The impact of Covid-19 on people with a learning disability in Northern Ireland:
Implications for policy and practice.

Appendix 2: Research into the impact of Covid-19 on people with learning/intellectual disabilities.

This appendix brings together information about the impact of Covid-19 from three sources. First, international and national guidance is reviewed along with policy implications relating to recovery from Covid-19 and lessons learnt. Second, the key findings from published research studies are summarised. Third, information particular to Northern Ireland is presented.

1. International and national guidance

In early 2020, the World Health Organisation issued a document to all member countries entitled 'Disability considerations during the Covid-19 outbreak'[1]. In it they outlined the increased vulnerabilities of persons with disabilities:

- Difficulty in enacting social distancing because of additional support needs;
- The need to touch things to obtain information from the environment or for physical support;
- Barriers to implementing basic hygiene measures, such as handwashing.
- Barriers to accessing public health information due to literacy and communication difficulties.
- People with disability may be at greater risk of developing severe disease if they become infected because of pre-existing health conditions underlying the disability; and barriers to accessing health care.
- People with disability may also be disproportionately impacted by the outbreak because of serious disruptions to the services they rely on. Moreover, their limited literacy and IT skills makes tele-practice less suited to their needs.

The WHO guidance went on the delineate the specific actions that should be taken by Governments; Health-care providers; disability service providers in the community; actions for institutional settings; actions for people with disability and their household, and actions for the community.

A plethora of guidance in preventing and managing Covid-19 was later produced by various government agencies with variations across the four nations in the UK. This sometimes contradictory advice was often unsuited to the needs of people with learning

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[1] WHO reference number: WHO/2019-nCoV/Disability/2020.1

disabilities and was issued with little consultation with the agencies and personnel who were expected to implement the guidance[2].

In addition, people with learning disabilities are at increased risk because of their generally poorer health and lack of access to healthcare. "*Many of the risk factors that are associated with severe outcomes from Covid-19 infection, such as cardiovascular disease, diabetes and chronic lung disease are common in adults with IDD"* (ADMDD, 2020).

The NHS Clinical guidance[3] (issued 24 March 2020) for front line staff to support the management of 'patients' with a learning disability, autism or both during the coronavirus pandemic underscored their vulnerability: "*People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. At least 41% of them die from respiratory conditions. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people; all these factors make them more vulnerable to coronavirus*" (p.2).

A study of 163 persons who died from Covid-19 in England[4] proposed that public health and preventative measures should be targeted at people with intellectual disabilities who have respiratory disease, hypertension or obesity as these were identified as being associated with a greater risk of death from Covid-19. Concern was also expressed about the failure to detect deterioration of people living in community settings and poorer access to healthcare generally experienced by people with learning disabilities.

A further study of 66 deaths in a two week period in UK and Ireland[5] found that 83% were of persons who lived in supported living, residential or nursing homes. This suggests that a combination of multiple carers and living in close proximity to others (which was exacerbated during lock-downs) resulted in a higher risk of dying from Covid-19. Further studies in the USA confirmed these findings[6].

Review of Covid-19 experience internationally

Inclusion International (an international network of people with intellectual disabilities and their families drawn from over 115 countries spread across all regions of the world) obtained information from over 1,100 participants as well as from 68 member organisations in 48 countries[7]. They concluded that: "*Our consistent experience*

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[2] Details at: https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf

[3] https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf

[4] Heslop, P., Byrne, V., Calkin, R., Huxor, A., Sadoo, A., & Sullivan, B. (2021). Deaths of people with intellectual disabilities: Analysis of deaths in England from COVID-19 and other causes. Journal of Applied Research in Intellectual Disabilities, 34(6), 1630-1640.

[5] Perera, B., Laugharne, R., Henley, W., Zabel, A., Lamb, K., Branford, D., ... & Shankar, R. (2020). COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study. BJPsych open, 6(6).

[6] Landes, S. D., Stevens, J. D., & Turk, M. A. (2021). Cause of death in adults with intellectual disability in the United States. Journal of intellectual disability research, 65(1), 47-59.

[7] Inclusion International (2021) A Global Agenda for Inclusive Recovery: Ensuring People with Intellectual Disabilities and Families are Included in a Post-COVID World. Available at: https://inclusion-international.org/a-global-agenda-post-covid/

throughout the pandemic has been widespread human rights violations - there has been a lack of access to information, education, and services, denial of social protection measures, as well as other rights violations. The Covid-19 crisis has resulted in an increase in restriction, isolation, and coercion for people with disabilities, particularly those living in institutions".

They proposed an agenda for inclusive Covid-19 recovery with specific examples of recommendations. These included:

- **"Making information accessible to all**: information shared by governments must be produced in formats accessible to people with intellectual disabilities, including plain language and easy read, video, and other formats
- **Ensuring consistent access to support services:** services which support families, and services for people with high support needs are deemed essential.
- **Improving inclusivity in health systems:** Prioritise people with intellectual disabilities and family carers in vaccination drives.
- **Supporting families**: Provide support services to families, including during emergency and ensure access to mental health support.
- **Deinstitutionalization**: Plan for the closure of institutions and the transition of residents to communities. Fund community-based services and support for independent living".

The Royal Society of Canada[8] established a Task Force on Covid-19 and intellectual and developmental disabilities (IDD). It concluded that future policy requires "*both a mainstreaming of disability inclusion into all Covid-19 response and recovery policies as well as disability-specific policies to address the unique barriers and challenges encountered by people with IDD during the pandemic".* Nineteen recommendations were made that included those noted above but others were:

- "Recommendation 9: Allocate additional funding for community-based participation initiatives for people with IDD to support innovative solutions that are sustainable post-pandemic.
- Recommendation 11: Monitor the long-term impacts of the pandemic on learning for students with IDD through individualized assessments.
- Recommendation 12: Develop a National Disability Income Benefit sufficient to ensure a reasonable minimum income for all Canadians with a disability.
- Recommendation 13: Design disability-inclusive pandemic income supports .. (that) recognize persons with IDD and their families experience additional costs such as personal protective equipment (PPE) for support staff and technology needs.
- Recommendation 15: Invest in post-pandemic accessible employment support for people with IDD to support recovery from Covid-19 related job losses and reduced employment"

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[8] Majnemer, A., McGrath, P. J., Baumbusch, J., Camden, C., Fallon, B., Lunsky, Y., ... & Zwicker, J. (2021). Time to be counted: COVID-19 and intellectual and developmental disabilities—an RSC Policy Briefing.

UK National Review

The House of Commons Health and Social Care, and Science and Technology Committees undertook a joint review of Coronavirus: Lessons learned to date (October 2021)[9]. They concluded:

- "Planning for future pandemics should have a more developed and explicit consideration of the intense interaction between the NHS and social care. The prominence of social care within the Department of Health and Social Care should be enhanced and Ministers must address the relative lack of knowledge and experience of social care within the Department and senior levels of the NHS.
- The Department should ensure that future policy and guidance relating to the sector is well-informed and reflects the diversity of the sector. The Department must also set out how it plans to retain the expertise of the Social Care Taskforce on a more permanent basis.
- Long term reform of social care is overdue and should be pursued as a matter of urgency. It must ensure that there is parity between the health and care sectors so that social care is given proper priority in a future crisis.
- We endorse the Health and Social Care Committee's call for additional resources to be directed to social care".

With respect to learning disability, the Committee recommended:

- "In planning for future health emergencies, the Department of Health and Social Care and the NHS should consider the specific difficulties faced by people with learning disabilities and their families and recognise the barriers to understanding and communication which, if not overcome, can lead to avoidable deaths of vulnerable people.
- The NHS should improve the data it holds on people with learning disabilities so that this group of patients can be more appropriately considered for vaccination.
- The NHS should ensure the guidance on DNACPR (Do not resuscitate) notices is clear and properly understood by healthcare professionals and individuals, especially in circumstances where a patient's carer or advocate may not be able to be present in hospital".

2. Research studies into Covid-19 and people with learning disabilities.

From 2020, an increasing number of research studies have been published in international peer-reviewed journals that represent the 'science' in relation to Covid-19 and people with learning disabilities.

Taggart and colleagues[10] (2021) undertook a narrative synthesis of the emerging themes related to the Covid-19 pandemic for people with an intellectual disability from the literature, 18-months after the beginning of lockdown. The aim was to identify key learning

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[9] House of Commons: Coronavirus: lessons learned to date. Sixth Report of the Health and Social Care Committee and Third Report of the Science and Technology Committee of Session 2021–22

[10] Taggart et al (2021) Preventing, mitigating, and managing future pandemics for people with an intellectual and developmental disability - learning from COVID-19: A scoping review. Journal of Policy and Practice in Intellectual Disability (in press).

points for the provision of services and government interventions for people with an intellectual and developmental disability for future pandemics. In all 34 research papers (such as retrospective analysis, surveys, service evaluation, discussion papers) and grey material (such as commentary, editorial, guidance papers, guideline/protocol development, letters, opinion paper, policy briefing) were included within this review.

Three core themes emerged from the review.

- **Prevention/Protection**: accessible information, handwashing and social distancing, Personal Protective Equipment, shielding, track and trace, testing, vaccine compliance/hesitancy, and training.
- **Mitigation:** making reasonable adjustments both to where people live, and to community healthcare/clinical practice; and the use of technology as a pandemic response strategy.
- **Treatment/Management:** access to acute hospitals and lifesaving equipment, using a suitable Clinical Fatality Assessment instrument, stopping Do Not Resuscitate notices, individualised care plans and hospital passports, family/paid carers to support people in hospitals; and use of telehealth in clinical care.

The authors noted that the above themes can inform future public-health policies. This paper also exposed the negative impacts of public-health interventions in both High and Lower- and Middle-income countries for this population including lapses in upholding human rights. This data provides a basis for learning from the Covid-19 pandemic in planning for future pandemics.

Impact of Covid-19 on persons with learning/intellectual disabilities

Further studies have examined the impact that Covid-19 has had people with learning disabilities. A primary focus has been on their health and mortality. The Table below summarises the findings from 12 large-scale studies undertaken in 2020 and 2021 in UK, Republic of Ireland, USA, Spain and Netherlands, that addressed similar themes to those included in the UK research project. In part they confirm the importance of these themes for this population and also help to validate the wider applicability of the findings beyond those who took part in the research. The table content contains mainly verbatim quotes from the published papers.

Table: Summary of pertinent research articles on the impact of Covid-19 on people with learning disabilities

Title	Sample	Main findings
Covid-19 infection and outcomes in a population-based cohort of 17,173 adults with intellectual disabilities compared with the general population. Henderson, A., Fleming, M., Cooper, S. A., Pell, J., Melville, C., MacKay, D., ... & Kinnear, D. (2021). medRxiv. https://doi.org/10.1101/2021.02.08.21250525;	17,173 Scottish adults with, and 195,859 without, intellectual disabilities.	Adults with intellectual disabilities had higher rates of Covid-19 infection; severe infection; mortality; and case-fatality. Poorer Covid-19 outcomes remained after standardising for age, sex and deprivation: standardised severe infection and mortality ratio were higher among 55-64 year olds. Conclusions: Adults with intellectual disabilities were more likely to be infected with Covid-19, and had worse outcomes once infected, particularly those under 65 years. Non-pharmaceutical interventions directed at formal and informal carers are essential to reduce transmission and all adults with intellectual disabilities should be immediately prioritised for vaccination regardless of age.
Covid-19 registration in people with intellectual disabilities in Dutch long-term care facilities. Koks-Leensen, M., Schalk, B., Bakker-van Gijssel, E., Cuypers, M., van den Bemd, M., Nägele, M., ... & Leusink, G. L. (2021). European Journal of Public Health, 31(Supplement_3), ckab164-835.	6500 Dutch patients with (suspected) Covid-19 infection observed in 2020	People with ID are vulnerable to Covid-19 at a younger age compared to people in the general population. Case fatality rate was 3-4 times higher among people with ID compared to the general population, and mortality was already higher in younger age groups (40 years and older). Their living circumstances matter: in group home living circumstances more infected people with ID were observed. The etiology of the ID, especially Down syndrome, is an unfavorable predictor.
Understanding inequalities in Covid-19 outcomes following hospital admission for people with intellectual disability compared to the general population: a matched cohort study in the UK. Baksh, R. A., Pape, S. E., Smith, J., & Strydom, A. (2021). BMJ open, 11(10), e052482.	A large sample of 506 patients with intellectual disabilities in UK and 1518 well-matched controls.	Subjective presenting symptoms such as loss of taste/smell were less frequently reported in ID patients, whereas indicators of more severe disease such as altered consciousness and seizures were more common. ID patients were admitted with higher respiratory rates and were more likely to require oxygen. Despite this, ID patients were 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation and 50% less likely to be admitted to the ICU while in hospital. They had a 56% increased risk of dying from Covid-19 after they were hospitalised and were dying 1.44 times faster compared with controls. Conclusions: There have been significant disparities in healthcare between people with ID and the general population during the Covid-19 pandemic, which may have contributed to excess mortality in this group.
Covid-19 risk: Adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions. Schott, W., Tao, S., & Shea, L. (2021), Autism, 13623613211039662.	Medicaid Data on over 600,000 adults with intellectual disability in USA and	Those with intellectual disability had higher odds of risk factors for becoming infected with Covid-19 (living in a residential facility, receiving services in the home from outside caregivers, having had a long hospitalization, and having had avoidable hospitalizations) and they had three times higher odds of having a high-risk health condition. Clinicians should anticipate high prevalence of comorbidities and risk factors for severe illness from

	sample of 1 million beneficiaries without ASD or ID.	Covid-19 among ID populations. Health officials and non-governmental organizations should target these groups with outreach for the Covid-19.
The impact of coronavirus disease 2019 (Covid-19) on older adults with an intellectual disability during the first wave of the pandemic in Ireland. McCarron, M., McCausland, D., Luus, R., Allen, A., Sheerin, F., Burke, E., ... & McCallion, P. (2021). HRB Open Research https://doi.org/10.12688/hrbopenres.13238.1	710 adults with intellectual disability aged 40+ years in Ireland	High rates were identified of health conditions associated with poorer Covid-19 outcomes, including overweight/ obesity (66.6%, n=365), high cholesterol (38.6%, n=274) and cardiovascular disease (33.7%, n=239). Over half (53.5%, n=380) reported emotional, nervous or psychiatric disorders. Almost two-thirds (62.4%, n=443) were tested for Covid-19, with 10% (n=71) reporting symptoms and 2.5% (n=11) testing positive. There were no instances of Covid-19 related mortality. Common symptoms included fatigue, fever, and cough. Over half (55%, n=383) reported some Covid-19 related stress/anxiety; and a similar proportion reported positive aspects during this period (58%, n=381).
Supports for people with intellectual and developmental disabilities during the Covid-19 pandemic from their own perspective. Navas, P., Amor, A. M., Crespo, M., Wolowiec, Z., & Verdugo, M. Á. (2021). Research in Developmental Disabilities, 108, 103813.	582 individuals with IDD in Spain	People living in residences had fewer natural supports, while those living with their family relied heavily on it. Participants also lacked supports considered necessary. It is worth stressing that persons with IDD have also provided support to others. Conclusions: Although people with IDD have generally received the assistance they need during the lockdown, it must be ensured that appropriate supports are provided regard-less of the context in which they live.
The impact of coronavirus in people with learning disabilities and their parents, carers and supporters. Scottish Commission for people with learning disabilities (2020).	223 responses from parents, carers and supporters in Scotland plus 127 from persons with learning disabilities.	The most common concerns were the reduction or removal of supports, increased social isolation. Compounded by digital exclusion and mental health impacts. Increased pressure on family carers because of reductions in support from care providers and pressure on paid carers due to staff shortages and changes in how support was given. People expressed feelings of anxiety and uncertainty about how long measures would last and whether their usual supports would return once measures were lifted.
The impact of disability on employment and financial security following the outbreak of the 2020 Covid-19 pandemic in the UK. Emerson, E., Stancliffe, R., Hatton, C., Llewellyn, G., King, T., Totsika, V., ... & Kavanagh, A. (2021). Journal of Public Health (Oxford, England). doi:10.1093/pubmed/fdaa270	13,036 UK adults aged 16–64 for whom disability data were available	During the first 3months of the introduction of the first lockdown in the UK, respondents with disability were more likely than their peers to be working reduced hours and experience higher levels of financial stress. Conclusions Working age adults with disability were particularly disadvantaged by the financial impact of the Covid-19 lockdown in the UK

Social support as a mediator of stress and life satisfaction for people with intellectual or developmental disabilities during the Covid-19 pandemic. Fisher, M. H., Sung, C., Kammes, R. R., Okyere, C., & Park, J. (2021). Journal of Applied Research in Intellectual Disabilities.	2028 US individuals with and without disabilities, 181 adults with intellectual or developmental disabilities (or proxy) responded.	Most respondents with intellectual or developmental disabilities (92.8%) reported negative impacts from the pandemic, with 55.2% of the 96 employed pre-pandemic reporting impacted employment, including job loss. The negative impact of the pandemic was a significant predictor of stress level; social support was related to reduced stress. Stress level and the negative impact of the pandemic were inversely related to life satisfaction. Comprehensive services and social support systems are needed to combat the impact of the pandemic.
The role of coping in the wellbeing and work-related quality of life of UK health and social care workers during Covid-19. McFadden, P., Ross, J., Moriarty, J., Mallett, J., Schroder, H., Ravalier, J., ... & Gillen, P. (2021). Journal of Environmental Research and Public Health, 18(2), 815.	3,425 personnel who worked in health and social care in the UK during its first wave of Covid-19	Positive coping strategies, particularly active coping and help-seeking, were associated with higher wellbeing and better quality of working life. Negative coping strategies, such as avoidance, were risk factors for low wellbeing and worse quality of working life. The results point to the importance of organizational and manage-ment support during stressful times, which could include psycho-education and training about active coping and might take the form of workshops designed to equip staff with better coping skills.
An audit of the well-being of staff working in intellectual disability settings in Ireland during the Covid-19 pandemic. McMahon, M., Hatton, C., Stansfield, J., & Cockayne, G. (2020). Tizard Learning Disability Review. 25(4), 237-246.	285 staff in the Republic of Ireland working in intellectual disability settings.	Staff reported moderate levels of personal and work-related burnout and mild levels of anxiety and depression. Higher mean scores were recorded across scales from staff who worked in independent living settings and from staff who supported individuals with challenging behaviour. Employers need to consider staff well-being, given the levels of personal and work-related burnout, and anxiety and depression that were found.
The Covid-19 Pandemic and Quality of Life Outcomes of People with Intellectual and Developmental Disabilities, Friedman C, (2021) Disability and Health Journal, https://doi.org/10.1016/j.dhjo.2021.101117	2,284 adults in USA receiving ID services comparing 2019 and 2020 outcomes.	There were significant differences in the following quality of life outcomes: continuity and security; interactions with other members of the community; participate in the life of the community; intimate relationships; and, choosing goals. Conclusions. Our findings suggest the Covid-19 pandemic has negatively hindered the quality of life outcomes of PWIDD and in many ways it has simply intensified an underfunded and fractured IDD service system. However the IDD service system evolves during and after the pandemic, it must be done in a way that prioritizes the quality of life of PWIDD and what is most important to them.

3. Research undertaken in Northern Ireland.

Thus far there has been no published studies undertaken in Northern Ireland in relation to Covid-19 and people with learning disabilities. However reports are available from various surveys.

The **Department of Health**[11] commissioned a rapid learning initiative in 2020 into transmission of Covid-19 into and within care homes in Northern Ireland. Although homes for residents with learning disability were included, the responses were not separated in the report. A mix of online surveys and in-depth interviews were conducted in early July 2020 with responses from nearly 400 residents, 81 families, 112 staff and 70 care home managers. The main conclusions were grouped into the four areas selected for consideration in the review along with examples of important themes.

- **The Experience of Residents, Families and Staff**: Strategies to support residents to remain stimulated and engaged with their environment are vitally important to support their health and wellbeing. Strong leadership from Care Home managers and teamwork are essential in supporting the health and wellbeing of staff and to delivering safe and effective care.
- **Symptom Monitoring, Interventions and Testing**: Enhanced clinical support was required during the height of the outbreaks in Care Homes. Accessible and timely medical support is critical in managing any future surges and/or outbreaks of Covid-19 infection. Formal information and guidance should be consistent in detail, clear and unambiguous.
- **Infection Prevention & Control:** Mechanisms to ensure no disruption to the PPE supply chain would be crucial. Partnership working with HSC Trusts to obtain PPE was vital to maintaining the required standard of practice and keeping people safe.
- **Physical distancing, reduced footfall and restricted visiting:** Formal information and guidance regarding visiting should be consistent in detail, clear and unambiguous and provide in a timely manner. Implementation of physical distancing measures were particularly challenging. Guidance and training around dynamic risk assessment that considers human rights alongside risks of infection transmission would be beneficial".

In all 24 recommendations were identified on which action is needed. The Chief Nursing Officer was to write to the PHA asking them to work with the five HSC Trusts, the Independent Sector and other relevant stakeholders to co-ordinate the implementation of the recommendations and report back Chief Nursing Officer within 3 months" (p.31). It is not clear the extent of the follow-up and the implementation of recommendations.

NICVA, the Northern Ireland Council for Voluntary Action[12] undertook a survey of community and voluntary organisations about the impact of Covid-19 on their activities. However services for persons with learning disabilities were not singled out.

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[11] https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-rli-task-finish-group.pdf

[12] https://www.nicva.org/resource/results-of-nicva-research-on-the-impact-of-covid-19-on-voluntary-community-and-social

From 216 responses, two thirds had stopped their activities, 60% no longer could use their volunteers and over one third had furloughed their staff. Around one quarter estimated they were delivering between 75% to 100% of the services/activities provided pre-Covid but 40% were delivering less than 50% of pre-Covid provision. Over half estimated that upwards of 50 beneficiaries had been affected per week. Two thirds reported their financial position would be difficult up to critical in the coming three to six months.

Families Involved in NI (FINI) undertook a short survey in July/August 2020 to determine the impact of day centre closures on 57 families with adults with disabilities across Northern Ireland. At the time of the survey, families had been coping for over four months without vital services for their family members as the day centres had been closed.

- The **health and well-being of the adult with a disability** was foremost in relatives' minds as they see the quality of their lives reduced. The extra burden of care that families have had to carry during this time has also had an adverse impact on the physical and mental health of the family carer.
- **Lack of family access** to sons, daughters and siblings in supported living, residential and nursing homes has compounded family concerns and the well-being of service users who have been unable to leave these places and have limited day-time activities.
- Explaining to families the **difficulties of meeting Infection Control Guidelines** but including them in developing possible solutions would go some way in allaying growing anxiety.
- Families feel they have supported efforts of the Health & Social Care system by picking up the work previously done by Health Service staff but **are now struggling**.
- The Covid-19 pandemic may have had its initial impact on the Health Service but we should not underestimate the greater and looming impact on Health & Social Care services as **services users and their families, having been pushed to their limits, are now in need of urgent support**.
- **Communication during the Covid-19 pandemic has been lacking** and on the future rebuilding of services within each Trust area, families still do not know what this looks like.
- **Involvement of families and service users** in the rebuilding of the services is not evident in any of the Trusts. There is also a lack of urgency in meeting the needs of service users and families are worried of the impact on their mental and physical health.
- There was **limited evidence of any replacement services** or offer of direct payments.

The Association for Real Change (ARC) NI commissioned a review of the impact of Covid-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland[13]. One-to-one interviews were conducted by Zoom with 23 senior staff from 17

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[13] The report is available at: https://arcuk.org.uk/northernireland/files/2021/02/Final-report-ARC-Review-17th-November-2020.pdf

services and an online, self-completion survey was completed by respondents from a further 10 services. Among the key findings were:

- At the time of this review, there were **very few infections among service users** and staff in the Northern Ireland services included in this review: a tribute to the prompt actions that had been taken by them and by the Department of Health.
- **Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities** and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise.
- The **immediate closure of face-to-face services** in late March created unprecedented pressures on the non-statutory sector. They responded speedily and creatively to maintaining supports to their service-users, albeit in adapted ways.
- Responding to Covid-19 placed **extra demands on staff** who in most instances undertook extra duties and worked longer hours despite justifiable concerns for their own families and personal wellbeing.
- Families carers were not only cut-off from face-to-face support provided by ARC-NI members but this was compounded by the **abrupt closure of statutory services**, such as day centres, respite care and professional services.   The withdrawal of these services left many family carers unsupported. The slow and reduced opening of these services has prolonged the carers' stress and anxiety.
- **Covid-19 highlighted certain weaknesses in the provision of learning disability services** across Northern Ireland in the non-statutory as well as statutory sector. These need to be addressed as part of an evidence-based recovery and renewal strategy post Covid-19. Such a strategy would contribute to, as well as benefit from a concerted effort to implement the long-awaited reform of adult social care.

Conclusions

The impacts of Covid-19 in Northern Ireland echo those reported from other jurisdictions although in common with much previous research, they fail to capture the lived experiences of people with learning disabilities by letting them speak for themselves. Moreover, few studies that have charted changes over the course of the epidemic and changes in lock-downs. Thus the UK-wide research study is particularly significant in both these aspects.