



All Party Group on Learning Disability

All Party Group on Learning Disability (APGLD)

June 2020: Briefing Paper on the Impact of Covid-19

The APGLD aims to promote a better understanding of the issues facing people with a learning disability and their families, and influence change to ensure their full participation in society

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Introduction

Before the Covid-19 crisis, people with a learning disability already experienced many social, economic and health inequalities. They are more likely to be socially isolated and lonely, which impacts on mental health, and to be unemployed and economically inactive. People with a learning disability also die on average two decades younger than the general population; and Covid-19 has increased the need to ensure that they have the right protections in place against discriminatory healthcare guidance and inappropriate treatment. Many parents / carers also have daily challenges balancing work and care, and in accessing appropriate levels of practical and financial support. This is exacerbated by the ongoing pandemic, leaving many without access to essential services and facing an uncertain future as lockdown eases but the virus remains present. It is vital that Government, organisations, individuals, and families work collaboratively to tackle the significant challenges posed by Covid-19 for people with a learning disability, especially when the long term societal and economic impacts remain unknown.

Key issues include:

Lack of data: The latest data in England shows that people with a learning disability are dying at double the rate than in previous years. No figures have been provided on the number of people with a learning disability and autism who have died because of suspected or confirmed Covid-19 in Northern Ireland; or the number of excess deaths amongst this population compared to the same period last year. It is vital that people with a learning disability in Northern Ireland are not forgotten in this crisis.

Reduction in essential services / increased isolation: Without a vaccine, the continued presence of the virus will result in greater isolation for some families as they continue to shield while wider society returns to a degree of normality - they cannot be expected to carry on in crisis for an unspecified period without appropriate levels of support. While the voluntary and community sector has moved swiftly to maintain and reshape services to ensure continued delivery for vulnerable people in challenging circumstances,¹ other essential services have been withdrawn or restricted. This is being reported by many organisations, and usefully illustrated by a recent Family Fund² survey of parents raising disabled or seriously ill children in NI. It found that, following the Covid-19 outbreak:

- Over two thirds (68%) of parents reported a decrease in formal support. The figure on the right highlights the range of paediatric, allied health and mental health support which were no longer being received.
- Over two thirds (67%) of parents reported a decrease in informal supports such as travel / transport (86%); recreation and play (82%); emotional support (62%); and information and advice (47%).



There also appears to be some inconsistency in provision across the different Health and Social Care Trusts. It is unclear what Trust-provided respite care facilities are still operational, and what if any additional services are being provided in each area to assist families caring for someone with a learning disability. We know that many parents / carers were

¹ For example, organisations in the APGLD Planning Group have reconfigured services such as outreach in the form of socially distanced visits and delivery of care / activity packs; and provided virtual programmes, including mentoring; service user forums/friendship sessions; training; youth clubs; TV shows and videos.

² Family Fund (2020) Impact of Covid-19 research <https://www.familyfund.org.uk/Handlers/Download.ashx?IDMF=0dcfffe-f803-41de-9a4a-ccc8fef282d4>

already under significant pressure and were barely coping even with a level of care and respite in place. A recent survey of carers in NI³ shows that:

- **78%** are providing more care during Covid-19
- **87%** are worried about their loved one getting ill
- **64%** are feeling overwhelmed and worried that they are going to burn out in the coming weeks.

Prolonged isolation over the course of the pandemic puts parents / carers at greater risk of experiencing chronic stress, anxiety, or depression. Little acknowledgment is given to the essential unpaid care they are providing 24-7 outside health settings for vulnerable children and adults, many with multiple conditions and complex needs. Some are providing home schooling on top of this, which parents with additional needs and who maybe cannot read or write are finding particularly challenging and are receiving little or no support.

Special Schools: The lack of service provision also extends to special schools, which is further compounding what is already a difficult situation for many families struggling to meet their children's needs. In addition to losing out on valuable learning, a lot of children are now without the allied health therapies and interventions they received during school. Parents experience of remote learning offered by the schools has been mixed, and they are facing a long summer with limited support and a lack of clarity about the shape of provision in September.

Employment: The proportion of working age disabled people in employment is much lower in Northern Ireland (35%) than in the rest of the UK (45-50%).⁴ While there are limited statistics, estimates suggest the employment rate for people with a learning disability is even lower, ranging between 9% - 17%.⁵ The European Social Fund (ESF) is the primary and consistent source of funding for employment projects for people with a disability / learning disability in NI. However, there is no clear plan in place to ensure continuous funding for ESF projects after March 2022, and it typically takes 3-5 years to develop a new programme. This situation is further compounded by Covid-19 and the uncertainty the ongoing pandemic and downturn in the economy will bring to current and future employment / training opportunities for disabled people. Many are employed in the hospitality and retail sectors, which are two of the worst affected sectors. It is important to consider that people with a disability are twice as likely to remain unemployed when they fall out of work for an extended period.⁶

Access to, and confidence using, technology: As more services move increasingly online, both now and in the future, this impacts on some people with a learning disability who do not have access to wi-fi and / or know how to use the internet. It is not simply a person's ability to use digital technology which poses a problem but also poor infrastructure; a lack of access to the necessary equipment; over cautiousness and concerns about online safety; and in some cases, a lack of knowledge amongst parents / carers and supporters.

Financial support: The Covid-19 crisis has highlighted several issues relating to funding, including:

- Parent / carers are currently under more pressure than ever and are not receiving a level of financial support which recognises their critical role.
- There is a lack of flexibility for people receiving Direct Payments to use resources creatively.
- Following the Covid-19 outbreak, nursing / residential living environments (care homes) were provided with an additional funding amount based on the number of residents, which they were able to access immediately. This package of support was not made available to alternative providers, such as supported living.
- To be entitled to Supporting People funding, an individual must be in receipt of Housing Benefit and therefore have no more than £16,000 savings. People with a learning disability are continuing to be supported throughout the pandemic, however their levels of choice and associated spending activity have significantly reduced, and there is a risk they could lose their benefit entitlement.

³ Carers UK (2020) Caring behind closed doors

⁴ Joseph Rowntree Foundation (JRF) (2016) A prosperous, poverty-free Northern Ireland. JRF, York

⁵ <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/employment-research-and-statistics>

⁶ Cited in Ulster University Economic Policy Unit (June 2020) Labour market implications of COVID-19: How have restrictions on work impacted different types of workers in Northern Ireland?

The APGLD is calling on the NI Executive to take the following actions:

- Undertake a full and accurate assessment of Covid-19-related deaths of people with a learning disability across all settings.
- Produce a plan to restore essential education and social care services for children and adults with a learning disability, clearly identifying the additional provision needed while Covid-19 remains present, and how independent and voluntary social care providers and families will be supported to respond. Ensure that the approach taken is joined up and consistent across HSC Trusts.
- Recognise family carers as key stakeholders and ensure a co-production approach is taken to involve them in the delivery of core services during the ongoing Covid-19 pandemic, and in the wider rebuilding of health and social care systems.
- Formally recognise the key role of families / carers in supporting their loved ones by committing to extending carers legislation to NI and thereby bringing the rights and entitlements of carers in NI in line with those across all other parts of the UK.
- Identify people with a learning disability and parent / carers as a priority group requiring emotional and mental health support services.
- Produce a strategy and action plan to support people with a disability / learning disability into training and employment following labour market disruption due to Covid-19; and provide clarification that there will be no gap between existing and new funding streams post-ESF.
- Invest in the necessary IT infrastructure to enable greater use of digital and technological support.

Financial support

- Increase financial support for carers through increasing Carers Allowance or introduce some form of supplementary payment for carers.
- Ensure that pending guidance addresses the lack of flexibility for people receiving Direct Payments to use resources creatively.
- Provide a similar package of additional funding received by nursing and residential care homes to alternative living environments, including supported living.
- Ensure a flexible approach is taken to the £16,000 savings threshold over which people could lose their entitlement to housing benefit, and as a result Supporting People funding.

