A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland.

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The independent review was commissioned by ARC (NI) and funded in part by the Department of Health (NI).

Format of the report

The report is in the form of an extended executive summary of the review findings and recommendations with a series of Appendices that provide more detailed information on specific issues.

Contents

Acknowledgements

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Disclaimer

The contents of this report and the views expressed in it are those of the author. They should not be taken to represent the views of ARC (NI), their member organisations or members of the Steering group.

Executive Summary of Review Findings and Recommendations

Background to the review

Learning Disability is a life-long condition that affects cognitive and social functioning resulting in the need for ongoing support and supervision for many persons throughout their life. In Northern Ireland, most people live with family carers often into their old age. They too require support.

There are no accurate figures of the number of adult persons with a learning disability receiving health and social care in Northern Ireland[1]. Estimates vary from around 8,000 persons known to HSC Trusts (reported in 2015) to around 14,000 (based on 1% administrative prevalence rate in the adult population of NI)[2].

The Learning Disability programme of care accounts for at least 7% of the Health and Social Care budget in Northern Ireland[3]: a spend of around £370 million in 2018-2019[4]. A breakdown of this spending is not available from the five HSC trusts who are in receipt of most of the monies for the provision of services which they directly provide or through contracts with non-statutory providers. A relatively small proportion of these monies are for services delivered by voluntary providers.

The non-statutory sector provides a range of services for people with a learning disability and their families across the five HSC trust areas. This includes supporting living, residential and nursing homes, day opportunities, vocational training and supported employment, short break (respite) for family carers, leisure and advocacy schemes. Their funding comes from HSC trusts, Supporting People, ESF and charitable grants (see Appendix 1).

From March 2020 onwards, Covid-19 caused a major disruption of services to people with learning disability and their families. This rapid review was commissioned by ARC-NI. This was in response to their member's concerns that the learning from Covid-19 be captured and shared in order to highlight the impact on people with learning disability and their family carers and the effective responses made by services. Equally the review could identify the implications for future working relationships with the statutory sector and governmental agencies.

An independent consultant to undertake the review was selected from persons who responded to an expression of interest request publicised by ARC-NI. A Steering Group was appointed and the Department of Health agreed to part fund the review.

Aims of the review

1. To review and evaluate, from a providers' perspective, what has worked well and not so well during the Covid crisis, with a view to building on positive achievements and ways of working, so as to strengthen the capacity of the sector in the event of a second wave of Covid;

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[1] Murphy, E. (2014) Statistics on People with Learning Disabilities in Northern Ireland. NI Assembly: Research and Information Service, Briefing Paper 50/14.

2 Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. (2011) Prevalence of intellectual disability: a meta-analysis of population-based studies. Research in Developmental Disabilities. 32(2):419-36.

[3] RQIA (2016) Review of Adult Learning Disability Community Services Phase II, October 2016

[4] Northern Ireland Budget 2019-20 – Explanatory Notes & Tables

2. To identify how to enhance relationships and new ways of working that could deliver better outcomes for people with a learning disability and their families in Northern Ireland;
3. To examine the pivotal role of the community and voluntary sector in the ongoing delivery of services and in planning for, and responding to, HSC crises in NI.

Information gathered

- One-to-one interviews were conducted by Zoom with 23 senior staff from 17 services who are members of ARC-NI. These services represented the diversity among the ARC-NI membership. Also an interview was undertaken the ARC Director for Northern Ireland.
- An online, self-completion survey was completed by respondents from a further 10 services.
- An online meeting was held with HSC Board staff and the Assistant Directors in the five HSC trusts responsible for learning disability services. An interview took place with the Director for Learning Disability Services in the Department of Health.
- A documentary review was undertaken of pertinent guidance relating to Covid-19 and for learning disability services in particular (see Appendix 3).
- In order to contextualise this review, an analysis was undertaken of the actions taken in Northern Ireland in relation to the reform of adult social care and to learning disability services in particular (See Appendix 6). The contribution of the voluntary sector to learning disability services was analysed (see Appendix 7).

Further details about the review methodology are given in Appendix 4. Time and resources for the review were limited. As a consequence, the views of other stake-holders were not fully explored: notably those of service-users and family carers. However plans are in hand for this to happen in a UK-wide project funded by the Medical Research Council due to begin in November 2020[5].

Outcomes from the Review

The outcomes from the review are presented under the three aims set for it. They are presented both as a record of what took place over the past six months and as a guide for how services can be better prepared in the future. The latter includes new ways of working which the Covid experience hastened but which hold promise for creating more efficient and effective services for persons with learning disability and their families.

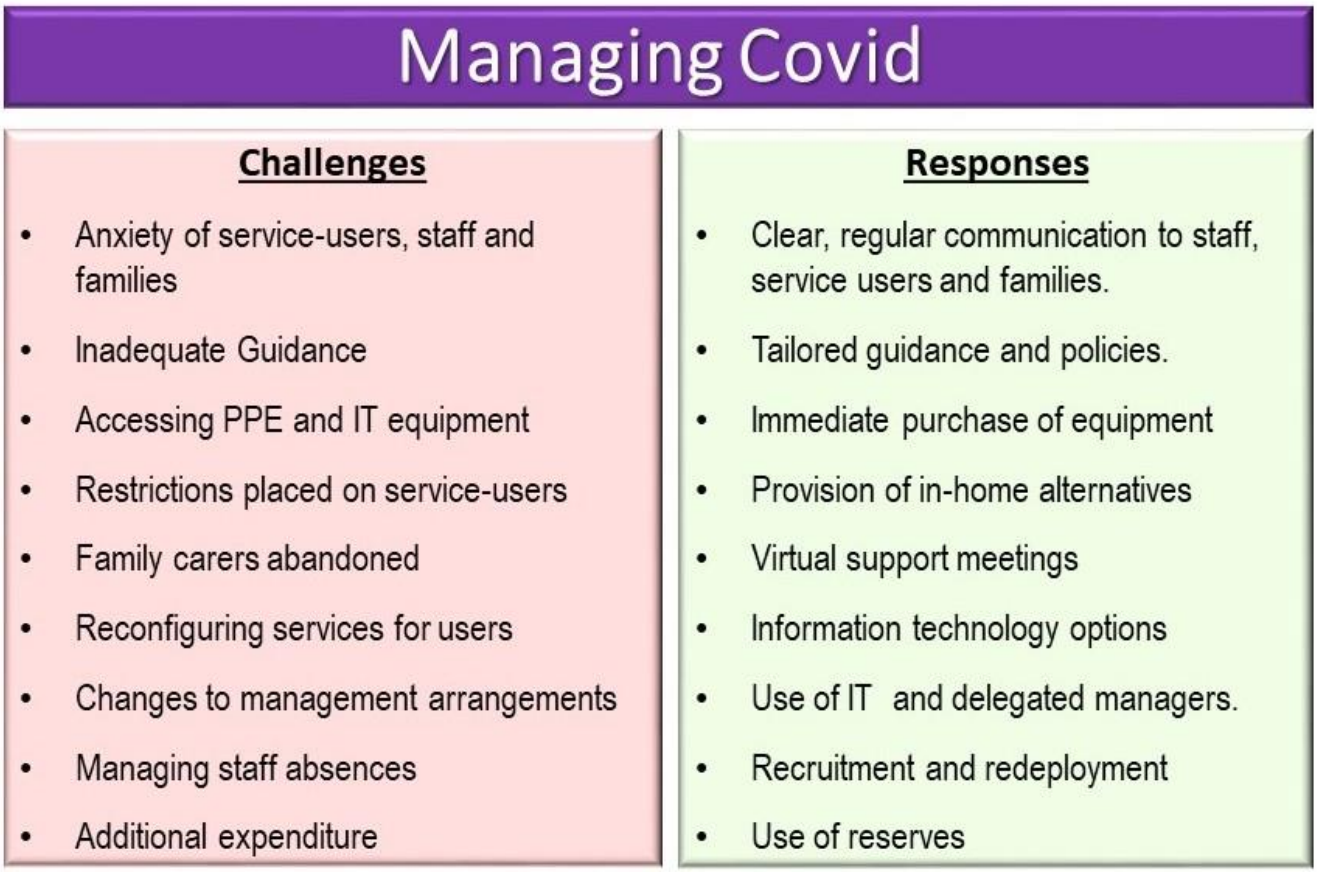
Aim 1: The Impact of Covid-19

Respondents to the review described the last six months as 'unprecedented' and the initial unrelenting pressures experienced by them during April and May. The closure or suspension of the services was never considered as an option. The services were so strongly committed to supporting the people they serve that they saw no other alternative but to continue regardless of the personal and financial resources required. However this decision meant that familiar routines had to be speedily recast. Figure 1 overleaf summarises the specific challenges reported mainly by ARC-NI

[5] https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability

respondents and the main steps they had taken in response to them. Fuller details are given in Appendix 5.

The challenge services faced are listed individually in the Figure, but each impacted on the other, creating a 'never-ending' succession of challenges. Consequently, the senior management staff often worked 12 hour days, seven days a week. Likewise many front-line staff showed extraordinary commitment in working longer hours or double shifts.



The Figure lists the main responses that were commonly made across the sector and Appendix 5 describes them in more detail. Although these responses recurred across organisations, the salience of them varied according to the type of services they provided as described in Appendix 1.

Many of the challenges and responses are echoed in the findings of the rapid learning initiative of Covid-19 and care homes in Northern Ireland (summarised in Appendix 3) and in the specific guidance that has emerged in relation to learning disability from bodies such as Public Health England (see also Appendix 3).

In addition, respondents noted the factors that had contributed to the success of their responses:

- the coherent and visible leadership given by experienced and long-serving senior managers;
- a focus on positivity - 'can-do' approach;
- being confident and self-reliant in decision-making while taking advice from other organisations. ARC-NI had been especially helpful.
- the diversity of services offered within organisations enabled speedy transfer of staff and expertise;

- increased and regular engagement with Board members/Trustees which boosted the organisation's expertise and gave confidence in their decision-making.

When respondents were asked to identify their proudest achievements, the three most commonly mentioned were that their services were largely Covid free, services to users were maintained or quickly resumed and their staff responded 'magnificently': "running to the fire rather than away from it".

The main frustration encountered was the 'avalanche' of conflicting, inappropriate guidance that descended on them and which had to be interpreted for service users with learning disability, family carers as well as their staff. Respondents were angry with the lack of consultation with the non-statutory sector and the reduction in support available to them from statutory services especially when the closure of their services had immediate consequences for their operations.

In summary, Covid-19 tested the resilience of the voluntary sector as never before. The learning captured in this and other reviews, will enable them to be better prepared for any further lock-downs or similar emergencies. The responses that services created are a valuable compendium from which others can learn.

Aim 2: Enhancing partnerships

Covid-19 highlighted the importance of relationships and partnerships in successfully reconfiguring services: an endorsement, if one were needed, of the Department's Guidance on Co-Production[6] of partnerships as being essential to transformational change in health and social care. *"Co-production … reflects the need for distributed leadership and distributed ownership of policy, strategy and delivery within and across systems" (p.33).*

In this review, respondents from the non-statutory sector expressed concerns about the power imbalance they had encountered in forging partnerships with statutory agencies. They also noted difficulties in partnership working with other non-statutory providers. Equally statutory providers pointed to the difficulties they had experienced with certain non-statutory providers at various times around over-promising, inflated costs, contract compliance and the fragmentation of the sector.

Among the obstacles identified to partnership working prior to and during Covid were: differences in values and priorities; lack of recognition of expertise; few opportunities to build relationships across sectors; short-term contracting and financial constraints. Further details are given in Appendix 5.

Given the multiplicity of providers and personalities involved in service delivery, disagreements are inevitable and inequities in practices will arise. But it is important to tackle systematic obstacles that threaten the creation of robust partnerships between the statutory and non-statutory sectors which are arguably even more vital in the post-Covid era. Partnerships need to be built on respectful, supportive and trusted relationships that are cognisant of the constraints within which each sector

[6] Department of Health (2018) Co-production Guide: Connecting and Realising Value Through People. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/health/HSCB-Co-Production-Guide.pdf

operates. These values apply equally to partnerships that each sector needs to build with service users, family carers and service staff in order to ensure they are co-produced.

Among the examples for building partnerships in learning disability services were:

- Common endorsement of shared vision and values for learning disability services.
- Parity of esteem is given to the expertise in non-statutory sector learning disability services by Government Departments, commissioners and HSC trusts.
- Personalisation of supports need to be promoted and reliance on communal service settings such as care homes and day centres needs to reduce. The Covid-19 experience has given extra incentive for this transformation.
- Northern Ireland seems to have lagged behind the rest of the UK in the use of direct payments and self-directed support as a means of implementing the personalisation of services and widening choice and opportunities for service users and family carers.
- Greater emphasis needs to be placed on evidencing outcomes for service users in all sectors rather than a focus on activity monitoring. Cost-effectiveness needs to be demonstrated.

Good examples of partnership working and co-production are present in learning disability services but they can be improved so that services become more resilient, efficient and effective in responding to the needs of people with learning disability and their family carers. Service leaders need to be committed to nurturing partnerships.

Aim 3: The pivotal role of the community and voluntary sector

The so-called 'mixed economy' within learning disability services in the UK is not just a historical accident. The devolution from mostly statutory provided services in recent years has served various purposes although cost savings have been a potent reason. Arguably Covid-19 raises the issue as to whether the voluntary sector played a pivotal role in responding to the needs of people with learning disability. And if so, should their contribution become even more important in the future?

Respondents to the review clearly felt the sector had played a pivotal role in maintaining supports to their service-users and indeed extending them to other family carers who were outwith their services. The sector felt it had played a leading role in advocating for the needs of persons with learning disability with government departments, political representatives and HSC agencies. ARC-NI had played a valuable role in uniting the voluntary sector around a common challenge. Moreover the expertise gained in adjusting Covid-19 guidance to settings such as supported living is a resource that can be shared more widely with other client groups and similar community services. The use of information technology with service users increased greatly during Covid-19 and forms a basis for new forms of service delivery.

But their contribution goes deeper (see Appendix 7). The sector has been to the fore in creating and implementing a variety of person-centred, community-based services that were envisaged in governmental reviews such as Bamford. They have been able to draw down funding from a diversity of sources which reduced the financial contributions from HSC. They are locality-based and can draw on community resources and volunteers to further the social inclusion of their service users.

The sector is well regulated, governed and managed. Annual reports and financial accounts are publicly available as are inspection reports for their regulated services.

Respondents cited various impediments to a flourishing voluntary sector and the pivotal role they could play in the recovery plans post-Covid and the transformation of social care. These included:

- The dilution of the ethos that motivates and sustains voluntary services through requirements imposed by commissioners and regulators.
- The re-creation of institutionalised thinking and approaches based around financial considerations that is at variance with government policy and the person-centred, community-based services that demonstrably enhance a person's quality of life.
- The competitive tendering process has reinforced a sense of competition among voluntary providers which has fostered a reluctance to share details of their operations with one another or to engage in partnership or consortia bids. Also it results in contract-driven services rather than ones based around vision, values and the needs of service-users.
- A failure across all providers to coalesce around an evidence-based, action plan for service reforms and to build alliances to lobby for change.
- The capacity and funding of the voluntary sector as service providers needs strengthened.
- The bureaucracy and duplication across statutory health and social services - Departments, PHA, HSC Board, RQIA and Five HSC Trusts – and with other government departments and agencies.

Similar issues are echoed in the reviews of adult social care (see Appendix 6). A valuable outcome from the Covid-19 experience might be a renewed determination in Northern Ireland to transform the provision of social care to adults with learning disability and their family carers; to which the voluntary sector can make a major contribution.

The voluntary sector has played a pivotal role in the provision of learning disability services in Northern Ireland before and during Covid and will likely continue to do so in the future. There is a need for their contribution to be enhanced and extended both at a local and regional level. This should form part of the transformation of adult social care.

Conclusions and recommendations

The key messages from this review as voiced by respondents are summarised below along with eight recommendations arising from them which are noted in italics.

- People with a learning disability are particularly vulnerable to the impact of Covid-19 in terms of the restrictions placed on them, the withdrawal of familiar support services and the increased risk of death (see Appendix 2). However 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.

1. *Services need to have in place individualised and service contingency plans for the continuation of supports to persons with learning disability and their families in the event of further Covid surges or similar emergencies. The plans must include access to PPE and the management of staff absences. These plans should be based on shared risk assessments with regulators and contractors that balance the safety of persons with their emotional and social wellbeing.*

- 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. Over the past six months revised guidance has been available but a lack of consultation remains an issue beyond Covid-19.
- The heightened anxieties of service-users, family carers and frontline staff were addressed through regular, clear and personalised communications.

2. *Official guidance from government agencies in relation to Covid-19 should take into account the needs of persons with learning disability. The guidance should be developed in consultation with those managing services for persons with learning disability and be informed by available guidance from other jurisdictions and professional bodies* (see Appendix 3). *This guidance must be presented by services to their service-users, family carers and frontline staff in accessible language and using various modes of communication.*

- 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. New forms of support, based around various information technologies, evolved jointly with service-users. The most popular and successful ones should be incorporated into future provision.
- In terms of service management, new ways of working in response to Covid-19 have proved effective and should be retained as they are more cost-efficient. This includes administrative procedures, online meetings and changes to the recruitment and training of staff.

3. *This report should be shared with ARC-NI members and to service providers across all sectors as an example of shared learning that a networking organisation can produce. Regulators and contractors need to agree on, and to support and endorse new models of service delivery and administration.*

- Responding to Covid 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. Their commitment to, and knowledge of service-users was unrivalled as was their expertise is making adjustments to meeting their needs in very constrained circumstances. As with the wider social care sector, the staff in non-statutory services felt under-appreciated and under-valued in contrast with the focus on NHS staff.
- The introduction of new procedures for the recruitment, induction and training of new staff resulted in increased applications and speedier filling of vacancies. These changes may need to be maintained in order to cover increases in staff absences in future surges.

4. *Workforce issues need to be addressed in partnership across all sectors involved in the provision of services to people with learning disability; starting with the workforce issues arising from Covid. However this beginning should continue and 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 6).*

- 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.

5. *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. This work needs to be continued beyond Covid as it forms a key element of the reform of social care and the supports provided to family carers of people with learning disabilities. Existing policy documents can guide this work which should be informed from experiences in neighbouring jurisdictions.*

- The response of learning disability services provided by ARC-NI members during the Covid-19 surge confirmed the robustness of the sector in responding effectively to an unprecedented situation despite the loss of income they experienced. Their increased expenditure has not been fully covered in terms of both pay and non-pay revenues costs. Assurances also need to be given regarding continuity of contracts in 2021/2022 to ensure the financial stability of the services provided by the non-statutory sector.

6. *To ensure uniformity across all HSC trusts and service providers, the HSC Board needs to issue instructions for the payment of claims for additional expenditures in this financial year in accordance with the guidance that has been issued. Agreements for the continuation of services in 2021/22 need to be made urgently*.

- ARC-NI played a key role in advising and guiding their members in the absence of appropriate Covid guidance from HSC agencies as well as facilitating the sharing of knowledge across members and liaising with the Department of Health.

- More broadly, the voluntary and community sector in Northern Ireland has made a major contribution to transforming the social care provided to persons with learning disability, notably towards a more person-centred, community-based approach. Their experience and expertise qualify them to be full partners with statutory services in the process of recovery and renewal of services Post-Covid in line with the aspirations for the transformation of adult social care (see Appendix 6 and 7).

7. *ARC-NI is uniquely placed to become the lead body for non-statutory providers of services to people with learning disability that can partner with government departments, other HSC agencies and RQIA as envisaged in the Department's Co-Production guidance. ARC-NI needs increased resources to undertake this function.*

- Covid 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. Such a strategy would contribute to, as well as benefit from a concerted effort to implement the long-awaited reform of adult social care.

8. *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 non-statutory providers and contains guidance on the partnerships that are required to underpin the model in line with the Department's Co-Production Guidance.*

Covid was a stimulus to greater partnership working within and across service providers, and between different sectors. This momentum needs to be maintained so that existing services are more resilient to unexpected challenges. And there is greater purpose: to produce more effective and efficient services that will improve the quality of life of persons with learning disability and their family carers. In recent months they have sacrificed much. The least we can do in return, is to ensure they have a better future.

Appendix 1: Membership of ARC NI.

This Appendix describes ARC-NI and lists its membership as at September 2020. In a second part, information is provided on the services provided by ARC-NI members and the impact Covid-19 had on their service-users and staff.

Association for Real Change (ARC)

ARC is a UK wide charity that operates since 1982 in all four nation countries. Its Board consists for five trustees drawn from member organisations across the UK. There is no separate board for NI. ARC is a company limited by guarantee with activities overseen by Companies House and the relevant Charity Commissions for England and Scotland. The accounts are held centrally with no separate bank account for each nation. Each nation makes a contribution from their income for the shared services provided by ARC centrally such as finance, HR and Health and Safety. Otherwise they act fairly autonomously in each country.

ARC-NI started in 1999 and has a fulltime Director for Northern Ireland. In September 2020 a further three staff were in employment. The income for ARC-NI is derived from three sources: membership fees, training activities and projects. No core funding is provided from any of the statutory agencies.

The accounts are held centrally with no separate bank account for NI. In 2019/20 the turn-over nationally was nearly £2 million and of this £215,000 was for ARC-NI. A Strategic review of ARC-NI is planned for late 2020.

Current members are organisations from within the voluntary, private and statutory sector and this diversity is welcomed as it encourages cross-sector collaboration.

The member organisations as at September 2020 is given overleaf (* Indicates organisations who contributed to the individual interviews).

ARC-NI is also listed as a provider agency through the funding it receives for its advocacy projects (TILLI) in Belfast/Lisburn, Fermanagh, Downpatrick and Bangor and in Muckamore Abbey Hospital. These are funded by HSC trusts.

ARC exists to improve the quality of life for people who have a learning disability by supporting anyone who is involved in the planning or delivery of support and services. Details of the services ARC-NI provides are available at: https://arcuk.org.uk/northernireland/. These include advocacy, training courses and workstreams/forums on common issues including Adult safeguarding, senior managers think-tank and RQIA & ARC Executive Exchange.

Members of ARC-NI

Action Mental Health

Apex*

ARC-NI*

Autism Initiatives

The Beeches Professional & Therapeutic Services Ltd*

Belfast Central Mission

Belfast Health & Social Care Trust

Camphill Community, Clanbogan*

Clanabogan Camphill Community, Glencraig*

Camphill Community, Holywood

Camphill Community, Mourne Grange

Camphill Communities Trust NI

CAN*

Caring Breaks*

Castleview Private Nursing Home*

Cedar Foundation*

Clanmil Housing Association

Cornerstone Care 212 Ltd

The Croft Community

Derg Valley Care

Extra Care

Four Seasons Healthcare

Friendship & Caring Trust Ltd (FACT Ltd)

Harmoni

incredABLE (formerly Enable NI)*

Inspire Wellbeing

Kilcreggan Homes Ltd*

L'Arche Belfast

Leonard Cheshire*

Livability

Mainstay DRP*

Mencap NI*

MindWise

Northern Health & Social Care Trust

Orchardville Society Ltd*

Parkanaur College

Priory Adult Care

Positive Futures*

Potens

Praxis Care*

Presbyterian Council for Social Witness

Shelter NI

South-Eastern Health & Social Care Trust

Southern Health & Social Care Trust

Trackers Ltd

Triangle Housing Association*

Western Health & Social Care Trust

**Members that took part in interviews*

Part 2: Learning Disability services delivered by ARC-NI members

Of the 47 members of ARC-NI listed they can be grouped as follows:

- 14 Large Voluntary organisations mainly for persons with learning disability *(Annual Turn over £1m plus)*
- 11 Small voluntary organisations mainly for persons with learning disability
- 8 Voluntary organisations for other social care groups but including some persons with learning disability
- 3 Housing Associations for other social care groups including those with learning disability
- 6 Private sector providers mainly for persons with learning disability.
- 5 Statutory sector HSC trusts

Details about the number of service users with learning disability and associated staffing were provided by 20 non-statutory organisations from across this spread of providers (10 large voluntary organisations for persons with learning disability; 4 small voluntary organisations for persons with learning disability; 2 Voluntary providers of different social care groups; 2 Housing associations; 2 Private providers.) Hence the information given below is an under-estimate for the ARC-NI membership as a whole. All the large voluntary providers of learning disability services are members of ARC-NI and only one of whom failed to provide information on their services. Also there may be other small voluntary organisation who are not members of ARC-NI.

In addition there are many other private providers (mostly residential and nursing homes) and the HSC trusts are also direct service providers mostly of day centres, in-patient assessment and treatments services, and clinical and social work personnel. In due course, comparative data about the impact of Covid-19 in these sectors on the services they provide to people with learning disability may also be forthcoming[7].

Services provided

The following services were provided by the 20 organisations who responded to an online questionnaire (the number of services is given in brackets): Supported living (13); Day Opportunities (11); Domiciliary/Floating support (9); Respite/Short breaks (9); Residential/ Nursing Homes (8); Advocacy (4); Vocational training/Supported employment (4) and Family Support (3).

The number of organisations taking referrals from each HSC Trust area is: Belfast (14); South-Eastern (14); Northern (13); Southern (10) and Western (8).

The 20 organisations provided services to both children and adults across a range of impairments conditions as well as learning disability. These included autism (8 services for children and 19 adults);

[7] The rapid learning initiative into transmission of Covid-19 into and within care homes in Northern Ireland collected information on people with a learning disability but they were not differentiated in the report (see Appendix 3).

mental health difficulties (3 children and 9 adults); acquired brain injury (3 children and 10 adults); and 5 for elderly adults.

The 20 services had a median of 160 service-users (range 15 to @ 2,500) serving nearly 10,000 persons in total (this includes persons with other impairment conditions). They had a median of 140 staff per service, both full-time and part-time (range 10 to 1,500) totalling over 5,000 persons.

Impact of Covid

In 11 services, no service-users had tested positive for Covid-19 but 32 had done so in eight services (range 1 to 15 -the latter was across all service-users including elderly persons).

In 8 services no staff had tested positive for Covid-19 but 48 staff had done so in 12 services (range 1 to 9).

The number of service-users who had to shield for 14 days or more, was not known in four services. However an estimated 100 service-users in total had to do so (range 2 to 25). These figures are across all service-users.

Three services had no staff who were required to shield but in total 460 staff across the other 17 services had shielded (range 1 to 60).

In 14 services, no service-users were hospitalised because of Covid-19, but 11 persons had been admitted in four services. Five service users died from two services (including persons others than those with learning disabilities).

In only one service were two members of staff hospitalised with no deaths.

Impact on staffing

The highest number of staff absences at any one time ranged from 1 to 63 in 18 services.

Around 220 staff from 14 services (range 2 to 47) were furloughed in the past six months.

In all 23 staff from five services were made redundant (12 of which had been planned due to the ending of a contract with a commercial organisation).

Recruitment of new staff occurred in 17 services, over 400 in all (range 1 to 134).

There were around 80 redeployments in 11 services (range 1 to 41) mostly internally within the same service. One service reported redeployment of three staff from an HSC trust for a couple of weeks.

Conclusions

The non-statutory sector involved with persons with learning disability who are members of ARC-NI is diverse in size and nature.

The services that provided information are present in all five trust areas; providing a range of services to children and adults; including persons with impairments other than learning disability.

Fairly small numbers of service-users and staff had tested positive for Covid-19 and even smaller numbers of them had been hospitalised although five service users had died (0.05% of the total number of persons served by these organisations).

The impact on staffing levels was relatively minor with the speedy recruitment of new staff off-setting the low proportion of staff absences as did redeployment of staff from within the services.

Appendix 2: The increased vulnerability of people with learning disabilities to Covid-19.

People with learning disability have experienced greater excess deaths from Covid-19 as well as being disproportionately affected by the lock-down procedures implemented by the UK Government and the four devolved administrations.

Increased mortality

The Care Quality Commission for England and Wales undertook an analysis of excess deaths from 10 April to 15 May 2020 of persons with learning disability (CQC, June 2020). "This analysis looked at all deaths notified to CQC between 10 April and 15 May from providers registered with CQC who provide care to people with a learning disability and/or autism (including providers of adult social care, independent hospitals and in the community), and where the person who died was indicated to have a learning disability on the death notification form".

In all 386 people with a learning disability, some of whom may also be autistic, died in the six-week period who were receiving care from the above services. Moreover an additional 54 deaths occurred of people who were detained under the Mental Health Act some of whom will have had learning disabilities. However for the period 2nd March to 9th June 2020, 615 Covid-related deaths of people with a learning disability were reported to the Learning from Death Reviews (LeDeR) programme at the University of Bristol.

The CQC review compared the 2020 deaths to the same period last year, and found that "165 people with a learning disability, some of whom may also be autistic, died who were receiving care from services which provide support for people with a learning disability and/or autism. This is a 134% increase in the number of death notifications this year. Of the 386 people who have died this year, 206 were as a result of suspected and/or confirmed COVID-19 as notified by the provider and 180 were not related to COVID-19. In all, 184 people were receiving care from community-based adult social care services and 195 from residential social care settings".

In the United States, "COVID-19-related fatality rates among people with IDD who have tested positive for COVID-19 are, in some states, more than three times the mortality rates among the general population who have tested positive for COVID-19" (ADMDD, 2020).

The NI Statistics and Research Agency (NISRA) undertook a review of excess deaths in Northern Ireland and reported 885 excess deaths from 1st March to 30th June 2020, 17.4% above expected levels (average deaths for the same period over the last five years). However no information was provided on those with a learning disability. For regulated services, the number of deaths should be available from RQIA and although learning disability is not necessarily recorded on death certificates, this could be another source of information in Northern Ireland, possibly through NISRA.

Increased vulnerability

In early 2020, the World Health Organisation issued a document to all member countries entitled 'Disability considerations during the COVID-19 outbreak'. (WHO reference number: WHO/2019-nCoV/Disability/2020.1). 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.

In addition, people with learning disability 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 (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 preliminary analysis of 50 deaths from Covid in England of people with learning disabilities drew six broad conclusions with a fuller report on additional deaths due to be published in the coming months.

> "1. Mobility impairments and/or mental health needs may be proxy indicators of people at risk of catching the virus, or may underpin prejudicial attitudes towards care, treatment and judgements about ceilings of care.
>
> 2. It would seem appropriate to consider people with learning disabilities and epilepsy as being at increased risk of death from the virus and pay attention to protecting them.
>
> 3. The key symptoms of COVID19 in the general population (fever, new continuous cough, loss of sense of smell or taste) may not be as apparent in people with learning disabilities.
>
> 4. The use of DNACPR decisions and the initiation of palliative/end of life care should be monitored to ensure that this population is not being disadvantaged.
>
> 5. Close attention needs to be paid to safe and appropriate hospital discharge planning. One in five of the completed reviews indicated that the person had previously been discharged from hospital, only to be readmitted again soon afterwards.
>
> 6. Additional resourcing for specialist learning disabilities staffing and expertise in primary and secondary care appears to be indicated from the findings of this small study".

Prejudicial assumptions

In the initial stages of the epidemic, NICE proposed the use of a frailty scale (CFS) to identify patients who were suitable for admission to critical care. Although designed for use with older people, it would unfairly discriminate against younger people with disabilities who are dependent on others for support in daily living activities. After intensive lobbying, the NHS made clear that it did not recommend the CFS be used for those with learning disabilities and other groups. NICE then issued revised guidance which stated that clinicians should take any decisions about care in conjunction with patients and their carers where possible.

A further controversy related to the placing of Do Not Resuscitate (DNR) orders without consultation in the medical records of people with learning disabilities, especially those of older residents living in nursing and residential homes. This too was later retracted and the emphasis placed on personalised assessments in consultation with support staff and family carers well known to the resident.

Both of these actions, were at odds with the UN Convention of the Rights of Persons with Disabilities (2006) which the UK has ratified. Article 25 states: "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."

The UK Disability Discrimination Act (1995) which is applicable to Northern Ireland had earlier reinforced these rights: "Under the DDA, discrimination in the provision of goods, facilities and services occurs when: 1) a disabled person is treated less favourably than someone else and the treatment is for a reason relating to the person's disability, and this treatment cannot be justified and 2) there is a failure to make a reasonable adjustment for a disabled person" (Equality Commission NI, 2011).

Nonetheless concerns remain that people with learning disabilities may be less of a priority in terms of access to Covid testing and hospital admissions.

A further concern is now coming to the fore in relation to Deprivation of Liberty. In September 2020, the Department issued revised guidance on the Mental Capacity Act (2005) (MCA) and deprivation of liberty safeguards (DoLS) during the coronavirus (COVID-19) pandemic which could affect people with learning disability (see Appendix 3). However "this guidance is only valid during the COVID-19 pandemic and applies to those caring for adults who lack the relevant mental capacity to consent to their care and treatment…. During the pandemic, the principles of the MCA and the safeguards provided by DoLS still apply." (p.1).

This guidance leaves unresolved how the rights of people with learning disability who are deemed to have mental capacity should be protected if the restrictions placed on them exceed those which Covid-19 regulations place on the general population. Guidance from the Department of Health and RQIA would be helpful in this regard.

Appendix 3: The guidance provided to services and reports on the impact of Covid-19 on services and users.

From January 2020 onwards, guidance has been produced by Public Health agencies internationally, nationally and regionally. As the effect of Covid-19 on populations was largely unscoped with no known treatments, the initial guidance aimed to protect health services while limiting the spread of the virus.

In the early months of the pandemic, there had been close co-ordination between the four administrations in the UK although there were some differences in policy and guidance[8]. However the devolved governments of Scotland, Wales and Northern Ireland are responsible for key public services such as NHS, education and public transport, and for implementing the lockdown within their territories. From May onwards as lock-downs were eased, differences appeared across the four nations. This created uncertainty among the public with variations emerging in the guidance issued by government bodies in each country.

More specific guidance was also issued in relation to public services such as health and social care, schools and transport[9]. Also previous guidance was revised in the light of experience which compounded the uncertainty around 'proper' procedures that different agencies within Northern Ireland were recommending. This was especially so when the guidance had to be interpreted and applied to particular groups (such as people with learning disabilities) or in other service settings such as supported living with an ethos and practices that were markedly different from nursing and residential care homes. Consequently these non-statutory service providers had to issue their own guidance to staff, service users and family members thereby taking the risk that their interpretation might be taken to breech the published guidance.

This Appendix lists the guidance that was issued in Northern Ireland as it pertains to persons with learning disability. Also details are given of guidance related to learning disability in other jurisdictions or organisation for further and future reference. A second part summaries the findings of reviews that have been undertaken or are underway, of the impact of Covid-19 on services and users.

Guidance issued in Northern Ireland

The Department of Health

The Department's Guidance is available at: https://www.health-ni.gov.uk/covid-19-guidance.

This includes:

Care Homes

- COVID-19: Regional Principles for Visiting in Care Settings in Northern Ireland
- Guidance for Nursing and Residential Care Homes in Northern Ireland - July 2020

[8] https://www.instituteforgovernment.org.uk/sites/default/files/publications/four-nation-exit-strategy-coronavirus.pdf

[9] https://www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public

Children's Homes

- COVID-19 - Guidance for Residential Children's Homes in Northern Ireland
- COVID-19 - Guidance for Foster Care and Supported Lodgings Settings

Direct Payments

- Covid-19 - Guidance for Direct Payments

Domiciliary Care

- Guidance for Domiciliary Care Providers - 12 May

Visiting Guidance

- COVID-19: Regional Principles for Visiting in Care Settings in Northern Ireland

Supported Living

The Department is currently preparing guidelines for person in supported living settings. This is in partnership with HSC agencies and providers from the non-statutory sector including ARC-NI.

Public Health Agency (PHA) Guidance

The PHA Guidance is available at: : https://www.publichealth.hscni.net/covid-19-coronavirus

The PHA Guidance for healthcare professionals, carers and care homes includes the following (hyperlinks to documents are provided on the PHA website including links to the Department of Health guidance noted above):

- COVID-19 infection prevention and control guidance.
- Guidance for Domiciliary Care Providers
- Guidance on visiting hospitals and care settings.
- Guidance for Nursing and Residential Care Homes.
- Regional nutrition guidance for care home residents with suspected or confirmed COVID-19.
- Advice for staff in care homes on eating, drinking and swallowing during COVID-19.
- Guidance for visiting in care settings in Northern Ireland.
- Advice for care home staff to help communication with clients during the pandemic.
- Guidance for carers and care home staff on the wide range of symptoms which can be associated with COVID-19.
- Key principles for HSC Trust staff visiting community settings.
- Staff health and wellbeing.
- Swabbing for COVID-19: Guidance on swabbing for COVID-19 in care homes and supported living centres (with video).

Registration and Quality Improvement Authority (RQIA)

RQIA guidance is available at: https://www.rqia.org.uk/guidance/guidance-for-service-providers/covid-19-(coronavirus)/.

RQIA website states: “Care homes can ... avail of the support team of experienced inspectors and managers, which is available from 9am to 5pm, Monday – Friday via the RQIA main phone line. This support team will provide guidance and support to managers coping with the impact of COVID-19 on their services”. A similar announcement is available for Domiciliary Care Agencies but with a different phone number and email contact. 028 9536 1111, or by the RQIA Update app: https://rqiani.glideapp.io/. It is intended to increase this helpline to 7 days availability (personal communication).

Northern Ireland Social Care Council (NISCC)

NISCC outlined the actions they had taken to support registrants, providers and people using services during this time. The document was published on 25th March and was intended to be updated as the epidemic and its consequences unfolded. However no updates appear on their website.

https://niscc.info/coronavirus-and-our-work-what-you-need-to-know

Guidance relating to people with learning disabilities

The only guidance relating to Learning Disability that was produced in Northern Ireland appears to be the following four-page, easy-read leaflet from the Department of Health/PHA which contains information on Covid-19 symptoms and protection measures.

COVID-19 guidance for people with Learning Disabilities in Easy Read format (external link opens in a new window / tab)

Public Health England (PHE)

PHE issued three workforce guidance documents covering mental health, learning disabilities and autism, and specialised commissioning services during the coronavirus pandemic.

- This document aims to ensure safety in the workplace is maintained during the COVID-19 outbreak.

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0074-MHLDA-Covid-19-Guidance-Workforce-final-v1-1.pdf (8th April,2020)

- This guidance assists with the identification of potential equality impacts of the COVID-19 pandemic on people with mental health problems or a learning disability and/or autism.

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0290_Supporting-patients-who-are-unwell-with-COVID-19-in-MHLDA-settings.pdf (30th April)

- This guidance concerns the impact of COVID-19 on the use of the Mental Health Act and supporting systems to safeguard the legal rights of people receiving mental health, learning disabilities and specialised commissioned mental health services. It was to be regularly updated to reflect the rapidly changing context and questions/concerns and feedback from the sector (no update has been issued up to end of September).

https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0454-mhlda-spec-comm-legal-guidance-v2-19-may.pdf (19th May 2020)

NHS England

“Clinical guidance for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialities” was issued by

NHS England on 24 March. The suggested approach to these patients covered issues such diagnostic overshadowing; listening to parents/carers; make reasonable adjustments; tips on communication and mental wellbeing and distress.

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

Department of Health

In September 2020, the Department issued revised guidance on the Mental Capacity Act (2005) (MCA) and deprivation of liberty safeguards (DoLS) during the coronavirus (COVID-19) pandemic which could affect people with learning disability.

https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity/the-mental-capacity-act-2005-mca-and-deprivation-of-liberty-safeguards-dols-during-the-coronavirus-covid-19-pandemic

Social Care Institute for Excellence (SCIE)

SCIE issued a COVID-19 guide for care staff supporting adults with learning disabilities or autistic adults: Updated: July 2020. The guide aimed to help care staff and personal assistants supporting adults with learning disabilities and autistic adults through the COVID-19 crisis and assist high-quality care and support during the pandemic.

https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff

Mencap

Mencap established a website containing guidance and advice aimed at people with a learning disability, support workers and health professionals.

https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19

Learning Disability Professional Senate

The British Institute of learning Disability established the "LD Professional Senate which is made up of members of the various Colleges and Societies that represent groups of clinical professionals who provide specialist health support to children and adults who have learning disabilities. It covers the jurisdictions of England, Scotland, Wales and Northern Ireland. Its aim is to provide a single voice through which "we can lead and inform NHS England, Department of Health and other strategy leads about the needs of children and adults with learning disabilities and champion inter-agency, multi-disciplinary, holistic approaches".

The resources relating to Covid-19 produced by the Senate are listed on their website:

https://www.bild.org.uk/ldsenate/

Journal article

An article by English clinicians and academics was published in September 2020. Guidelines are proposed for the care and treatment of people with IDs during the COVID-19 pandemic for both community teams providing care to people with IDs and inpatient psychiatric settings. The authors note: "As there are specific issues associated with providing care to people with intellectual disability, appropriate action must be taken by care providers to ensure that disparity of healthcare is addressed during the COVID-19 pandemic".

The reference is: Alexander, R., Ravi, A., Barclay, H., Sawhney, I., Chester, V., Malcolm, V., ... & Howell, A. (2020). Guidance for the Treatment and Management of COVID-19 Among People with Intellectual Disabilities. *Journal of policy and practice in intellectual disabilities*, 17(3), 256-269.

It is available at: https://onlinelibrary.wiley.com/doi/epdf/10.1111/jppi.12352

Part 2: Review of impact on services and users in Northern Ireland

The Department of Health commissioned a rapid learning initiative into transmission of Covid-19 into and within care homes in Northern Ireland[10]. Chaired by the deputy CNO, four subgroups, consisting of personnel from different sectors, were established to undertake different work streams. 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 and they are quoted verbatim below. Although homes for residents with learning disability were included, the responses are not separated in the report.

The Experience of Residents, Families and Staff

- "Strategies to support residents to remain stimulated and engaged with their environment are vital important to support their health and wellbeing. For relatives of residents with cognitive impairment this is highlighted as a priority.
- The use of technology during COVID-19 had both positive and negative impact upon residents, relatives and staff
- 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
- Official information and guidance regarding management in the Care Homes was not consistently shared with residents and families
- Residents reflected upon the absence of medical support and management."

Symptom Monitoring, Interventions and Testing

- "There was positive experience of in-reach from Trust Care Home Support Teams.
- 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
- Guidance on Covid-19 risk assessment and related care planning is needed and would be beneficial.
- Testing for residents and staff should be accessible and timely.
- Formal information and guidance should be consistent in detail, clear and unambiguous.
- Access to and training in the use of the required clinical equipment for monitoring of resident symptoms in particular within residential settings is vital."

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

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.
- PPE related information and guidance issued from Regional/National organisations to Care Homes needs to be clear and consistent.
- Enhanced cleaning, particularly of touch points is crucial. Care Homes who increased domestic provision/altered shift patterns reported positive outcomes. There is no recognised regional training on environmental cleanliness which Care Home teams can access.
- Placement of hand hygiene facilities is vital in enabling effective hand hygiene practices. Embedding these practices only a daily basis are critical.
- IPC education and training for Care Home staff including donning and doffing was critical.
- Feedback from Care Homes on mutual aid arrangements for workforce was positive though views from Care Home Support Teams was limited by a low response rate from those teams".

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.
- Additional technology was and will be required to facilitate virtual visiting.
- Accessible and timely medical support is critical in managing any future surges and/or outbreaks of Covid-19 infection.
- Identification of a cohort of staff to work when required in individual nursing and residential homes will be beneficial in terms of reduction in footfall.
- Student nurses should be enabled to remain working in the nursing or residential home they are employed in.
- An agreed and consistent process for testing of residents prior to admission to a Care Home is required.
- Implementation of physical distancing measures were particularly challenging for a number of reasons. 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. Once approval is given from the Minister and DoH Management Board overseeing the rebuild of services, "the Chief Nursing Officer will 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).

Domiciliary Care

A similar rapid learning initiative into domiciliary care commissioned by the Chief Social Worker is currently underway. Its terms of reference are:

"1. This initiative will collate and consider any learning about domiciliary care issues during the Covid 19 pandemic in NI.

2. It will focus on four themes;

- Service user and carer experience
- Service provision
- Workforce experience
- Infection prevention and control

3. The initiative will ask four key questions;

    - What worked well?
    - What didn't work well?
    - What lessons have been learned?
    - What next/recommendations for action?

4. The learning will be used to inform current and future planning in relation to domiciliary care provision during the ongoing pandemic".

"The report is due no later than 9th October 2020". As at 23rd October a draft report containing a scoping literature review only, has been shared with members of the Steering group.

Future reviews relating to learning disability

A Four Nations Project in the UK, funded by a substantial grant from the Medical Research Council, will involve interviews with service users, family carers and frontline staff in Northern Ireland. The local lead is Dr Laurence Taggart, Ulster University. Information gathering will start once ethical approvals are in place: likely in late 2020 into 2021. Repeat interviews are planned throughout 2021 and into 2022 to identify longer-term impacts. Further details are available from l.taggart@ulster.ac.uk or at: https://warwick.ac.uk/fac/soc/cedar/covid19-learningdisability

An international research project has commenced led by Dr Christine Linehan from University College, Dublin. The local lead is Professor Michael Brown from QUB. An online questionnaire has been designed to obtain reactions from all stakeholders although the chosen methodology is more suited to service staff and family carers. Details are available at: https://hrbopenresearch.org/articles/3-39

Appendix 4: Review Methodology

The independent review was commissioned by ARC (NI) and expressions of interest were invited from personnel in Northern Ireland who were known to ARC (NI). Emeritus Professor Roy McConkey (RMC) was selected to undertake the review. His details are available at: https://ulster.academia.edu/RoyMcConkey.

A fee was payable to him but he chose to have it paid to charities involved with Covid-19 in less developed countries.

The review began on 15th September, 2020 and a preliminary report was submitted on 9th October and the draft final report was submitted on 16th October, 2020. Following feedback and consultations, revised versions were submitted on 23rd October and on 2nd November, 2020. The final report was submitted on 17th November 2020.

Steering Group

A Steering Group was recruited to oversee the review. Chaired by ARC NI Director, Leslie-Anne Newton, and attended by Roy McConkey, the members are:

- Eddie Rooney (formerly PHA)
- Nigel Chambers (Department of Health)
- Theresa Nixon (formerly RQIA)
- Agnes Lunny (ARC NI Trustee)

The Steering Group's purpose was:

- To provide comment and advice to the work of the review.
- To act as a sense check for the analysis of findings and the recommendations arising.
- To sign off the final report

Information about the review

An information sheet was prepared describing the review and the consent procedures (see Annex to this Appendix). This was made available to all persons invited to contribute to the review including the Assistant Directors responsible for learning disability services in the five HSC Trusts.

Information gathered

- A collection of documents was assembled relating to Covid in NI, Great Britain and internationally. These include guidance documents, reports on the extra vulnerabilities of people with LD to Covid; reports on impact of people ID and families and reports on the reform of social care.
- A series of questions were developed by RMC based on the aims of the review, previous reports of the impact of Covid that had been collated by ARC (NI) and documentation gathered at the start of the review as noted above. The steering group commented on and approved the questions.
- One-to-one interviews were conducted by RMC via Zoom with 23 senior staff in 17 organisations chosen by ARC(NI) to represent the range of service provided by members and the trust areas across NI in which they operate. Although a list of questions was provided in advance to the interviewees, the format was more free-flowing and a check towards the end of each interview

confirmed that all the information they wanted to provide had been covered. The interviews were audio-recorded and lasted on average 50 minutes. In all nearly 15 hours of recordings were made.

- An online, self-completion survey was available for all ARC organisations and associates to contribute their experiences. The questions asked covered factual details about the organisation and the number of service users and staff who had been affected by Covid (Part1) along with questions relating to their experience of Covid (Part 2). Participants typed in their answers and at the end were given the opportunity to speak with RMC none took up this offer. Copies of the questionnaire are available from ARC-NI.
- A group interview via tele-conference call was held with the HSC Board lead for learning disability and the Assistant Directors in the five HSC Trusts to obtain their views on the response to Covid-19 by the non-statutory sector and their perceptions on future partnership working. A Zoom interview also took place with the Director of Mental Health, Disability and Older People at Department of Health, Northern Ireland. Together these lasted around 45 minutes.
- A Zoom interview was conducted with the ARC Director for Northern Ireland which covered the organisation's net-working functions as well as the advocacy services (TILLI) they provide through contracts with various HSC Trusts. The interview lasted 90 minutes.

Analysis of Information

Qualitative approaches were used for analysing the information gathered; inform by grounded theory and thematic content analysis. Particular attention was paid to establishing the credibility, depend-ability, and confirmability of the themes identified in the analysis.

The interview data was used to capture the themes that were commonly mentioned across interviewees as to their lived experience of dealing with Covid and service delivery over the past six months. The themes were grouped into two superordinate themes: the challenges presented by Covid and responses made to them. Their perceptions were also sought about the processes respondents had used to facilitate the responses that they had made to the challenges they had encountered. A further section of the interview dealt with their thoughts on future service delivery facing the voluntary sector and again the emerging themes were grouped into the superordinate themes of Challenges and Responses.

The first analysis of the themes was undertaken after nine interviews had been completed and figures summarising the themes were shared with the Steering Group for comment and clarification. In the subsequent eight interviews, probes were used to further test the validity of the themes and adjust-ments were made to the summary of themes accordingly. These interviews confirmed that data saturation had been attained, in that no new themes emerged although the detail may have varied.

The final thematic analysis from the interviews was cross-checked with the information gained from the online questionnaires obtained from other organisations who had not been interviewed. Finally a summary of the themes was shared with interviewees as a form of member checking. No dissenting comments were received.

Information gained from interviews with senior staff in the statutory sector further confirmed and extended the themes. The main findings are summarised in Appendix 5.

Data repository

RMC has created a password protected, computer-based repository of all the audio-recordings made and the responses received to the online questionnaires. Although this information is confidential to him, he could negotiate with the respondents the release of their data to a third party wishing to verify the information. This information will be retained by RMC and not passed to ARC-NI.

Constraints

The scope of the review was constrained in various ways.

- The review was to be completed in a four-week period.
- One consultant was engaged with a limited number of contracted days (although extra days were spent on the review).
- The response to participate in the review came mainly from the voluntary providers who are members of ARC-NI. Other non-statutory service providers who are not members of ARC-NI were not invited to participate.
- The views of HSC trusts and the Department of Health were not explored to the same extent as for the other informants.
- The experiences of service users with learning disability and family carers were reported by the respondents rather than at first-hand.

In due course, further reviews will hopefully give these stake-holders an opportunity to share their experiences of Covid.

Annex: Information sheet

COVID Reflection – An Independent Review of the Learning Disability Sector.

ARC has commissioned **Professor Roy McConkey** to undertake a review of their member's experiences of Covid-19.

Why? ARC-NI wanted to capture their member's experiences in recent months. The review has these aims:

7. To review and evaluate, from a providers' perspective, what has worked well and not so well, with a view to building on positive achievements and ways of working, so as to strengthen the capacity of the sector in the event of a second wave of COVID;
8. to identify how we can further enhance relationships and ways of working which will deliver better outcomes for people with a learning disability and their families in Northern Ireland
9. to promote the pivotal role of the community and voluntary sector in the ongoing delivery services and in planning for and responding to HSC crises in NI.

What will happen?

- One-to-one interviews will be conducted by telephone with senior staff from a representative number of ARC NI members from across Northern Ireland.
- An online, self-completion survey will be available for all organisations to make a response.
- An analysis will be made of the guidance and advice received from government agencies and the input sought from the voluntary and community sector.

Then what?

A report, written in plain English and suitable for a range of audiences will be prepared and distributed to all ARC members in the first instance. The report will provide a basis for ARC NI and its members to increase awareness of the particular needs of people with a learning disability and their families, and how the sector has responded. It will be used to identify policy gaps and key priorities for future collaborative working. ARC will attempt to highlight the report and recommendations through a range of mechanisms, including the Health Committee; the All Party Learning Disability Group and the NI Social Care Council.

Confidentiality

The views provided by individuals and organisations will be confidential to Roy. No one will be identified in any reports. Participants decide the content of the information they provide. However if disclosures are made of potential abuse, Roy is obligated to follow standard procedures.

Further Information

Please contact Leslie-Anne Newton, ARC NI Director; (E) leslie-anne.newton@arcuk.org.uk ; (P) 028 9038 0960; (M): 07762 185 261; (T):

Appendix 5: The impact of Covid-19 on learning disability services and lessons for the future.

"An old man on the point of death summoned his sons around him to give them some parting advice. He ordered his servants to bring in a bundle of sticks and said to his eldest son: "Break it." The son strained and strained, but with all his efforts was unable to break the bundle. The other sons also tried, but none of them was successful. "Untie the bundle", said the father, "and each of you take a stick." When they had done so, he called out to them: "Now, break," and each stick was easily broken. "You see my meaning", said their father.

Aesop's Fables, 1867 (Source https://etc.usf.edu/lit2go/)

The 'Bundle of Sticks' metaphor seemed especially apposite in capturing the learning from this Covid-19 review.

- Throughout the interviews with those who had lived through the Covid-19 experience, they spoke of how managers, staff, service users and family carers had bundled together as team to meet the many sudden challenges they faced.
- CEOs of services and senior staff recounted the bundle of valuable support – emotional and practical - they had received from other service providers through networks such as ARC-NI.
- And the metaphor is implicit in Covid-created phrases such as "we are all in this together". This is especially true when it comes to social care and the supports provided to people with learning disabilities and their family carers. Statutory, voluntary and private providers are stronger when working together as a cohesive bundle and in partnership with service users (see Appendix 6).

The detail that follows in the first part of this Appendix, illustrates the stresses that the individual service providers – the 'sticks' - were placed under and the responses they made. This learning will enable services to be better prepared for any further crises and indeed for them to maintain the new ways of working that have proven to be effective.

The second part examines how the ties that bind service 'bundles' need to be strengthened. Covid-19 has highlighted yet again, how fragile some of these ties are in relation of social care provision in Northern Ireland and for learning disability services in particular: a theme further explored in Appendices 6 and 7.

The interviews yielded very rich information. Qualitative research methods were used for analysis in line with the dual aims of the review as to how Covid-19 was managed and the lessons for the new 'normal'. In relation to each aim, commonly occurring 'themes' across the informants were named. From these two super-ordinate categories were identified: the challenges presented and the responses services had made to them. A further dimension of analysis aimed to identify processes in the responses that had facilitated the responses as well as unresolved issues that persisted.

The tables below describe the themes but two points need to be borne in mind. First, the order of presentation is not important: certain themes may have been more salient in some services than others. Second, the themes noted under challenges and responses often overlapped and had to be attended to in combination which added to the challenge but also is a reminder that no one response was adequate.

Part 1: Managing Covid

Anxiety of service-users, staff and families	**Response**
Covid-19 was an unprecedented crisis and media reporting compounded anxieties about its impact. The sudden change in routines made service users anxious as the reasons for it were not easily understood. Staff too experienced these anxieties but were also concerned about their personal safety as well as that of their families. Family carers were anxious about their relative's wellbeing. Managers were anxious about how best to adjust the services to meet the users' increased needs while managing the anxieties of staff and family carers. Reper-cussions from statutory agencies were feared if guidance was not followed.	Management issued clear, regular communication to staff, service users and families based on attentive listening to people's concerns. Daily calls were made to service-users/family carers locked down at home. Positive thinking was promoted – "we can cope". Easy-read leaflets were prepared for service-users and explained to them. Having experienced and committed staff was an asset. A team culture was encouraged from the top-down. Managers were available 24/7. Consensus decision-making reduced conflict and negativity. Staff received letters of thanks and tokens of appreciation.

Inadequate Guidance	**Response**
An 'avalanche' of documents from various governmental agencies hit services for immediate implementation and with no prior consultation. Initial guidance was vague and parts were inappropriate for supported living services. Conflicting advice was given by different agencies and by staff providing telephone helpline advice. The guidance appeared to be written by persons lacking practical experience which featured too in helpline staff. Access to clinical staff, care managers and social workers in the trusts was cut-off and has only slowly returned.	Senior staff took responsibility for interpreting the guidance for their services. ARC-NI became a valuable resource for information exchange through their well-established distribution lists. An ARC network meeting was facilitated on a fortnightly, sometimes weekly, basis during April-June with policy makers and advisers also attending. Providers of similar services were in regular contact via Zoom, What's App and telephone to share their guidance. Services with GB links had access to their insights about guidance in GB. The PHA resources were helpful. In later months, more guidance specific to learning disability services became available from England (see Appendix 3).

Access to PPE, IT and other supplies	**Response**
The difficulties faced by other non-acute medical and social care services with respect to PPE were experienced by ARC-NI members. Disparities arose around the provision of PPE by trusts and the responsibility of the Housing Executive Supporting People Programme to provide PPE to their schemes. The cost of PPE purchased by the voluntary providers had increased markedly and was an unbudgeted expense. Much time and effort had to be expended in sourcing PPE. Staff and service users did not have IT equipment. Accessing food supplies was a further difficulty in the early weeks of lock-down both for individuals and for bulk purchases.	Services sought their own supplies of PPE. ARC-NI facilitated the purchase of a large quantity of PPE by a bulk purchase order on behalf of some members. In later weeks the supplies of PPE came via Trust or the Supporting People programme. Although some services had reasonable IT equipment such as mobile phones, laptops and Internet access, more was quickly purchased to facilitate new ways of working. Grants were obtained to do this. Extra shopping had to be undertaken on behalf of service users which ordinarily they would have done for themselves.

Restrictions placed on service-users	**Response**
The sudden imposition of lock-down meant that the routines of service-user changed without warning. No day care was available. No visitors were allowed to their home – including family members nor could they visit their family or neighbours in supported living schemes. They were, and many remain, house-bound. Concerns about the infringement of rights and deprivation of rights of service-users. Some showed more challenging behaviours while others enjoyed a more relaxed life-style with fewer pressures. Access to therapies stopped. People in supported employment lost work placements.	Day activities increased in care homes. Online support was quickly activated for individuals through telephone calls, What's App, Facetime to maintain contact with staff and family carers. Zoom brought groups together for fun activities – disco, karaoke, choir, cookery, quizzes. Dynamic risk assessments were introduced. Day centre bases resumed with social distancing and outdoor activities. The resilience and adaptability of service users surprised staff as they became more proactive in using the technology and inventing new activities. Service users have started to challenge an infringement of rights beyond those experienced by the general population.

Family carers abandoned	**Response**
The sudden closure of day centres without contingency plans in place meant many family carers had to undertake 24/7 care for their relatives. Social workers or day centres were not contactable for support. Short breaks (respite) service also closed. No family visits were allowed for people in care homes or supported living. The slow re-opening of services mean that carers are getting much reduced support with extra demands placed on them such as transporting their relatives to centres.	Regular newsletters with photographs were sent to carers. Facetime, What's App calls were set up between users and families. Service staff had regular telephone contact. They also held Zoom meetings with parents to share information and some grew into mutual support for parents. Some 'bending' of the rules took place according to individual circumstances and after taking advice. Services also provided advice and support to other family carers whose relatives were not supported by their service.

Reconfiguring services to users	**Response**
Community access by service users with disabilities ceased thereby eliminating meetings with friends and participation in leisure and sporting activities. Likewise the closure of day centres, day opportunity bases and short break homes had similar consequences. College attendance, training programmes and work placements also terminated. People with learning disability had been given little or no opportunity to be prepared for these changes.	Immediate measures were taken to maintain support to services users in a different format as noted previously. Possible longer-term reconfiguration of services are being considered, such as blended training using IT as well as face-to-face teaching. Increased use of Direct Payments would widen user choice. Supported living staff took responsibility for day activities in and out of the home. Greater use was made of peer-to-peer learning, user advocacy and attuning support to their choices.

Changing management arrangements	**Response**
Pre Covid-19, a significant amount of managerial time was taken up by meetings (internal and external) and traveling to/from them. Likewise face-to-face clinical reviews necessitated staff and users traveling sizeable distances for very brief contact. Staff recruitment and induction took longer than necessary. Service policies did not adequately cover the new practices. Managerial structures could impede quick	Administrative staff worked from home but managers maintained personal contact with frontline staff. Meetings by Zoom could occur more frequently, they took up less time, they were more focussed and productive. Policies were updated especially with respect to safeguarding and business contingency plans. Greater engagement between Trustees and services occurred. Front-line managers were

decision-making and understanding of pressures on staff and service users.	given greater responsibility through delegated decision making. Staff recruitment was fast-tracked: it moved on line, telephone interviews were held with speedier registration and induction training.

Managing staff absences	**Response**
During Covid-19 staff absences could increase due to positive testing for Covid-19, shielding requirements and sickness. Redeployment, redundancies and furloughing also reduce staff numbers. There were inconsistencies in the agency staff covering shifts. Volunteer contributions in services ceased as did family engagement, such as taking their relative for overnight stays. Lower staff morale and exhaustion were heightened risks. The lack of media attention to social care workers in comparison to NHS staff was disheartening. Early indications suggest that managing staff absences in a further wave of Covid would be more challenging.	The voluntary sector experienced low levels of staff sickness and shielding with relatively few redundancies and furloughing. Redeployment of staff occurred within services. Very limited redeployment of staff from trusts occurred but not vice-versa. Staff willingly undertook extended and extra shifts to cover for absences. Time and half was paid for overtime. Vacancies were quickly filled. The dependency on agency staff was then reduced in some services. Plans need to be drawn up for how services plan to manage staff absences in any further waves based on lessons learnt. Cross-sectoral working is needed.

Additional expenditure	**Response**
Services were hit by immediate and unexpected increase in costs for PPE, staff salaries and IT equipment. Income generating activities through social enterprises and charity shops reduced markedly. Certain services were threatened by a trust with the withdrawal of present and future contracts. Lump sums provided by Government did not cover the deficits. Services who furloughed staff risked 'double funding' if their contracts continued to be paid in full. The small or no uplift in funding over recent years has resulted in cutbacks in staffing and other costs.	Negotiations are continuing as to how deficits will be covered but meantime, the voluntary organisation's reserves are being used to cover cash flow problems and deficits. Having a diversity of funding sources allowed extra financial security. One-off grants were made by Government. Various financial packages were provided depending on service types. Assurances were given of continuation of community contract funding initially until June but with an extension to September although this may change in the coming months. Voids in residential placements were covered but this may not continue. A lack of new referrals would threaten the financial viability of services.

Respondents were asked about the changes they would maintain and incorporate into their service provisions and those aspects of services they were keen to re-instate. Their responses are summarised in the following table.

Activities needing to be re-instated	**Changes to be maintained**
• Social activities and outings. • Choices offered to service-users. • Visiting friends and neighbours at home. • Day opportunity bases re-opened. • Respite breaks for family carers and their relatives with learning disabilities. • Home visiting with family carers and domiciliary supports. • Face-to-face support in work placements and for those in employment and with employers as well trainees. • Restarting social enterprises. • Advocacy groups.	• Staff meetings via Zoom meetings more often. • Zoom meetings with external agencies (saving on travel time and costs) • Zoom consultations for service-users review with clinicians. • Greater delegation of decision-making to frontline managers. • On-line recruitment and selection of staff. • Hybrid training opportunities including e-learning for staff and service-users. • Zoom activities led by service-users. • Facilitating support for family carers. • Monthly newsletters • Alternatives to day centre attendance for service users. • Greater attention to inflection control.

Throughout the interviews, probes were used to elicit insights into the processes respondents had used to facilitate the responses that they had made to the challenges noted above. The examples given varied across personnel and organisations, but some common themes were discernible which were augmented by the reviewer's experience and literature searches.

The processes that facilitated the responses to Covid-19

- Coherent and visible leadership by experienced and long-serving senior managers.
- A focus on positivity: 'can-do' approach.
- Self confidence and self-reliance (despite attempts to weaken both.)
- The diversity of services offered by organisations and across the sector enabled speedy transfer of staff and expertise.
- Increased and regular engagement with Board members/Trustees boosted expertise and confident decision-making.
- Having committed, valued and well trained staff.

Information was also requested as to how the services had evaluated the impact of the changed ways of working. The table below summarises the responses made by different providers with monitoring meetings being the most common.

Evaluation

The services used a variety of means to evaluate the effectiveness of their actions.

- Regular monitoring and review meetings were held by managers with staff.
- Feedback surveys were undertaken with staff and with family carers.
- Zoom consultations and resident meetings were held with service users.
- Engagements with service users were tracked via Social Impact tracker.
- Case studies were collated of service users who were 'thrivers' and those who were 'strugglers'.

Creating respectful partnerships across learning disability services

A recurring theme throughout the responses to the review (and in the literature on transforming social care – see Appendix 6) was that of partnership working as being essential to efficient and effective service provision. Respondents from the voluntary sector expressed concerns about the power imbalance they had encountered in making partnerships work with statutory agencies and at times with other non-statutory providers. Equally statutory providers pointed to difficulties they had experienced with certain providers at various times.

Given the multiplicity of providers and personalities involved in service delivery by all sectors across Northern Ireland, disagreements are inevitable and inequities in practices will arise. But it is important to tackle systematic obstacles that threaten the creation of robust partnerships between the statutory and non-statutory sectors which are likely to be even more vital in the post-Covid era. Partnerships need to be built on respectful, supportive and trusted relationships that are cognisant of the constraints within each sector operates. These values apply equally to partnerships that each sector needs to build with service users, family carers and service staff (see Appendix 6).

The respondents in this review identified the obstacles they had encountered. Admittedly the views of the voluntary sector were to the fore although self-critical comments were made about the sector. Also the experiences were obtained of senior staff in the HSC trusts and HSC board involved with learning disability services which were supplemented by the experiences of other interviewees from the voluntary sector who had worked in HSC trusts.

Legacy Issues

The respondents from the voluntary sector especially voiced their concerns about issues that existed Pre-Covid but which the crisis had accentuated and which might be amplified post Covid. They were seen as long-standing impediments to meeting the needs of people with learning disability and their families which reduced the efficiency and effectiveness of their service provision. These issues are echoed in the reviews of adult social care (see Appendix 6). A valuable outcome from the Covid-19

experience might be a renewed determination in Northern Ireland to transform the social care of adults with learning disability.

Legacy Issues

- Dilution of the ethos that motivates and sustains voluntary services through requirements imposed by contractors.
- Lack of vision and coherent understanding of the needs of people with learning disability and family carers among contractors.
- The re-creation of institutionalised thinking and approaches that is at variance with the person-centred, community-based services that demonstrably enhance a person's quality of life.
- The lack of a level 'playing field' with statutory funded services and the fragility of post Covid funding especially if austerity measures are put in place and referrals are not made to fill voids.
- The bureaucracy, hierarchical decision-making and duplication across statutory health and social services - Departments, PHA, HSC Board, RQIA and Five HSC Trusts – and with other government departments and agencies.
- The lack of accountability within HSC agencies for service performance and implementing change.
- The risk aversive culture in these agencies and a conservatism around change and innovation.
- The burden of reporting required from diverse agencies with a focus on activity rather than outcomes.

Statutory agencies identified various improvements which the voluntary sector needed to address such as over-promising, inflated costs, contract compliance and the fragmentation of the sector which are expanded in Appendix 7.

The following analysis attempts to scope the issues that appear to have impeded partnership working and possible approaches that were suggested as well as the insights provided by reports on the reform of adult social care. The intention is to work towards a shared understanding of how to improve partnerships working especially between the statutory and voluntary sector in particular.

Enhancing partnerships in learning disability

Among the examples for building partnerships in learning disability services which this review and others have proposed are:

- An endorsement of the shared vision and values; such as those set out in the Bamford Equal Lives review.
- Parity of esteem is given to the expertise in voluntary sector, learning disability services by Government Departments, commissioners and HSC trusts.
- Year-on-year contracts and funding needs to be replaced by longer-term, rolling contracts.

- The role of HSC Trusts as both commissioners and providers of services needs to be changed. Funding for learning disability services needs to be ring-fenced within HSC Trust budgets and accounted for transparently.
- Greater emphasis needs to be placed on evidencing outcomes for service users in all sectors rather than a focus on activity monitoring. Cost-effectiveness needs to be demonstrated.
- Personalisation of supports need to be promoted and reliance on communal service settings such as care homes and day centres need to reduce. The Covid-19 experience has given extra incentive for this transformation. Alliances in support of new service models need to be built with a concerted lobbying for change.
- Northern Ireland seems to have lagged behind the rest of the UK in the use of direct payments and self-directed support as a means of implementation of personalisation and widening choice and opportunities for service users and family carers.
- If needed, legal challenges should be taken with respect to unfair and discriminatory practices. This could include investigations by the Equality Commission and Judicial reviews.
- The procrastination in Northern Ireland around the reform of adult social care needs to end. Political pressure and leadership within the devolved government will be essential to making this happen.

Conclusions

In this section I have striven to reflect the views that were expressed to me by respondents, but any errors and misunderstanding are mine. I was impressed by their passion, commitment and frankness and admired their concern to do the best by their service users and family carers. During the last six months they and their colleagues have walked beyond the proverbial extra mile.

The review is limited by not incorporating the views of service users and family carers although plans are in hand for doing this in Northern Ireland as noted previously. Nor were the views of Trust clinical staff, social workers and care managers sought as to how their clients were served by the non-statutory sector. This could be taken forward within the spirit of partnership creation.

The next two Appendices offer a boarder context for understanding the need for change and to validate the views expressed by the voluntary sector.

Appendix 6: Transforming adult social care.

This section is in two parts. Part 1 examines the proposals for the wider reform of adult social care across the UK and in Northern Ireland. Part 2 summarises proposals in relation to the transformation of learning disability services in Northern Ireland. To date, the response to both of these reforms from government across the UK has been lethargic and inconclusive with rhetoric and intentions far outstripping practical and meaningful changes.

Part 1: Reform of social care in the UK and NI.

A plethora of documentation is available relating to social care reform in the UK. However a recent report from the Social Care Institute for Excellence (2020) entitled "*Beyond COVID: New thinking on the future of adult social care*[11]" summarises the present position and future direction of travel.

It states: "*The NHS has benefited from having a long-term plan for health. We believe it is now vital that we have a long-term plan for adult social care, clearly setting out a vision and plan for social care. This should be co-produced with the sector and with people who use services and carers" (p.3).*

To inform this plan, the review paper sets out three strategic shifts which are needed to overcome the immense challenges to be faced, along with 21 recommendations to help facilitate rapid progress towards these goals.

- Shift 1: To shift the sector from surviving hand-to-mouth, to the point where it has long-term and sustainable funding.
- Shift 2: To shift investment and focus away from remedial and acute services, towards community-centred preventative models of care, support, housing and technology.
- Shift 3: To shift the workforce away from low pay, low recognition and poor conditions, towards higher pay, better conditions and parity of esteem with the NHS.

The contribution of the community and voluntary sector

In 2016, a review of partnerships and investment in voluntary, community and social enterprise (VCSE) organisations in the health and care sector was undertaken in a partnership with representatives of the VCSE sector and the Department of Health, NHS England, and Public Health England[12]. This acknowledged the important contribution that the VCSE sector made to social care but cautioned that: *"Neither ad hoc grant giving, nor contract-based procurement, appear to create a diverse, creative and sustainable VCSE sector"* (p.8).

In all, 28 recommendations were for transforming the sector and its relationships with statutory commissioners. With respect to strategic processes they noted: "*Any future transformation programmes … should only be approved if proposals are included for involving the full range of local VCSE sector, taking its views into account in strategic decisions and utilising its delivery expertise"* (p.11).

[11] https://www.scie.org.uk/care-providers/coronavirus-covid-19/beyond/adult-social-care

[12] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/524243/VCSE_Investment_Review_A.pdf

Northern Ireland

In Northern Ireland, a consultation document was produced by DHSSPS in 2012: "*Who Cares? The Future of Adult Care and Support in Northern Ireland*" and widely circulated across NI. Over 600 people attended public events or meetings and 185 responses to the consultation were received. A document analysing the results of the consultant was published in August 2013[13]. The vision for social care set out in the document was endorsed by around 80% of respondents as was the proposition that care and support should continue to be provided on a partnership basis between the statutory, private and voluntary sectors.

However the report also noted that certain issues were raised on a consistent basis throughout the consultation … "*the need for greater user involvement, choice and control; the need for transparent accountability and monitoring arrangements; the issues caused by social isolation and loneliness; the difficulties experienced by people trying to navigate and understand the care and support system; the need for greater collaboration between sectors and government departments; and the need for more support for carers*"(p.34).

The DHSSPS indicated in 2013 that *"the second stage of the reform process will focus on the development of a range of proposals for change to the current care and support system … Stage two of reform may take some time to allow for complex financial modelling"* (p.45). It seems that Stage 2 proposals are still awaited.

Expert panel

In 2016, two leading experts in social care were appointed by the then Minister for Health (now deputy First Minister) to work closely with the Department to provide an independent perspective on possible solutions to meet the challenges facing the care and support system and ensure it is sustainable and fit for purpose.

The resulting report by Des Kelly and John Kennedy, entitled "*Power to the People: Proposals to reboot adult care & support in N.I*"[14] was published in December 2017. They summarised four desired outcomes for service users of a reformed social care system:

> *"Having choice and control over day-to-day and significant life decisions;*
>
> *Maintaining good relationships with family, partners, friends, staff and others;*
>
> *Spending time purposefully and enjoyably doing things that bring (people pleasure and meaning).*
>
> *(And having) The organisational and service factors which enable these outcomes to be achieved and sustained."*

The external panel made 16 proposals for the reform of adult social care services. Of note for this review were these proposals:

"*Proposal 13: The Expert Advisory Panel proposes that the Department of Health oversees the introduction of a whole-systems approach to facilitating joint working between commissioners, health*

[13] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/who_cares_consultation_analysis_report.pdf

[14] https://www.health-ni.gov.uk/articles/power-people

services and care providers, which include a clear mechanism for involving people receiving services and carers within all the HSC Trusts.

Proposal 14: The Expert Advisory Panel proposes that the HSC Trusts promote a collaborative, rather than competitive, ethos which fully involves all key stakeholders in the care and support system" (p.91).

In response, the Department of Health stated on their website that*: "An action plan based on the 'Power to People' proposals is currently being developed by a Reform Project Board and Project Team. This action plan will outline the Department's proposed way forward for the reform of adult care and support and will form the basis of an extensive public consultation in 2019".* To date, neither the action plan nor the consultation seems to have taken place.

NI Affairs Committee report

In November 2019, Northern Ireland Affairs Committee of the House of Commons published their first report on Health funding in Northern Ireland having taken oral and written evidence from a range of stakeholders[15]. They made a series of recommendations relating to social care.

- "The Department (of health) should further set out what steps are being taken to progress the proposals set out in Power to People for equalising pay and conditions across the social care workforce in response to this report".
- "Three-year minimum budget allocations are needed for the Department of Health. This should facilitate the Department moving towards a minimum five-year partnership model with community and voluntary providers in which commissioning and investment are based on progress towards agreed outcomes".
- "The Committee recommend that a task force be established with the remit and the authority to remove unnecessary and duplicated paperwork and streamline existing paperwork - though this should not be at the expense of high-quality assessments or casework. This should be completed by summer 2020".

It is unlikely that the Department of Health has acted on these recommendations given their pre-occupation with Cobvid-19 during most of 2020.

Transformation Implementation Group

Following Professor's Bengoa report, the then Minister of Health launched a 10 year approach to transforming health and social care: "Health and Wellbeing 2026: Delivering Together". This included the formation of a Transformation Implementation Group (TIG) to lead "the design, development and implementation of the Transformation Programme. The Transformation Implementation Group is chaired by the DoH Permanent Secretary, and includes leaders and clinicians from across the Department and the Health and Social Care system."

[15] https://publications.parliament.uk/pa/cm201919/cmselect/cmniaf/300/300.pdf

The group commissioned a practical guide to support the application of co-production across the health and social care system as this was seen as one of five enablers of transformation[16]. "The guide requires all HSC organisations to review the extent of partnership working across its services and to develop an integrated plan in order to strengthen co-production between people who use services, staff, their representatives, local communities and multi-agency partners" (p.6).

The Guide explains why co-production is important and gives guidance on how to co-produce for various stake-holders groups including Policy Makers; People with Lived Experience and Peer Networks; Operational Managers, Team and Clinical Leads, and for Communities. The importance is stressed of collective and reciprocal recognition.

It is unclear the extent to which this Guidance has been implemented across HSC and partner agencies.

Part 2: Reform of learning disability services in Northern Ireland

The need for the reform of learning disability services predates the wider reform of adult social care although the themes are very similar.

Bamford review

The Bamford Review of Mental Health and Learning Disability commenced in 2002 and its first report was *"Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland"* [17]. This was published 15 years ago in September 2005.

The report proposed five core values with which all policy and service developments must be underpinned and outlined 12 core objectives that would direct future policy for improving the lives of people with a learning disability. The 12th objective was "*To promote improved joint working across sectors and settings in order to ensure that the quality of life of people with a learning disability is improved and that the Equal Lives values and objectives are achieved."* (p.8).

Northern Ireland Executive accepted the broad thrust of the Review's recommendations. The Executive's response to the findings of the Bamford Review, *Delivering the Bamford Vision*, was consulted on in 2008. This led to the publication in October 2009 of the Bamford Action Plan 2009 – 2011 with a further revised action plans covering the period 2012 to 2015.

In 2016, the Department of Health embarked on an evaluation of *"the action Government has taken to implement the Bamford vision, and more importantly, what impact these actions have made on the lives of people with mental health problems or a learning disability".* The consultation closed on 14 March 2016 but no findings have been published from the responses received.

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[16] Department of Health (2018) Co-production Guide: Connecting and Realising Value Through People. Available at: https://www.health-ni.gov.uk/sites/default/files/publications/health/HSCB-Co-Production-Guide.pdf

[17] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/Equal%20Lives%20Report.pdf

Within the Patient and Client Council, a Bamford Monitoring Group was also established consisting of service users and family carers[18]. They met monthly with the notes of the available up to 1 December 2017. It seems no further meetings have taken place since then.

Service Framework

In 2013, DHSSPS launched a *Service Framework for Learning Disability* with a revised version published in January 2016 following a consultation process [19]. The Framework built on the principles from the Bamford review and aimed to improve the health and wellbeing of people with a learning disability, their carers and families. It *"set out the standard of care that service users and their carers can expect, and are also to be used by health and social care organisations to drive performance improvement through the commissioning process".*

In all 34 standards were described along with key performance indicators and anticipated performance levels. Although the responsibility for monitoring the implementation of the standards rested with the Health and Social Care Board (HSC Board), it was not made clear how this would be done given the major shift involved from activity counting to outcomes-based contracting.

In 2016, RQIA undertook a second phase of a Review of Adult Learning Disability Community Services[20]. The purpose was to highlight the progress made by the five Health and Social Care (HSC) trusts, in the implementation of the 34 standards in the Service Framework. Although some improvements were noted in five areas, many more areas were noted that required action. In all, 25 recommendations were made; the first of which was: *"The commissioner should ensure effective use of resources through accountability meetings and seek evidence based improvements in learning disability services across trusts"* (p.51). However with the then proposed demise of the HSC Board, RQIA were unsure whose responsibility it would be to monitor the learning disability standards.

To date, no evaluation appears to have been undertaken of the implementation of the service framework for learning disability and more especially the impact they have had on the lives of people with learning disability.

Regional model for learning disability services

Possibly in response to variations in learning disability services across the five HSC trusts which the RQIA report had highlighted, in 2019, the HSC Board announced that it was leading on a regional project to improve Adult Learning Disability Services across Northern Ireland in association with the five HSC trusts[21]. *"The HSCB is looking to create a new Regional Model for Adult Learning Disability Services… This new model will inform future services, taking account of population changes, experiences and the needs of adults with learning disabilities and supportive roles played by both*

[18] https://patientclientcouncil.hscni.net/policies-and-procedures/bamford-monitoring-group/bamford-monitoring-group-meetings/

[19] https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/service-framework-for-learning-disability-full-document.pdf

[20] https://rqia.org.uk/RQIA/files/4a/4a883fbc-92a7-4fda-97b0-ac2e664e5d8d.pdf

[21] http://www.hscboard.hscni.net/our-work/social-care-and-children/learning-disability/

statutory and community/voluntary sector providers across the region… We will use co-production principles to develop the new model and hope to produce a report on this work early in 2020."

A consultation on the proposed new model was completed in September 2019 but at the time of writing no publicly available report has described the proposed model.

Abuse at Muckamore Abbey Hospital

In recent years, particularly concerning has been the abuse uncovered at Muckamore Abbey Hospital that started to emerge in November 2017[22]. To date, eight members of staff have been charged by the PSNI with 62 members of staff suspended. The Trust chairman and the Chief Executive expressed their regrets and spoke of a "deep sense of shame".

In September 2020, the current Minister of Health announced that he is establishing a statutory public inquiry into the abuse at Muckamore Abbey Hospital[23]. This follows two previous inquiries. One review, *A Way to Go*[24], was commissioned by the Belfast Trust to examine safeguarding at the hospital between 2012 and 2017. The second by the Department of Health on a review of leadership and governance at Muckamore[25].

Press reports have suggested that an extra £12 million over three years has been spent on the pay of suspended staff, agency nurses and sick leave[26]. Reportedly 48 patients currently reside at the Hospital, a small number of whom were due to be resettled but this has stalled during Covid-19[27].

Conclusions

Despite widespread recognition that much of existing adult social care provision in Northern Ireland is not fit for purpose, there has been no sustained momentum to instigate reform.

A similar conclusion applies to learning disability services with varied initiatives over the past 15 years seemingly producing little real change in transforming the commissioning and delivery of these services. More depressing is that Northern Ireland is home to one of the worst abuse scandals of people with learning disability in these islands. A public inquiry will likely reinforce the actions needed to reform services that has already been identified. Awaiting its findings cannot be made an excuse for inaction now.

[22] https://www.bbc.co.uk/news/uk-northern-ireland-49498971

[23] https://www.health-ni.gov.uk/news/swann-announces-public-inquiry-muckamore-abbey-hospital

[24] https://belfasttrust.hscni.net/2019/02/15/summary-of-a-review-of-safeguarding-at-muckamore-abbey-hospital-a-way-to-go/

[25] https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-mah-review.pdf

[26] http://www.irishnews.com/news/northernirelandnews/2020/08/31/news/spiralling-financial-cost-of-muckamore-abuse-scandal-revealed-as-health-trust-spend-millions-keep-hospital-afloat-after-62-s-2051627/

[27] https://www.irishnews.com/news/northernirelandnews/2020/04/11/news/resettlement-of-muckamore-patients-stalled-by-pandemic-as-families-continue-to-push-for-public-inquiry-1898577/

Appendix 7: The contribution of voluntary organisations in N. Ireland to services for persons with learning disability.

In comparison with other jurisdictions, the voluntary sector is a minor provider of services to people with learning disability in Northern Ireland. In the Republic of Ireland for example, an estimated 90% of services are provided by voluntary bodies.

In Northern Ireland, the bulk of services are either directly provided by HSC trusts (including in-patient assessment and treatment units; clinical and social work services; residential and domiciliary care, day centres and respite care) or through private companies (mainly nursing and residential care homes).

This Appendix examines the contribution that the voluntary sector makes to service provision across Northern Ireland in terms of its strengths and improvements. This analysis is largely derived from information gathered as part of the review from those working within the sector as well as from staff working in the statutory sector and those who have experience of both sectors. Additional insights were gained from documentary analyses and the author's personal experience of working in the sector in the Republic of Ireland, Scotland and Northern Ireland as a staff member, service manager, trustee and an evaluator of services provide by this sector.

The unique contribution of the voluntary sector to learning disability services

The voluntary sector involved with learning disability services in Northern Ireland is unique in various ways by comparison to the statutory or private sector.

- The sector provides services across all five HSC trusts; including both child and adult services. It has first-hand experience of the variations and inconsistencies that exist in how trusts operate which other reviews have confirmed[28].
- Although the primary focus of the sector is on persons with learning disability, they have widened their provision to include allied impairment conditions such as autism, acquired brain injury and mental health. These provides a more integrated, needs-led, local response compared to services that remain largely provided on the basis of impairment rather than needs.
- They provide a range of services that often embody the new ethos promoted by the Bamford review. They include supported living arrangements, floating support for independent living, community-based day opportunities allied with vocational training and supported employment, short-break (respite) and leisure activities, home-based family support, domiciliary care and the promotion of advocacy.
- Most services are well connected to local communities in the locations they serve and are reflective of local cultures. These connections assist with the recruitment of staff and volunteers as well as furthering the social inclusion of their service users.
- Although the sector is primarily engaged with the Department of Health, they are also actively engaged with the Department of Communities (for Housing) and Department of Economy (for

28 RQIA (2016) https://rqia.org.uk/RQIA/files/4a/4a883fbc-92a7-4fda-97b0-ac2e664e5d8d.pdf

vocational training and employment). The sector can bridge the lack of cross-departmental working that persists in NI.

- The voluntary sector has providers who are part of UK wide organisations that gives them access to additional expertise and resources. Other providers operate also in the Republic of Ireland which brings similar benefits.
- The sector has successfully sourced sizeable grants from charitable funders including the Big Lottery which has enabled new services to be developed and funded for up to five years at little cost to the HSC. Moreover they can create a basket of funding from different revenues streams that helps to make them financially stable should income from one source decline.

The sector is well regulated, governed and managed.

- Most of the voluntary providers have local boards of trustees that include persons with expertise in finance, business, the law and HR alongside service-user representatives. Taken as a whole, these volunteer board members represent a breadth of engagement with local communities that is unmatched in the statutory sector and absent in the private sector.
- The voluntary providers lodge their annual reports and statement of accounts for each financial year with the Charities Commission for Northern Ireland and/or Companies House. These are public documents and represent a degree of accountability and transparency that is not expected of the statutory or private sector.
- As appropriate the voluntary sector register the services they provide with the Regulation and Quality Improvement Authority. All the inspection reports by RQIA are publicly available.
- The CEOs, directors and mangers of many voluntary providers are professionally trained and have accumulated many years of experience in service provision. Moreover there has been a low turn-over of persons in senior posts within this sector; a further difference with the statutory services.
- In line with Government requirements, the voluntary providers maintain Reserves which have been used to fund new initiatives or to cover cash flow problems in times of unforeseen expenditures as happened during Covid-19.

Improvements to the voluntary sector[29]

- The focus of most voluntary organisations has been on responding to the needs of the services users in their geographical area with little energy left to challenge existing practice and policies affecting the sector as a whole even though these may not be supportive of their aims.
- The sector is fragmented with little sense of collegiality when it comes to lobbying on strategic issues. Rather individual members take on this role with the risk that it may advance their own interests rather than that of the sector as a whole. However the Covid-19 crisis and a

[29] Various authors and reports have noted improvements that are more specific to individual organisation, such as Charles Handy (1990) *Understanding voluntary organizations: How to make them work more effectively* (Penguin Books) and Dickenson et al., 2016: *The Role of the Third Sector in Delivering Social Care (National Institute of Health Research).*

previous one relating to staff payments did bring the sector together under ARC-NI's facilitation.

- The competitive tendering process has reinforced a sense of competition among voluntary providers which has fostered a reluctance to share details of their operations with one another or to engage in partnership or consortia bids.
- At times, some services have 'over-promised' on what they can deliver; such as their capacity to meet the needs of certain people with learning disability which has led to placement breakdowns.
- Various networks exist that aim to bring the non-statutory sector together including the Northern Ireland Council for Voluntary Action (NICVA), Chief Officers third sector (CO3), NI Federation of Housing Associations, the Independent Health & Care providers (IHCP) as well as ARC-NI. However they appear to operate largely apart of each other and only ARC-NI focusses on learning disability services.
- The financial robustness of the sector is threatened by year-by-year funding contracts, no uplifts for inflation and imminent changes to European Social Fund monies due to Brexit and possible financial pressures on HSC social care funding due to demands from the acute sector. A survey by NICVA of over 500 agencies in NI found that one quarter felt their future was threatened.[30]

Conclusions

The voluntary sector in Northern Ireland has provided valuable and valued services to people with learning disabilities and their family carers for five decades. Their value base and range of services would be extremely difficult to replace. In recent years, the sector is better managed, governed and regulated. They have earned the right to be considered as full partners in the planning, commissioning and delivery of learning disability services in Northern Ireland.

As with all sectors, further improvements could be made to individual services as well as to intra-sector coordination and collaboration. But the challenge of creating more effective inter-sectoral partnerships needs to tackled as this too will be a driver of change within all services and sectors.

[30] https://www.nicva.org/article/how-covid-19-is-impacting-sector-organisations

Appendix 8: Summary of recommendations

1. Services need to have in place individualised and service contingency plans for the continuation of supports to persons with learning disability and their families in the event of further Covid surges or similar emergencies. The plans must include access to PPE and the management of staff absences. These plans should be based on shared risk assessments with regulators and contractors that balance the safety of persons with their emotional and social wellbeing.
2. Official guidance from government agencies in relation to Covid-19 should take into account the needs of persons with learning disability. The guidance should be developed in consultation with those managing services for persons with learning disability and be informed by available guidance from other jurisdictions and professional bodies (see Appendix 3). This guidance must be presented by services to their service-users, family carers and frontline staff in accessible language and using various modes of communication.
3. This report should be shared with ARC-NI members and to service providers across all sectors as an example of shared learning that a networking organisation can produce. Regulators and contractors need to agree on, and to support and endorse new models of service delivery and administration.
4. Workforce issues need to be addressed in partnership across all sectors involved in the provision of services to people with learning disability; starting with the workforce issues arising from Covid. However this beginning should continue and 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 6).
5. 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. This work needs to be continued beyond Covid as it forms a key element of the reform of social care and the supports provided to family carers of people with learning disabilities. Existing policy documents can guide this work which should be informed from experiences in neighbouring jurisdictions.
6. To ensure uniformity across all HSC trusts and service providers, the HSC Board needs to issue instructions for the payment of claims for additional expenditures in this financial year in accordance with the guidance that has been issued. Agreements for the continuation of services in 2021/22 need to be made urgently.
7. ARC-NI is uniquely placed to become the lead body for non-statutory providers of services to people with learning disability that can partner with government departments, other HSC agencies and RQIA as envisaged in the Department's Co-Production guidance. ARC-NI needs increased resources to undertake this function.
8. 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 non-statutory providers and contains guidance on the partnerships that are required to underpin the model in line with the Department's Co-Production Guidance.