

The impact of COVID-19 on people with learning disabilities in Northern Ireland: Implications for policy and practice[1].

[1]This report is a co-production between a team from Ulster University led by Professor Laurence Taggart, Professor Roy McConkey, Dr Peter Mulhall and three organisations providing services and support to people with learning disabilities in Northern Ireland (CAN, Mencap NI and Positive Futures) and Families Involved in Northern Ireland (FINI). It forms part of a UK research project funded by the Medical Research Council with Professor Chris Hatton (Manchester Metropolitan University) and Professor Richard Hastings (University of Warwick) as Principal Investigators. Further details about the project are given in Appendix 1. The Appendices to accompany the report can be downloaded at: **https://www.ulster.ac.uk/covid-19-impact**.

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Overview

People with learning disabilities were more affected than other citizens in Northern Ireland by COVID-19 and by the actions taken by Government and statutory services.

They continue to experience many restrictions in accessing health and social care supports. These have not resumed to pre-COVID-19 levels.

Many family carers were left unsupported for many months with the sudden closure of day centres and respite services. Where services have resumed, they are not getting the same level of support they had before the pandemic.

Creative responses evolved during the pandemic which reinforce the need to urgently transform the policy and practices around learning disability services in Northern Ireland.

Action is needed by Government to address two immediate risks: further curtailment of health and social care services due to winter pressures in health services, and the difficulties in recruiting and retaining social care staff.

Government and service providers may soon face accusations of infringing the human rights of people with learning disabilities and of discriminatory practices.

1.0 Learning Disability in Northern Ireland

Children and adults with marked learning disabilities form around 1% of the Northern Ireland population; some 18,000 persons in all. Their need for additional health, social care and educational support is well recognised. Around 6% to 7% of the NI Department of Health budget is spent on learning disability services.

Most people with learning disabilities live with family carers; more so than in other parts of the UK and Ireland. Although more people are being supported to live in their own homes with people of their choosing, sizable numbers continue to live in group living schemes, residential care and nursing homes; more so than in other parts of the UK.

Although many adult persons with learning disabilities aspire to having an ordinary lifestyle - combining work, further education and training, alongside friendships and leisure pursuits - attendance at large day centres has been the dominant form of post-school provision; more so than in other parts of the UK.

The Bamford Review published their Equal Lives report 15 years ago. It detailed new policies for learning disability services and support for family carers. Although the recommendations were accepted by Government and Actions Plans were developed, many of their recommendations have yet to be fully implemented. Many people with learning disabilities still live in hospitals, in congregated residential settings, attend day centres with few in any form of employment and family carers getting less support.

Most people in Northern Ireland are still supported by statutory health and social care services with the private sector providing many of the residential and nursing home placements. Although the voluntary and community sectors have been to the fore in providing innovative, person-centred services, this has been for a relatively small proportion of service-users.

People with learning disabilities in Northern Ireland were disadvantaged even before COVID-19 and were put at greater risk from it because of the way services are delivered.

2.0 Research into the impact of COVID-19 on people with learning disabilities

Internationally a growing number of research studies have been undertaken into the impact of COVID-19 (see Appendix 2 for a review). Countries faced similar challenges with three dominant themes being How to Prevent, How to Mitigate, and How to Treat/Manage:

- **Prevention/Protection:** The provision of accessible, appropriate, and consistent information, e.g., maintaining social distancing, access to Personal Protective Equipment, shielding, track and trace, COVID-19 testing, access to vaccines, and training for support staff and persons with learning disabilities in infection control.

- **Mitigation:** making reasonable adjustments both to where people live, and to community healthcare/clinical practices; and the use of technology as a pandemic-response strategy.

- **Treatment/Management:** Access to acute hospitals and lifesaving equipment, 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.

In all countries, Governments found the money to expedite and implement changes in acute health services and infection control initiatives allied to new forms of community support. A great deal was achieved, and much learning has been gained in handling any future public health emergencies.

However, the primary focus was on responses to COVID-19 in acute hospitals and in public health strategies. Little consideration appears to have been given to the impact these measures would have on the social support needs of people with learning disabilities and their family carers.

Moreover, their additional health needs were largely ignored. Consequently, in England people with learning disabilities were six times more likely than their peers to die from COVID-19 and those with Down Syndrome, 12 times more likely. Those living in congregated settings were more likely to catch COVID-19 than those in community settings or living with families. However comparable data for Northern Ireland is not available.

There is growing international concern that the human rights of persons with learning disabilities continue to be infringed by actions taken during the COVID-19 pandemic. Also, reforms are needed to reduce the health inequalities they currently experience which exacerbated their vulnerability to COVID-19.

About this study

> ***As a parent of a learning-disabled adult of 43 years, after 20 years of managing his independent living arrangements and personal assistants, my husband and I found ourselves in March 2020 bringing him back to live with us. He had a shielding letter from his GP from the outset, so life has not been the same since.***
>
> ***This COVID-19 project has been invaluable in assuring us as a family that we were facing the same risks and challenges even though experience was varied and responded to in so many different ways. It has been a unique opportunity to hold a mirror to a special population enduring and emerging from a catastrophe that may have changed their lives forever.***
>
> ***It has been strangely comforting to share in this gathering of knowledge. The manner in which the questions evolved to match a changing environment and widened to capture our perception of how our world is changing, reveals not just our realism about the future but our optimism about a better life for our family members.***
>
> Words of a family carer: FINI

Current research studies have been based primarily on administrative data and the views and experiences of professional staff. A consortium of 22 UK researchers received funding from the Medical Research Council to hear how adult persons with learning disabilities in the four UK nations had been affected by COVID-19 and to examine if the restrictions had reduced for them.

The primary aim of the project was:

> ***'To identify the wellbeing, health, and social effects of the COVID-19 pandemic, including social restrictions and changes to how adults with learning disabilities were supported across the UK and to determine changes that occurred over nine months.'***

In all, 621 persons with mild and moderate learning disabilities were recruited (127 in Northern Ireland[2]) and individually interviewed by telephone or Zoom. The interviews started in December 2020 (just as restrictions were easing) and were repeated in April 2021 and August 2021.

Also 378 carers of persons with more severe or profound learning disability (62 in Northern Ireland) completed an online questionnaire on three occasions. In all, information was initially gathered on 999 persons.

This is one of the largest studies involving people with learning disabilities and family carers to date. See Appendix 1 for further details of the study.

The main findings are presented below with further details given in Appendix 3. In general, the same pattern of results was found across the four nations although ongoing analyses will highlight any significant differences pertinent to Northern Ireland.

[2] Northern Ireland was over-represented in the total UK sample based on its population.

3.0 Research Findings

A summary of the key findings is presented under pertinent themes.



3.1 COVID-19 Infections

Over half of all persons with learning disabilities had underlying health conditions that were of concern if they caught COVID-19. The most common were asthma and epilepsy.

People with learning disabilities contracted COVID-19 at a younger age, developed more severe symptoms and were at greater risk of hospitalisation with a higher mortality rate compared to the general population.

During 2020, just over 6% of people with learning disabilities had tested positive for COVID-19: the same percentage as for the total cumulative prevalence of people in the UK in the year. A further 4% thought they had COVID-19.

Of those testing positive or thought to have COVID-19, one in seven were hospitalised.

In all, 13% had some-one close to them that had died.

People with learning disabilities experienced COVID-19 at least to the same extent as the general population with some more severely affected and a higher mortality rate.

[3] The Appendices that accompany the report can be downloaded at: https://www.ulster.ac.uk/covid-19-impact)

3.2 Compliance with COVID-19 regulations

> ***There were pictures that explained to wash your hands and wear a mask. The pictures helped yeah. We knew how to be safe outside by wearing a mask and using hand sanitizer.***
>
> ***The staff gave me an easy read document about the COVID-19 vaccine.***
>
> ***I realised if I did not get it, I would have been more at risk due to some of my underlying conditions.***
>
> ***Staff could not have done anymore to help me understand COVID-19 – we were all in a difficult situation where rules kept changing – staff kept me updated but sometimes staff were confused themselves about rules and restrictions – but they did remarkably well in very difficult circumstances, they couldn't have done anymore.***
>
> Words from adults with learning disabilities about their COVID-19 experience: Positive Futures

During 2020 around one third of people had been tested for COVID-19: a higher percentage than the general population (20%). Just over one in ten tests were positive: a similar proportion to the general population. In August 2021, around 40% of people with learning disabilities reported having a COVID-19 test in the past four weeks.

Eight out of nine persons with milder learning disabilities wore a face mask when out. In August 2021, three quarters reported that mask wearing, and social distancing should be maintained even when restrictions were lifted.

In 2020, over four in five people stated they would take the vaccine if offered and by August 2021, 96% had been vaccinated with 86% willing to take a booster jab.

In August 2021, around 85% of persons reported it should be compulsory for support staff to be vaccinated.

One third of persons with milder learning disabilities had shielded at some point in 2020 which rose to over half with those who had more severe disabilities. These are much higher percentages than for a similar aged general population. By August 2021, the percentage shielding had dropped to less than 10%.

One quarter of persons with milder forms of learning disability had downloaded the COVID-19 App for their country and were using it. Although nearly all persons or their carers had access to a mobile device, many had not downloaded or used the App.

People with learning disabilities have been responsible citizens in complying with public health advice.

People with learning disabilities have difficulties accessing technology.



3.3 The impact on people's health

Nearly two in five people with learning disabilities rated their health as being 'OK' or 'not good' in 2020. This was still the case in August 2021.

Family carers considered that for nearly one third of persons with more severe disabilities, their health had worsened since the start of the pandemic.

In 2020, nearly two-thirds of people with learning disabilities reported feeling angry or frustrated, sad, or down, and worried or anxious at least some of the time over the last four weeks. By August 2021 this proportion still remained high at 60%.

Just under half of people who usually receive an annual health check, had not had one in 2020. By August 2021, this had risen to over 50%.

In 2020, around half of persons who regularly saw their GP, reported seeing them less with contacts mostly by phone. People also saw less of their community nurses, psychiatrists/psychologists/counsellors and therapists.

Around one quarter of persons had planned medical tests or hospital appointments cancelled in 2020.

The physical health and emotional wellbeing of people with a learning disability has not improved as restrictions have lifted.

Their access to health services continues to be limited.

3.4. Impact on social relationships

> *I cannot go and stay at my friend's house.*
>
> *The shop where I worked closed down during lock-down – I missed my work.*
>
> *I stayed in my flat watching TV – I couldn't see me friends.*
>
> *I couldn't visit my family last Christmas – I spent the day alone in my flat.*
>
> *I'm scunnered about COVID-19 – I can't see my daddy.*
>
> *They're talking about things getting worse – that's what's worrying me.*
>
> Words from adults with learning disabilities about their COVID-19 experience: CAN

During 2020, 70% of people living in supported accommodation or residential care were not allowed by service providers to have visitors into their home. This was also the case for 20% of people living with families or in their own accommodation. By August 2021, around 5% of persons with a milder learning disability still had restrictions placed upon them but these restrictions rose to 25% of those with more severe disabilities.

Two-thirds of persons with severe or profound learning disabilities were reported by carers to have reacted negatively to visitor restrictions: isolation, boredom, frustration, and confusion about why things had changed.

Over 60% of people with a milder learning disability no longer took part in any community activities (e.g., community groups, shopping, cafes) in 2020 but this rose to 85% for those with more severe disabilities. Others reported using community activities less than before COVID-19. By August 2021, around 50% were still not using community activities.

For the small number of people with learning disabilities who had paid work prior to COVID-19, just over 50% were still at work at the end of 2020. Likewise, only 30% of those who had been doing voluntary work were still active. By August 2021, fewer than 30% had paid work and only 10% were undertaking voluntary work.

In 2020, when people with learning disabilities were asked about what would make their lives better right now, participants responded for COVID-19 to go away, or everyone got vaccinated, this would make their lives better. Other responses included spending more time with family and friends, going out to do different things, to get back to work, or have increased hours at work, and going on holiday.

In August 2021, people were looking forward to everyday things like being able to go out again, seeing family, friends, and partners. Some people wanted to go on holiday but just over one in ten had been able to do so.

In August 2021, fewer than 5% of persons reported that their lives had got back to normal and another 10% felt it could happen by the end of 2021.

The social lives of people with learning disabilities were severely restricted during COVID-19 and have yet to fully recover.

I would like someone to help me get out of the house and deal with my fears.

Gateway club has stopped, church has stopped, my sister is not allowed into the supported living scheme to visit me. I am not allowed to go out for a walk with my sister.

See my girlfriend – have not seen her since after Christmas.

I wish I could see my family as I have not seen them in about a year.

See my friends and family... hugs, loads of hugs, see friends more, and travel.

The words of the N Ireland adults with learning disabilities interviewed during the COVID-19 study



3.5 Access to supports

> *If anyone had said that our son would be without his support services for up to 6 months, we would have thrown the towel in straight away. However, in the initial phase everyone was in the same boat and we just had to get on with it. After 19 months with limited return of services, we have made it clear to the Trust that we need to be looking for long term care for our son outside the family home. Detailed plans on how services will be returned was promised by the Health Minister, but we are still to be informed on any details.*
>
> *I have never felt so powerless and distressed than when I had to peer through a Perspex panel to see our daughter. I appreciate all the efforts by staff to keep her and the other residents safe during this devastating time, but my biggest regret is ever letting her leave the family home to live in a nursing home. She no longer attends her day centre or can come home at the weekends. I am 83 and my husband is 90 and I think this has been the worst thing we have ever had to cope with. We worry so much about her future. Will we ever be able to take her home again?*
>
> *I feel totally drained doing 24/7 care. There is no letup; no time to regain a few hours rest. This has been constant, unbroken care. I am feeling the strain of the restrictive measures and limitations and feel isolated being at home alone with my daughter. I cannot afford to pay anyone to give me a break. But I can't impose on other friends any longer. This is having a financial impact as well as emotional and mental.*
>
> *I feel that the Trusts/Government is making me do more than I am physically or mentally capable of and it is abusive.*
>
> Words of family carers from FINI

For people with learning disabilities who had received day services prior to COVID-19, 57% no longer received any statutory day services and a further 35% had a reduced service.

By August 2021, around one quarter had attended a day service in the last four weeks but for the majority of persons this was a reduced service of between 1 to 3 days.

For those who had attended Further Education Colleges, 50% no longer attended and 40% had a reduced hours.

For those who had received short (respite) breaks, 60% had none in 2020 and 45% had a reduction in their breaks. By August 2021, fewer than one in five had received a short break in the last four weeks.

For those with milder learning disabilities, half no longer had visits from their social worker, and this rose to nearly three-quarters for those with more severe disabilities. By August 2021, one quarter reported having contact with social workers; mainly by telephone.

The support from statutory services available to people with learning disabilities disappeared or were markedly reduced during 2020 and they have not resumed to pre-COVID-19 levels.

3.6 Impact on carers

> *Our worst nightmare began on the 24th March 2020. The day we were told it was lockdown in our daughter's residential home. The day her life and ours changed forever. Firstly, came the fear, then the danger to our daughter's health and wellbeing. We knew from that day things would never be the same again in our lifetime.*
>
> *We are both in our late 70's. We almost collapsed with the pain and fear in our hearts for our very dear and special vulnerable wee daughter.*
>
> *The two of us held onto each other as we stood in the kitchen trying to understand the feelings of helplessness and the enormity of what lay ahead.*
>
> *Our daughter aged 51 is confined to a wheelchair and completely dependent on others to keep her healthy and safe and happy 24/7. She has severe learning disability, epilepsy and cerebral palsy and many other medical problems. How would she cope? We had never ever felt so helpless, so fearful or distraught. We couldn't reach out to her, touch her, or give her a hug. We did try to talk through a window, but it was impossible to make ourselves heard due to the traffic from a main road nearby. We did try to see each other on video calls but that was very difficult due to poor signal. It broke our hearts watching her become a little prisoner in a care home and a care system not fit for adults like our daughter.*
>
> *Is this the 21st Century? Why are adults with a severe learning disability so totally misunderstood, neglected, ignored, and don't have a voice?*
>
> *To this day our nightmare continues! Our daughter no longer has access to her outside world. The bus doesn't arrive anymore to take her to the day centre she attended five days a week. The special place she went to be with her friends and the staff who taught her so much and were such an important part of her little life. Instead, she mostly spends every day now fully vaccinated in a room looking at the TV with other residents and trying to understand why they've been forgotten.*
>
> *She is living her own nightmare each and every day.*
>
> Words of one family carer from FINI

In December 2020, one quarter of carers reported that they had difficulty finding accurate information about how COVID-19 affected them. A further quarter had some difficulties. The same pattern was reported in August 2021.

The most frequently reported ways that family carers' health had been affected by their caring role in the last four weeks during 2020 were general feelings of stress (65%), feeling tired (64%) and disturbed sleep (57%). Similar percentages were reported in August 2021.

One in seven carers reported having to contact their own GP in the last four weeks regarding their own health in 2020 and also in August 2021.

When family carers were asked what would make their life better right now, a common response was that having some respite from caring, with many participants indicating that they had not had a proper break, or any "me time" for a very long time.

Family carers have had to take on increased caring roles on a 24/7 basis for much of 2020 and this is continuing into 2021 as service reductions persist.

4.0 Policy and Practice Issues that need to be addressed



The findings from this study, alongside those from other reviews undertaken in Northern Ireland (see Appendix 2) and the international evidence-base, suggest the following policy and practice issues need to be addressed.

- Learning disability services need to be better prepared to cope with emergencies, such as COVID-19 and future pandemics. This includes related issues such as staff shortages which at the time of writing seems to be a current and critical threat.
- The public health response to a health emergency needs to take account of the impact on people's social and emotional wellbeing, their quality of life, and their rights to equality of treatment and opportunity. This is particularly true with vulnerable groups such as people with learning disabilities who are already more likely to experience loneliness, social isolation, and barriers to accessing healthcare.
- Social care services in Northern Ireland were already over-stretched and under-funded prior to COVID-19. The recommendations around Transforming Social Care that are longstanding, need to be speedily implemented as emphasised in the recent UK Parliamentary Joint Committee into the response to Coronavirus. The fear is that any additional resources will continue to be directed to acute health services.
- Learning disability services in Northern Ireland are still overly reliant on congregated residential and day services rather than offering person-centred, individualised supports. It is the latter that have been more resilient in keeping people safe during COVID-19 and in providing continuity of diverse supports during lock-downs. This is evident in reviews undertaken of the services provided by the voluntary sector in N. Ireland.

> ***I feel they are using the pandemic as an excuse to cut services and save money. There has been a lack of initiative to provide alternative services to compensate for reduced day centre hours and respite for adults. If special education schools could do it why not social care services for adults with learning disabilities.***
>
> ***I feel that the Trusts/Government is making me do more than I am physically or mentally capable of and it is abusive.***
>
> Words of family carers from FINI

5.0 Recommendations

5.1 Preparing for further COVID-19 outbreaks and lockdowns

Official guidance from government agencies in relation to COVID-19 should be reviewed to ensure that it considers the needs of persons with learning disability and their carers.

- This review should be undertaken in consultation with family carers, those managing services for persons with learning disability, and it should be informed by available guidance from other jurisdictions and professional bodies.
- The guidance should be consistent across all agencies.
- This guidance must be presented by services to the persons with learning disabilities, family carers and frontline staff in accessible language and using various modes of communication and technology.

Services need to have in place individualised and service contingency plans for the continuation of supports to each person with learning disabilities to whom they provide services.

- Similar plans should be drawn up for supports to be provided to family carers.
- The plans must include access to PPE and the management of staff absences.
- These plans should be based on assessments of managed risks that balance the safety of persons with their emotional and social wellbeing, and that of family carers. The plans should be agreed with regulators and contractors.



5.2 Recovery planning

As a matter of urgency, inter-sectoral plans based on a dynamic risk assessment need to be developed for the resumption of supports to family carers and their speedy implementation.

- These plans must involve family carers in their design.
- This work needs to be continued beyond COVID-19 as it forms a key element of the reform of adult social care and the supports provided to family carers of people with learning disabilities.
- Existing policy documents – revised and extended as needed – can guide this work which should be informed from experiences in neighbouring jurisdictions.
- Greater use should be made of self-directed supports and personal budgets that are more commonly used in Great Britain.
- The current crisis in workforce issues need to be addressed in partnership across all sectors (statutory, voluntary and private) involved in the provision of services to people with learning disability; starting with the workforce issues arising from COVID-19. The establishment of the Social Care Fair Work Forum is welcome, but its work needs to be speedily progressed.
- This work must address the wider issues around disparities in terms and conditions across the sector and take account of the proposals contained in the reform of social care in the Power to People Report (see Appendix 3).

5.3 New models of service provision

The Department of Health should ensure that the proposed New Service Model for Learning Disability Services being developed by the HSC Board is validated with persons with learning disabilities, family carers and current service providers.

Two major gaps need to be urgently addressed. First, guidance is needed on the partnerships that are required to underpin the model in line with the Department's Co-Production Guidance. Second, financial analyses are needed as to how the model will be funded; from the redeployment of existing resources as well as the new resources required.

- The model should contain proposals that direct commissioners of services to shift from congregated service settings to person-centred, individualised services.
- Regulators and contractors need to agree on, and to support and endorse new models of service delivery and administration.
- Departmental oversight is needed to ensure that agreed policies are implemented. As this has failed to happen in the past, changes must be made in departmental responsibilities or in the delegation thereof.

6.0 Proposed next steps

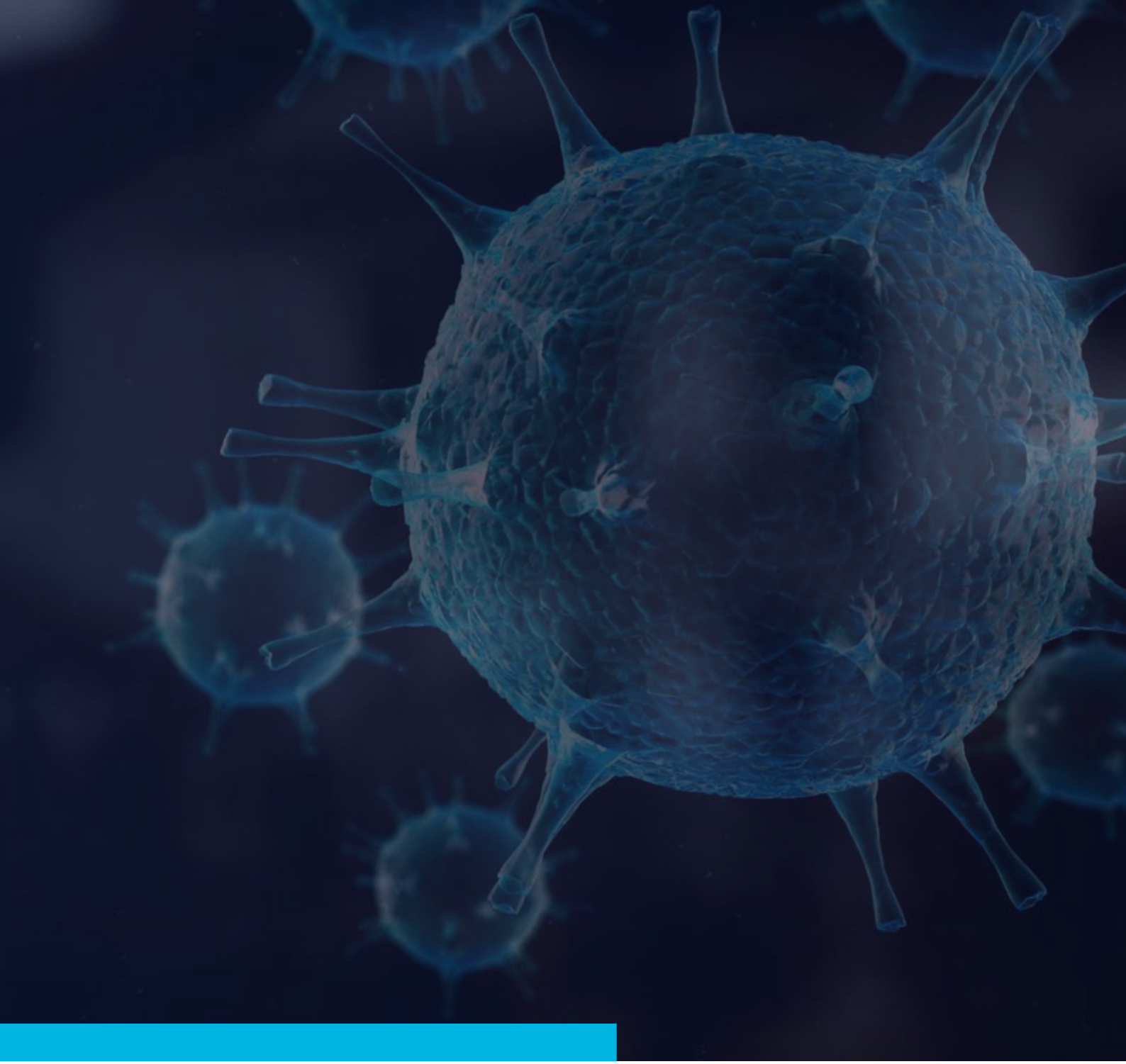
Feedback sessions are being organised by each of the partner organisations in Northern Ireland. These will help to validate the content of the report and endorse its recommendations.

In late November the report will be circulated to all stakeholders in learning disability who have been previously informed about the study along with the media.

The report will be discussed with the NI Assembly, All-Party Group for Learning Disability on 3rd December 2021.

Similar reports for Scotland, Wales and England are in preparation and will be made available to provide a broader context for decision-making within Northern Ireland.

If invited, the team leading the study are happy to meet with Ministers, Committees, officials to discuss the findings and assist with future planning.



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