

## RESCARE SPOTLIGHT ON:

### Covid-19 pandemic emergency legislation has an impact on the whole family

#### **The 2020 Coronavirus Act**

Clearly it is important for everybody in this country to be protected from infection during this crisis, but for our members, family contact and the maintenance of good quality care is also of vital importance. This means that during the last few months at Rescare we have had an urgent need to consider the legislation enacted due to the Covid pandemic, the subsequent official guidance and its effect on people with learning disabilities and their families.

The Coronavirus Act 2020 was enacted in March 25<sup>th</sup> and renewed in September. It comprises:

- Main Provisions
- Detailed Schedules, one for every affected sector.

The Schedules can be seen to drive the governmental Guidance to organisations and individuals, BUT we find the guidance which is important to our members has continued to change as circumstances and the patterns of infection change

For instance:

- the Guidance on '*policies for visiting arrangements in care homes*'<sup>1</sup> was updated on 15<sup>th</sup> October;
- the Guidance '*for supported living*'<sup>2</sup> was updated on 12<sup>th</sup> October;
- The Guidance on '*the Mental Capacity Act and deprivation of liberty safeguards (DoLS) during the coronavirus pandemic*'<sup>3</sup> was updated 15<sup>th</sup> October.

These may well all be updated again but the web links should always go to the latest version at. <https://www.legislation.gov.uk> [Coronavirus Act 2020](#)

#### **Visits during the Second Lockdown**

Vital to our members, an extra tier of Guidance<sup>4</sup> was published on 1<sup>st</sup> November, describing amendments to be implemented with 'Lockdown 2' on the 5<sup>th</sup> of that month.

Section 10 of the Guidance stated: ". *Visiting relatives in care homes Guidance on care home visits will be published ahead of Thursday. For now, you should follow existing guidance*"

However the new guidance arrived - not in the usual format, but as a press release<sup>5</sup> *new guidance to support safe care home visits during lockdown:* It read "*Care homes will be encouraged and supported to provide safe visiting opportunities as new national restrictions come into effect*".

The suggestions on how visits are to be made possible comprise visiting areas/pods with floor to ceiling screens, window visits and outdoor visits. Overall, it does seem to us that care

providers are having to judge their own situations and make their own local decisions when there are many suggestions but few firm guidelines. This is as confusing for families as it is for those being cared for.

It would seem a monumental task for a parent or carer to understand what guidance they (the carers), local authorities, care and support providers, and accommodation providers are being given, and the guidance has continued to change. We are finding that in terms of the care actually delivered, it seems to have come down to a matter of 'interpretation' and 'improvisation' by many service providers, sometimes by organisation managements, sometimes by individual care and support workers. This is important because overall restrictions on visiting have caused hardship and distress.

A Guardian article<sup>6</sup> by Madeleine Cowley describes this well. A former trustee of the charity Hft and mother of a 40 year-old son with severe learning disabilities living in a residential home she has had only had limited contact with her son since March. She considers herself lucky that her son understands and enjoys communicating using video technology; but worries for others, *"Other families have faced much greater challenges than ours. Some have not been able to see their relatives at all since the start of the spring lockdown. One [mother] told me: 'He must think that I've died, like his father.'* Others decided to bring their child back to the family home for the duration of the first lockdown, finding themselves faced with months of caring with no support." Access: [www.theguardian.com/society/2020/nov/04](http://www.theguardian.com/society/2020/nov/04)

In addition on the basis of calls to Rescare's helpline, we are aware that many of the suggested visiting safeguards are already in use and staff in many settings are doing their best. However things can be far from perfect. One client reported that their relative with learning disabilities was particularly distressed at being separated from her visitors by a Perspex screen, whose purpose she could not understand, and which additionally made hearing visitors difficult and confusing.

### **Digital exclusion.**

Even before COVID, there was much research into the 'digital divide' between those who have access to digital technology and understand it, and those who don't have access and/or cannot use it. We are acutely aware that some of Rescare's members are not 'online'; and that some of people whom our members care for have intellectual impairments that preclude the use of information technology. During the pandemic they have been excluded from activities and communications based on technologies such as Zoom.

In fact Rescare's latest AGM had to be held using video-conferencing software, and inevitably excluded some people. It also made us acutely aware of the additional difficulties that a slow broadband connection or poor mobile signal can cause. It seems the Covid pandemic has accelerated a reliance on technology for example remote GP consultations, which has worsened pre-existing health inequalities and identified a massive overlap between digital exclusion and social exclusion<sup>7</sup>

A report<sup>8</sup> into the effect of the Covid crisis on people with learning disabilities, commissioned for the Department of Health and Social Care states *"We have also seen people isolated and now digitally excluded as the world embraces technology which people can find inaccessible, confusing or unaffordable."*

### **Guidance on supported living**

With regard to care in settings other than care homes (upon which there has been the main media focus), I can speak from personal experience about supported living, having a son on the autistic spectrum who has a tenancy in a block of ten flats. In the guidance on supported living, in all its versions, the focus has been on combining continuity of service with risk management. It says:

*“Supported living services involve tenure rights – renting or ownership - with associated occupancy rights. Some provide regulated ‘personal care’ and others support daily living activities such as help with shopping, food preparation, access to the community or a combination of both. In some supported living models, it is not possible to defer the care and/or support provided to another day without putting people at risk of harm. It is therefore vital that these services are maintained... Given the different types of supported living and the associated care, support and help for people living there, this guidance cannot be specific to individual locations, and local managers should use it to develop their own specific ways of working to protect people’s wellbeing and minimise risks.”*

The support workers looking after my son did what (we think) they were being advised to do: be sensible and flexible. They also followed guidance and liaised with us, his parents. With an amusing degree of understatement, the author of the guidance states, *“Some people being supported may lack capacity to understand and make decisions based on advice about the COVID-19 pandemic. It is important that all steps are taken to communicate information with people in a way that they are most likely to be able to understand. For example, autistic people and people with learning disabilities, dementia, or mental ill health may have difficulties with understanding complex instructions or forget them”*. Understanding and compliance were indeed at major issues; to which I would add high levels of anxiety amongst higher-functioning individuals facing ‘information overload’

### **Caring for someone with learning disabilities in the family home**

On the basis of some calls to our helpline and of some press and social media coverage, a hidden crisis has developed amongst parents and people caring for someone with learning disabilities in the family home. Not only have some services been made unavailable because their provision would contravene guidance, or because staff were unavailable, but latest research is suggesting that local authorities have taken the opportunity to make wider cuts in service provision. This is very serious for families who can well be faced with other Covid related difficulties such as illness, loss of income. In August, a Mencap survey<sup>9</sup> found that: 69% people with a learning disability had their social care cut or reduced, 79% family carers have been forced to take on more unpaid care for their family member and 72% of families are scared of future cuts to social care.

A similar survey by the Disabled Children’s Partnership found parents reporting an increased caring load, both for themselves and for their disabled children’s siblings; parents feeling exhausted, stressed, anxious and abandoned by society; in many cases the support that families previously received now halted; and at a time when respite might have been most needed, complaints that it was unavailable. Rescare is especially worried that local authorities, having had their obligations under the Care Act diluted by the Coronavirus Act<sup>10</sup> seem to be failing to undertake adequate reviews and assessment of need, and denying carers adequate opportunity to participate in decisions or challenge them. One further sad consequence of deficiencies in suitable provision is that emergency referrals and placements to NHS Assessment and Treatment Units (ATUs) have recently risen sharply.<sup>11</sup> . We think this will further stretch these facilities and may well not be best suited meet desperate need.

### **Taskforce Advisory Group**

At the end of September, the 'Social Care Sector Covid-19 Taskforce', commissioned by the Department of Health and Social Care to describe lessons learnt from the first six months of the pandemic and to look ahead to the coming winter, published its final report.

The first two recommendations of the Taskforce's Advisory Group on People with Learning Disabilities and Autistic People<sup>12</sup> related to the failure to communicate guidance and the failure to meet identified eligible needs: It says (and we agree that)

*"Our highest priority recommendations are that government should:*

- Commit to accessible guidance and communications for people with learning disabilities and autistic people, and their families, being issued with or very soon after all future COVID-19 guidance...*
- Restore, maintain and adapt the support for individuals and families already assessed as having eligible needs..."*

It remains to be seen how many of its recommendations can be implemented with the arrival of winter and the second lockdown.

### **The Human Rights Perspective**

Meantime there have been a number of important pronouncements.

Mr Justice Hayden, Vice-President of the Court of Protection circulated a memo setting out his analysis *that regulations do permit contact with relatives and friends, and that visits are lawful i.e. that visits are legal.* This opinion was given in response to the then in-situ 'tier 2 & 3' guidance from the Department of Health and Social Care, recommending that that visiting should be stopped, apart from in exceptional circumstances such as the end of life; guidance which in many areas had triggered blanket bans on visiting.<sup>13</sup> He expressed concerns about the infringement of human rights (especially around Article 8 of the European Convention on Human Rights, the right to respect for one's private and family life).

This was reinforced by the Association of Directors of Adult Social Services in a document entitled 'Infection Control, Essential Visiting and Human Rights in Care Homes'<sup>14</sup>. There is concern not just about the legality but also the impact of blanket measures. This stated : *"When restrictions were first were introduced ... they were perceived as time-limited, and there seemed to be a general acceptance of policies excluding visitors from care homes...However, the impact of not seeing family and friends over a prolonged period (and with the prospect of this continuing for months to come) has seen that general acceptance break down. This in turn has highlighted the need to balance the safety afforded by controlling infection with the rights of the individual and the detrimental effect on people's emotional, mental and physical wellbeing of not having contact with people they need and the outside world."*

Public concern has been building reflected by increased media focus on the issue, MPs have been reading from distressed constituents' letters in the Houses of Parliament and as we go to press we note that newspapers and other media are taking up the issue. For example Janice Turner in a powerful article argues that care home visits are a basic human right.<sup>15</sup>

Finally the Minister for Care, Helen Whately announced on Friday 13<sup>th</sup> Nov. the start of a month long-pilot scheme in three counties, to assess the viability of allowing one person to make care home visits to a relative, under 'key visitor' status with special precautionary and testing measures in place.

This is a most welcome development, but many of our members believe this is too little and much too late; we must all await developments.

### **In Summary**

- The Covid-19 pandemic has thrown into sharp relief many of the ambiguities and inconsistencies inherent in the provision of care and support for people and families coping with learning disability
- During the pandemic legislation and guidance have been moving at a dizzying pace
- Implementation of guidance has not followed a uniform pattern
- Families find themselves left to negotiate for access and care on an individual basis with only a vague outline of the exact legal situation to help them.
- Providers themselves are in a difficult and un-precedented situation
- There is growing concern about human rights and the impact of blanket visiting restrictions.
- At Rescare we must continue to press for clarification of entitlement, also equitable, sensitive provision and procedures which meet the needs of the learning disabled and their families.

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