telephone support services evolved out of necessity during the crisis and proved to be useful in connecting people. This type of support needs to be developed further and particularly in the light of some of the loss of mobility and confidence that has resulted from the lockdowns and the crisis generally.

Ø New information technology skills were learnt during the crisis that were very useful in maintaining, and in some cases beginning, contact between people. Although these tools are neither appropriate nor accessible for many of the people that advocacy organisations support, they are useful to some. They are very useful in facilitating 'out of hours' support to volunteers and in scheduling meetings with professionals.

References to further reading:

Developing Community Based Approaches to 'Advocacy' - Advocacy Plus - a generic approach to protecting and promoting human rights and to building more inclusive communities.

NCAS 2015

About OPAAL:

We're the only UK based national organisation supporting independent advocacy services for older people. More information can be found at www.opaal.org.uk

About NCAS:

The National Coalition of Advocacy Schemes (C.A. Coalition) is an informal network of local organisations that are involved in the provision of a range of different models of advocacy across client groups. It was established with the primary aim of protecting and promoting informal volunteer citizen advocacy within local communities. For further information, please visit www.advocacynatcoalition.org.uk

Grateful thanks to Joe Monaghan and Molly Hardwick for undertaking the research and drafting the report.

