

## **Difficult learning: Covid-19 and adults with learning disabilities or autism**

### **Learning to live with lockdown**

For most people, learning to live in lockdown has been a challenge and the lockdown will have long-term repercussions for our health - mental and physical - and for the economy. People also face challenges spiritually. Churches remain shut to public worship and to private prayer.<sup>1</sup> People cannot be with their loved ones as they die, and they may not even get to the funeral. The lockdown has alerted people to the problems of isolation, loss of family relationships, dependence on others not only for shopping but also for safety, and to barriers to getting about in daily living. Employment prospects for some have become doubtful. Social interaction with strangers is marked by fear of contagion. Many people are perplexed by changing government strategies and the barrage of statistics. Many people are anxious for themselves and their loved ones, and they have fears for the future.

Put this way, for people with learning disabilities the challenges of lockdown may not seem so strange. Before anyone had heard of coronavirus the Equality and Human Rights Commission had already highlighted these kinds of everyday problems of isolation, dependence, barriers, inaccessibility, fear and perplexity for people with learning disabilities in its report *Being Disabled in Britain*.<sup>2</sup> However, for adults with learning disabilities the lockdown has greatly exacerbated these challenges and has brought added difficulties to existing problems and inequalities. Although everyone is susceptible to covid-19, adults with learning disabilities are more likely than many other people to be seriously impacted by covid-19.<sup>3</sup> Certainly, everyone's lives are being limited and everyone has to make changes, but the impact is especially acute for those with care and support needs.<sup>4</sup>

As we begin to see the end of this spike of the virus, the lockdown, at least for some, is easing. Although on 11<sup>th</sup> May the government issued new guidance on *Staying alert and safe*<sup>5</sup> the advice for clinically vulnerable people remains the same. It is important to learn from the lockdown experience because as we come out of this phase of the pandemic most people in England may 'stay alert', but people with learning disabilities may still be affected by measures taken in these extreme circumstances. What we learn from this experience may cause us to reflect more deeply on what we value.

### **Learning from life: the impact of covid-19**

Most adults with learning disabilities who receive long-term support live in their own homes, in families or in other households.<sup>6</sup> L'Arche house communities are examples of residential care where people with learning disabilities live in small house groupings alongside assistants. Many people with learning disabilities come under the category of vulnerable and so staying at home and social distancing is recommended.<sup>7</sup> For some people the simple things that disrupt the virus and give a measure of self-protection are not so simple: some people

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<sup>1</sup> <https://www.cbcew.org.uk/cardinal-on-safely-re-opening-churches-for-private-prayer/>

<sup>2</sup> Equality and Human Rights Commission *Being Disabled in Britain: A Journey Less Equal* 2017  
<https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf>

<sup>3</sup> DHSC *Covid-19: our action plan for adult social care* 1.3

<https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan/covid-19-our-action-plan-for-adult-social-care>

<sup>4</sup> <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/carers-family>

<sup>5</sup> <https://www.gov.uk/government/publications/staying-alert-and-safe-social-distancing/staying-alert-and-safe-social-distancing>

<sup>6</sup> <https://www.nuffieldtrust.org.uk/resource/adults-with-learning-disabilities-who-live-in-their-own-home-or-with-their-family>

<sup>7</sup> <https://www.gov.uk/government/publications/full-guidance-on-staying-at-home-and-away-from-others/full-guidance-on-staying-at-home-and-away-from-others>

need extra help with washing hands, they cannot stop themselves touching their mouths or faces, they have difficulty ‘catching’ coughs and saliva, they find keeping a distance difficult.<sup>8</sup> Many people with learning disabilities need help with their day to day living, especially with personal care. For these people social distancing is not an option. Helping people understand changes when their routines have been interrupted, when care and support packages have been reduced, when access to friends and family has been halted, when it is difficult to express real anxieties and worries, are ongoing challenges.<sup>9</sup>

Of course, it is impossible to speak about people with learning disabilities or autism in general as if they are all the same. Some people are in robust physical health, others have underlying conditions. Some people are zealous about washing hands to the point of obsession, others are totally dependent for their care and do not even initiate activity. Like all people some are angry, happy, frustrated, fulfilled, feel misunderstood, controlling, have difficult behaviour or are easy going. Adults with learning disabilities are neither children nor angels. Every person has their own particular gifts, limitations, weaknesses and strengths.<sup>10</sup> People with learning disabilities are no different from anyone else. Nevertheless, many people with learning disabilities live by the heart: they are trusting, open to others, and readily express emotive reactions. In this lies their vulnerability. Living by the heart and dependence on others are often seen as a sign of weakness because the person is entrusted into the care of others. And this is a risk.

L’Arche houses have had to be creative in keeping everyone engaged and indoors, especially when their members were used to going out for coffee or to the pub for lunch. L’Arche has shared stories about the experience of lockdown for members with learning disabilities and assistants.<sup>11</sup> These stories have resonance with the Care Quality Commission’s first ‘discussion document’ on the state of care, *Covid-19 Insight* which focuses on significant issues in adult social care, though it does not deal specifically with adults with learning disabilities.<sup>12</sup> At the outbreak of the pandemic community health support was reduced as resources were diverted elsewhere. Where people have assistants coming into their houses to help with their care, absences with carers being off sick or self-isolating have put significant pressure on services but also on the familiarity and continuity of care that many people with learning disabilities need. For L’Arche to replace volunteer assistants with other models of support is proving costly especially where assistants live in or are foreign nationals caught up in the travel restrictions. Support hours have been reduced but additional support is needed to respond to mental health issues and behaviour amplified by isolation.<sup>13</sup> The Care Quality Commission notes that the availability of PPE and the cost to care providers is of huge concern.<sup>14</sup> With difficulties in sourcing PPE some L’Arche houses have had to rely on expertise in the local community to provide supplies.<sup>15</sup> Testing has also been a challenge, not only in terms of practicalities but also in terms of who is tested. For adults with learning disabilities testing is especially problematic because priority is for homes that look

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<sup>8</sup> For helpful government advice see <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>

<sup>9</sup> <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/carers-family>

<sup>10</sup> Catholic Bishops Conference of England and Wales, *Valuing Difference* 1998, p.3.

<sup>11</sup> <https://cbcew.org.uk/plain/wp-content/uploads/sites/3/2018/11/valuing-difference-1998.pdf>

<sup>12</sup> <https://www.larche.org.uk/what-larche-is-doing-in-response-to-covid-19>

<sup>13</sup> <https://www.cqc.org.uk/sites/default/files/20200501%20COVID%20IV%20update%20number%201%20ACC%20ESSIBLE.pdf>

<sup>14</sup> <https://www.larche.org.uk/news/covid-19-statement-from-ceonational-leader-loren-treisman-phd>

<sup>15</sup> <https://www.cqc.org.uk/sites/default/files/20200501%20COVID%20IV%20update%20number%201%20ACC%20ESSIBLE.pdf>

<sup>15</sup> <https://www.larche.org.uk/what-larche-is-doing-in-response-to-covid-19>

after people over the age of 65. Desperately needed income from charities has been reduced as events like the London Marathon have been cancelled.

But there is also joy and laughter with improvised cinemas and creative use of technology. With development in new assistive technologies, remote access can keep people connected, though investing in technology is expensive.<sup>16</sup> Churches and faith-based organisations are at the heart of L'Arche, and online resources enable people to continue to participate in worship albeit in a limited way.<sup>17</sup> In these difficult times fun still happens, as one assistant explains, she goes food shopping for a number of houses and throws things through the window from the car much to the amusement and excitement of the residents.<sup>18</sup>

While many adults with learning disabilities live in caring and supportive environments, some do not. Reports over the years have shone light on not only poor care but appalling mistreatment.<sup>19</sup> The lockdown means that inspections have been suspended. To reduce pressure on hard-pressed healthcare staff, rules for detaining people under the Mental Health Act have been relaxed and the Coronavirus Act 2020 has created easements to the Care Act for the duration of the pandemic. This leaves a number of people with learning disabilities or autism who have been inappropriately segregated, hospitalised, restrained or detained under the Mental Health Act or admitted to inpatient units due to lack of suitable support services in the community still in situ.<sup>20</sup>

For people living in families or independently in supported accommodation there is a more acute risk of isolation especially since the lifeline of day centres and community activities have been closed for the foreseeable future. In terms of support, local authorities should continue to do everything they can to meet their existing duties but where local authorities are not able to do so the Coronavirus Act enables them to prioritise 'who is most in need of care and who might need to have care and support temporarily reduced or withdrawn in order to make sure those with highest need are prioritised.'<sup>21</sup> This may involve retrospective costs, a cause for concern for already vulnerable people who tend also to be trapped in poverty.<sup>22</sup> For those who rely on personal assistants, much of their assistant's allocated time is taken up in long waits for shopping or collection of medication, there are difficulties getting onto online shopping slots.<sup>23</sup> Life in lockdown is a challenge.

### **Learning from death: the impact of covid-19**

Although data on covid related deaths has been broken down by sex, age and ethnicity, data for adults with learning disabilities is not at all clear, reflecting perhaps historic failures in collecting relevant data.<sup>24</sup> To date there is only a partial account available based on death notified to the voluntary reporting scheme LeDeR programme.<sup>25</sup> A number of adults with learning disabilities detained under the Mental Health Act have died from suspected or

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<sup>16</sup> <https://www.larche.org.uk/news/covid-19-statement-from-ceonational-leader-loren-treisman-phd>

<sup>17</sup> <https://www.larche.org.uk/churches>; <https://www.cbcew.org.uk/home/our-work/health-social-care/coronavirus-guidelines/accessible-communication/>

<sup>18</sup> <https://www.larche.org.uk/what-larche-is-doing-in-response-to-covid-19>

<sup>19</sup> <https://www.mencap.org.uk/sites/default/files/2016-08/Out-of-Sight-Report.pdf>

<sup>20</sup> <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> p.85;

<https://publications.parliament.uk/pa/jt201919/jtselect/jtrights/121/121.pdf>

<sup>21</sup> <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

<sup>22</sup> <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> p.9;

<https://www.jrf.org.uk/report/uk-poverty-2019-20-social-security>

<sup>23</sup> <https://committees.parliament.uk/publications/644/documents/2697/default/>

<sup>24</sup> <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> pp.10, 77, 100

<sup>25</sup> The 2019 NHS *Learning Disability Mortality Review (LeDeR) Programme: Action From Learning*<sup>25</sup> was

commissioned to improve the standard and quality of care for people with disabilities  
<https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/>

confirmed coronavirus.<sup>26</sup> Alongside deaths from suspected or confirmed covid-19 there is an increase in the number of other deaths presumably because people are not accessing hospital or other healthcare services. Without testing the real number of covid related deaths remains unknown.

In its speciality guide for patients with learning disabilities and autism the NHS has identified some factors that make treating people with disabilities in hospital for covid-19 more problematic and implicitly less desirable: clinicians may have limited clinical contact with people with learning disabilities or with autism; some 41% of people with learning disabilities who died in 2018/2019 died as a result of a respiratory condition, and respiratory diseases tend to be associated with higher risk;<sup>27</sup> rates of mortality are generally higher.<sup>28</sup> It seems that disabled people with complex needs are better off staying at home if they are diagnosed with covid-19, not least because otherwise they will be with people who do not know them. The NHS and DHSC seek to provide evidence-based guidelines. However, *Being Disabled in Britain* showed that high rates of premature deaths resulted from a failure to adequately diagnose, treat and prevent comorbid physical health conditions in people with learning disability. 'In the worst cases, people receive less than optimal medical care and unnecessarily have unmet health needs.'<sup>29</sup> During this pandemic disability advocates have pointed to some potentially discriminatory practices<sup>30</sup> already identified in *Being Disabled in Britain* including an unprecedented number of DNAR notices for people with learning disabilities.<sup>31</sup> Fears about low priority for treatment,<sup>32</sup> denied access to life-saving treatment,<sup>33</sup> and reduced likelihood of hospital admission,<sup>34</sup> are rife, and there is real concern that a person would be alone in hospital.<sup>35</sup>

It seems that the covid guidance fails to take account of the existing inequalities that have led to these statistics on preventable deaths. Significantly, what may have been forgotten is the NHS guidance that people with mental health needs, learning disability or autism 'should receive the same degree of protection and support with managing Covid-19 as

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<sup>26</sup> <https://www.cqc.org.uk/news/stories/our-concerns-about-mental-health-learning-disability-autism-services>; there is an incomplete set of data on covid-19 related deaths of adults with learning disabilities <https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/>

<sup>27</sup> DHSC Covid-19: our action plan for adult social care 1.3 <https://www.gov.uk/government/publications/coronavirus-covid-19-adult-social-care-action-plan/covid-19-our-action-plan-for-adult-social-care>

<sup>28</sup> [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031\\_Specialty-guide\\_LD-and-coronavirus-v1\\_-24-March.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf)

<sup>29</sup> <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf> p.97 quoting BMA 2014 *Recognising the importance of physical health in mental health and intellectual disability: Achieving parity of outcomes*

<sup>30</sup> <https://www.mencap.org.uk/press-release/mencap-responds-deeply-troubling-new-nice-covid-19-guidance>

<sup>31</sup> <https://www.hsj.co.uk/coronavirus/unprecedented-number-of-dnr-orders-for-learning-disabilities-patients/7027480.article>

<sup>32</sup> <https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article>; <https://www.larche.org.uk/what-larche-is-doing-in-response-to-covid-19>

<sup>33</sup> <https://www.hsj.co.uk/coronavirus/learning-disabilities-patients-told-they-may-be-too-frail-for-mechanical-ventilation-if-they-get-covid-19/7027318.article>

<sup>34</sup> <https://www.theguardian.com/world/2020/apr/01/uk-healthcare-regulator-brands-resuscitation-strategy-unacceptable>

<sup>35</sup> <https://www.larche.org.uk/what-larche-is-doing-in-response-to-covid-19>

other members of the population’ and this may mean additional support including making ‘reasonable adjustments’<sup>36</sup> and the right to be accompanied.<sup>37</sup>

In NHS guidance on covid-19 and adults with learning disabilities vulnerability and dependence seems to be a two-edged sword. On the one hand there is the important recognition that people with learning disabilities or autism require significant and dynamic support to manage their physical and mental health during this crisis. Identifying vulnerabilities helps in providing necessary support.<sup>38</sup> On the other hand, guidance designates ‘mental health needs, a learning disability or autism’ as sources of additional vulnerability, and vulnerability counts against a person when providers have to make ‘difficult decisions in the context of reduced capacity and increasing demands’.<sup>39</sup> The need for support in everyday living has been equated with frailty and the level of frailty determines what treatment will be offered. This conflation is detrimental to people who have existing health conditions or disabilities unrelated to their chance of benefitting from treatment for covid-19. According to NHS guidance frailty should be assessed at ‘any first point of contact with acute care (including by paramedics).’<sup>40</sup> That this can be done in such a short time frame is a cause for concern when applied to adults with learning difficulties especially when family are not involved in the assessment, particularly since it risks becoming a tick-box exercise. Moreover, care staff supporting adults with learning disabilities or autism are specifically directed to the charity Compassion in Dying, sister charity to the euthanasia organisation Dignity in Dying for further information on care planning.<sup>41</sup> Implicit in some apparently benign approaches is the view that people are better off dead than disabled.<sup>42</sup>

## Learning and looking ahead

Although systemic failures have long been acknowledged, the rampant nature of covid-19 means that remedies have been put on hold. However, it has now been recognised that ‘in normal times’ staff working in adult social care work hard to communicate effectively, support and empower people, yet their skills, commitment and contributions often go unrecognised and are undervalued in our society.<sup>43</sup> One ‘important legacy’ from this crisis must be ‘the value we place on social care as an essential service’.<sup>44</sup>

Looking ahead, as a matter of justice, decisions should not be made based on negative value judgements about the worthwhileness of someone’s life.<sup>45</sup> The right to healthcare flows from the dignity of the human person and as a matter of justice treatment decisions must be based on objective and transparent criteria applied consistently, not on perceived

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<sup>36</sup> [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services\\_25-March-final-1.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services_25-March-final-1.pdf); <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>

<sup>37</sup> ‘Reasonable adjustments’ and the right to be accompanied are obligations under the Equality Act 2010. Notably, before the pandemic the *Learning Disability Mortality Review* pointed out that professionals did not have sufficient awareness of the need for reasonable adjustments <https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf>

<sup>38</sup> [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services\\_25-March-final-1.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/Managing-demand-and-capacity-across-MH-LDA-services_25-March-final-1.pdf)

<sup>39</sup> <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0074-MHLDA-Covid-19-Guidance-Workforce-final-v1-1.pdf> p.2

<sup>40</sup> <https://www.nice.org.uk/guidance/ng159/chapter/1-Admission-to-hospital>

<sup>41</sup> guidance offered by the Social Care Institute for Excellence, funded by the Department of Health and Social Care, <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>

<sup>42</sup> Anscombe Bioethics Centre, *Covid-19 Briefing Paper 3* 11<sup>th</sup> May 2020

<sup>43</sup> DHSC *Covid-a0: our action plan for adult social care* 2.1

<sup>44</sup> DHSC *Covid-a0: our action plan for adult social care* 2.38

<sup>45</sup> Anscombe Bioethics Centre *Covid-19 Briefing Paper 1* 8<sup>th</sup> April 2020

worthwhileness of a person's life.<sup>46</sup> Significantly the *Learning Disability Mortality Review* states that the NHS will work for people with learning disabilities 'to ensure that all vaccination programmes are designed to support a narrowing of health inequalities'.<sup>47</sup> Remembering this commitment will be particularly relevant once a vaccine has been produced for covid-19.

The assertion that people with disabilities have a right to equal access to healthcare and treatment can easily be taken to mean that they have an equal claim alongside the competing claims of people without disabilities: what is given to one will not be given to another. The temptation then is to evaluate competing claims in terms of certain characteristics such as dependence and need, values that are to the detriment of disabled people, and to undervalue the contribution people with disabilities do make to society. As public concern for vulnerable people has demonstrated, instead of an individualistic understanding of rights we live in a network of relationships. People should not be left to fend for themselves, and where they cannot manage, others step in to help: this is subsidiarity and solidarity in action.<sup>48</sup>

Certainly, the lockdown has demonstrated in a practical way that everyone's safety depends on everyone else's.<sup>49</sup> Moreover, the many public acts of kindness and concern for those in need, and the recognition that people should not die alone show a real sense of solidarity. It is truly heartening to see real public concern for vulnerable people put into action through support schemes to keep people connected.<sup>50</sup> This emerging sense of solidarity reminds us all that we exist in a network of relationships and there are common principles that apply to everyone no matter their situation or condition: we are one human family.<sup>51</sup> The lockdown may have destabilized our lives but we may find through a shared responsibility a deepening of our shared humanity.<sup>52</sup> While undoubtedly there will be multiple inquiries when we emerge from this pandemic, learning through ethical reflection during the time of crisis and not merely after it is crucial if we are not simply going to repeat past mistakes and if we are going to narrow the gap in equality. Learning may be difficult, and it may raise searching questions of values and priorities. But what we are prepared to learn as we go along will influence the kind of society we want to live in in the future. As Pope St John Paul points out, 'the quality of a society and civilisation is measured by the respect it has for the weakest of its members'<sup>53</sup> And 'only by recognising the rights of its weakest members can a society claim to be founded on law and justice.'<sup>54</sup>

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<sup>46</sup> Anscombe Bioethics Centre *Covid-19 Briefing Paper 1* 8<sup>th</sup> April 2020

<sup>47</sup> <https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf> p.23

<sup>48</sup> Pontifical Council for Justice and Peace, *Compendium of the Social Doctrine of the Church* Washington DC: Libreria Editrice Vaticana 2005, pp.81-87

<sup>49</sup> Pontifical Academy for Life, *Global Pandemic and Universal Brotherhood* [http://www.academyforlife.va/content/dam/pav/documenti%20pdf/2020/Nota%20Covid19/Nota%20on%20the%20Covid-19%20emergency\\_ENG\\_.pdf](http://www.academyforlife.va/content/dam/pav/documenti%20pdf/2020/Nota%20Covid19/Nota%20on%20the%20Covid-19%20emergency_ENG_.pdf)

<sup>50</sup> See for instance <https://www.newcastlegatesheadccg.nhs.uk/helping-people-with-learning-disability-or-autism-stay-connected-during-covid-19-pandemic/>

<sup>51</sup> Congregation for Catholic Education, *Guidelines for the Study and Teaching of the Church's Social Doctrine in the Formation of Priests*, 1988, 30-42.

<sup>52</sup> Pontifical Academy for Life, *Global Pandemic and Universal Brotherhood* [http://www.academyforlife.va/content/dam/pav/documenti%20pdf/2020/Nota%20Covid19/Nota%20on%20the%20Covid-19%20emergency\\_ENG\\_.pdf](http://www.academyforlife.va/content/dam/pav/documenti%20pdf/2020/Nota%20Covid19/Nota%20on%20the%20Covid-19%20emergency_ENG_.pdf)

<sup>53</sup> Pope St John Paul II, *Documento de la Sancta Sede para el 'año internacional de los minusválidos'* 4 March, 1981, I.3.

<sup>54</sup> Pope St John Paul II, *On the Occasion of the International Symposium on the Dignity and Rights of the Mentally Disabled Person* 5 January, 2004, 3