

**Impact of the social measures used to control COVID-19 on the physiotherapy needs of adults with a learning disability and their rehabilitation**

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David Standley

Clinical Specialist Physiotherapist, Community Adult with Learning Disabilities Team, Guy’s and St Thomas’ NHS Foundation Trust.

Research and Education Officer ACPPLD NEC

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# Introduction

2020 has been a very challenging year. The UK has been managing a pandemic which has completely changed the lives of the entire population. It has also impacted on the delivery of health and social care services. Specialist learning disability services have been significantly affected by the pandemic. Firstly, adults with a learning disability were identified early on as clinically extremely vulnerable, thus either officially shielded or following strict social distancing advice. Secondly, non-essential healthcare was suspended such as aspects of the community learning disability team, spasticity and falls services. And thirdly, opportunities for physical activity and community engagement such as day services and community activities were closed. These measures had a profound impact on the physiotherapy needs of adults with a learning disability; and the delivery of and demand for community learning disability physiotherapy services.

Following the first wave of COVID-19, community learning disability physiotherapy services were able to assess the impact of the pandemic on adults with a learning disability and recover some of their services within the ongoing social measure in place to manage the pandemic. In October 2020, a second wave of the pandemic commenced. This was proceeded by a month long national lockdown in November 2020 which impacted on service recovery. Since then a new variant of COVID-19 has accelerated the spread of the virus across the UK resulting in a 3rd national lockdown and significant pressure on healthcare services. This has again impacted the delivery of non-essential healthcare and caused the redeployment of staff into acute settings in the same way as the first wave of the pandemic. The pressure of a mass vaccination programme has further added strain to the system and some ‘non-essential’ staff are being redeployed to support the vaccine roll out. In addition, many services are still uncovering and managing the collateral damage from the first wave of the pandemic adding further pressure to overwhelmed and overstretched services. If this is not enough, problems with staff capacity compound these challenges.

To understand the impact of the pandemic on the physiotherapy needs of adults with a learning disability and explore how services are managing the changes in people’s physical and functional presentation a survey was developed. This was sent to the ACPPLD membership to complete between the 4th to the 30th November 2020. The survey was completed before the UK entered the latest lockdown therefore, a secondary aim of the results is to inform how specialist learning disability physiotherapy services manage the next phase of the pandemic.

# **Part 1:** Demographics

88 people responded to the survey from across to UK (Figure 1). 65 (73.9%) are members of the ACPPLD and 23 (26.1%) are non-members. The majority worked for health teams (37.9%) or Integrated Health and Social Care teams (34.5%). Although there was representation from the different types of learning disability services and teams (Figure 2).

***Figure 1:*** *Pie Chart representing the regions of the UK in which the participants live.*

***Figure 2:*** *Bar Chart representing the different types of services and teams that the respondents worked.*

# **Part 2:** Exploring the recovery of specialist learning disability physiotherapy services

Part two of the survey explored whether learning disability physiotherapy services where able to recover from the first wave of the pandemic. Question 4 asked participants whether they had restarted ‘normal services’ since the government’s relaxation of the nationwide lockdown in June. 63.1% reported that they have been able to restart services and 36.9% reported that they had not restarted. When this question was analysed further, the vast majority of respondents have been able to recover some, but not all aspects of their practice (Figure 3). Most reported that they have been able to re-start the management of mobility problems (96.9%); postural management (92.2%); and falls intervention and prevention (81.3%). Half (50%) were able to re-start community level respiratory management which is unsurprising considering COVID-19 impacts on a person respiratory health. Roughly a third of services re-started health promotion (39.1%) and dysphagia (35.9%). A small number of services commenced specialist level respiratory management (7%); and only 2 respondents were able to restart rebound therapy and hydrotherapy (3.1%).

***Figure 3:*** *Bar Chart detailing the different aspects that learning disability physiotherapy services have you been able to re-start since the first wave of the pandemic.*

Analysis of the qualitative data from part one of the survey confirmed that the majority of participants are unable to provide ‘business as usual’ due to the ongoing demand and restrictions caused by the pandemic. Many report that it is difficult to know when it will be possible for them to return to pre-pandemic activity. This is because:

* Services continue to be “very cautious with face-to-face visits due to the vulnerability of adults with a learning disability” and will risk assess each intervention/face to face visit.
* Many care homes are limiting face to face visits and are not supporting service users into the community.
* Personal protective equipment (PPE) provides a barrier to having ‘normal’ interactions with adults with a learning disability and restricts some treatment modalities.
* Ongoing closure of day services and activities limits options for physical activity and environments to delivery physiotherapy.
* Group physiotherapy sessions and therapeutic activities remain suspended due to infection control measures, social distancing and ongoing closure of or restricted access to gyms, day centres, and sport facilities. The lack of access to hydrotherapy was discussed throughout the survey. Participants felt that this significantly impacted on their ability to deliver successful physiotherapy.
* Delays with external services such as orthotics, wheelchair services and bespoke equipment orders has increased the length of episodes of care.

Whilst these limitations remain in place, many services have growing waiting lists of referrals that are not high priority; require the social distancing measures to be relaxed; or rely on other services and community activities to re-open. It is clear that the social measures used to control the virus will need to be relaxed significantly before ‘business as usual’ can resume. Even then public confidence will need to be restored.

There are wide variations in service recovery as you would expect due to the way the pandemic affected parts of the UK with different intensity and at different stages. The social measures used to control the pandemic have been relatively consistent across the UK, therefore, appear to have impacted on the physiotherapy needs of adults with a learning disability equally across the board. Therefore, all services have been and continue to be significantly impacted by the pandemic and are facing similar challenges to recover their normal practices.

Respondents reported that they are delivering a predominantly a reactive service rather than a ‘normal’ proactive model. This is due to:

1. a new urgent or high priority demand for physiotherapy services caused mainly by the indirect impact of the pandemic;
2. staffing capacity issues within teams;
3. restoring services after deployment of staff;
4. increased infection control measures in place; and
5. the ongoing presence of coronavirus in the community restricting the types of interventions.

One participant stated that they *“still feel like we are only dealing with the impact of lockdown”.* This is echoed by another respondent who reported that *“large proportion of workload remains dealing with 'crisis' situations as a result of impact of lockdown”.* One participant comments that their services has insufficient resources to be able to engage in prevention because they are being used to manage the crisis. The theme of only being able to react and respond to the high priority and urgent referrals runs throughout the survey. Services continue to be innovative in the way they provide physiotherapy in the face of the ongoing challenges. Most services are using remote and virtual methods to provide assessment and interventions to limit face to face contact with service users.

The high priority demand for physiotherapy not only impacts on a team’s ability to be proactive, but also to carry out important service development work. One participant commented that when reviewing the Standards of Practice for Physiotherapists Working with Adults with a Learning Disability, it highlighted the need to develop areas of postural care and community level respiratory locally. They reported that they do not currently provide community level respiratory care (this is all managed by GPs who refer to mainstream services) and they provide a very limited basic postural care service which is hampered by no clear postural care pathway and a lengthy funding process. These essential improvement projects have ceased due to the pandemic. Indeed locally two quality improvement projects were postponed. 1. to implement a proactive falls prevention and intervention service, and 2. an abdominal massage for constipation pathway for people with complex physical disability. It is important that this crucial service development work is re-started as soon as possible to ensure services are evolving in line with the evidence to meet the physiotherapy needs of the local population.

# **Part 3:** Exploring the indirect **impact** of COVID-19 on the physiotherapy needs of adults with a learning disability

Part three explored the indirect impact of the pandemic on the physiotherapy needs of adults with a learning disability. 96.9% of respondents reports that they have received referrals for deterioration in the physiotherapy presentation caused by the social measures used to control the spread of COVID-19. The most common reasons for referral was related to mobility (96%.3), falls (83.3%) and deterioration in transfers (75.9%). Participants also reported a high frequency of referrals for change to posture and body shape (68.5%) and pain (57.4%). A high number of referrals for pressure problems (35.2%), difficulties providing personal care (33.3%), neurological changes (25.9%) and respiratory problems (22.2%) were also received (Figure 4). The results highlight that adults with a learning disability have experienced a range of changes in their physical presentation. They indicate that individuals who are able to mobilise, walk and transfer, as well as those with complex physical disability have been significantly affected by the pandemic. Thus, services are likely to receive a high number of referrals for a range of physiotherapy problems as the pandemic continues. Especially, as the third national lockdown will further cause restrictions on the lives of adults with a learning disability and impact the health and social care services they access.

***Figure 4:*** *Reasons for referral in order of prevalence*

Analysis of the qualitative data relating to question seven and eight, support that the most common deterioration was in the individual’s transfers and mobility resulting in an increase in near misses, trips, falls and fractures. One participants stated. *“Absolutely. We’ve had so many falls and mobility referrals for people with deteriorating mobility because they’re not able to be as functionally active in the community”*. Another reported “*lots and lots of mobility. We actually wrote a paper to the CCG to suggest we would help more for adults with Learning Disability with falls and mobility problems. We usually send these referrals to our community colleagues but they were drowning so we felt we need to play our part. It’s very carefully planned and we will hand these types of patients back to community services once the main risks of Covid-19 reduced.*”

Respondents identified that deterioration in mobility is secondary to reduced opportunities for activity and to be mobile as a consequence of remaining housebound; a lack of therapeutic activities; sedentary behaviour; loss of outreach support; and no longer able to walk around the community. In addition, participants felt that the lack of specialist physiotherapy services to support networks of care to deliver programmes and take a positive view of risk during the pandemic has contributed to deterioration in mobility.

A number of participants highlighted the impact of the pandemic on adults with a learning disabilities strength and conditioning. They remarked that they have received an increase in referrals due to deconditioning and musculoskeletal problems such as back pain. Respondents reported that these changes are secondary to weight gain, and people being unable to go to day centres, gyms, or go to any public places which form part of their normal routines. Two participants acknowledge the impact of not being able to walk around large environments such as day services and shopping centre. It can be easy to overlook the importance of normal activities on people’s general health, fitness and wellbeing especially when they have a low physical and functional baseline.

The second most prevalent deterioration noted was in the physical and postural presentation of people with complex physical disability. These manifested in positioning equipment no longer being effective due to postural changes and decreased tolerance to equipment; increased stiffness; pressure sores; and contractures. Participants hypothesised that this is due to:

1. not accessing day services for regular postural management activities;
2. not having accessed to specialist services such as spasticity, wheelchair and orthotic clinics;
3. not receiving maintenance therapy at home;
4. limited opportunities for positional changes and an increased time in static postures;
5. not engaging in a wide range of activities that have postural benefits;
6. a lack of therapeutic activities;
7. lack of physiotherapy to support networks of care to deliver programmes; and
8. delay in accessing specialist learning disability physiotherapy services for assessment and reviews.

One participant commented that they have received *“many referrals for deterioration in people with Profound and Multiple Learning Disabilities (PMLD) (as well as detecting deterioration in our existing service user caseloads) in terms of postural and contracture management because they aren’t able to access their full physiotherapy programmes (including equipment and staff with training at day centres or respite, as well as hydrotherapy and rebound therapy).”* Conversely one participant commented that *“most of our people with PMLD have done well during lock down - all have sleep systems, wheelchairs, etc, so they have not shown any real deterioration and many have enjoyed the additional time with family!” A*nother, reports that they have observed *“less chest issues probably as more isolated so less sharing of viruses”.* These observations are not shared widely amongst the respondents but may be true for some individuals who receive the majority of their postural management at home.

Respondents acknowledged the impact of individuals remaining at home for a prolonged period of time has had on families. One participant comments that families *“are exhausted, and reluctant to accept respite or support because they are frightened of the risks of the virus. They have been shielding since March and have continued... the concerns for the families are my biggest concern.”* Family and carer fatigue is acknowledged as a significant concern throughout the survey.

In addition to the physical deterioration, participants have observed decline in mental health, cognition, motivation, confidence levels, mood and an increase in behaviours that challenge. Respondents reported that they feel these are secondary to a lack of social interaction; anxiety and fear of the virus; not accessing community; and restrictions in daily routines and activities. These changes have impacted on individual’s physical presentation and highlights the link between mental and physical health.

Worryingly, participants suspect that there is significant hidden need in adults with learning disability within the community that is not being seen at present due to the ongoing restrictions. They expect that an increase in referrals will be made once lockdown has ended and a vaccine means more 'normal life' resumes. One participant comments that they *“anticipate seeing a lot more referrals when the world opens up more next summer as people start to leave their house and realise then how much they’re struggling.”* In addition, another *“anticipates a massive need for health promotion, physical activity, balance, walking, bone health, body shape, meaningful engagement and access to routine healthcare in 2021.”* Only time will tell whether these insights become true but it is critical that services expect this surge in referrals and plan accordingly.

In question 9, participants ranked eight potential reasons why adults with a learning disability have deteriorated during the pandemic in order of impact (Figure 5). The results clearly indicate that, in the respondent’s opinion, the measures used to control the virus have impacted more than contracting the virus directly. Participants felt that the closure of day services and activities; the lack of access to physical activity and movement; and social distancing and isolation had the greatest impact. Respondents felt that the closure or postponement of non-essential healthcare services, either specialist learning disability and mainstream services also had a significant impact. Direct COVID-19 infections or hospitalisation during the pandemic was felt to have the least impact.

***Figure 5:*** *Potential reasons why adults with a learning disability have deteriorated during the pandemic in order of impact.*

In addition, to the eight factors above, participants highlighted a number of other potential causes that have be grouped and listed in table 6. The factors identified demonstrate that the changes experienced during the pandemic is multifactorial. This provides further evidence that respondents think the biggest impact is caused by the social measure used to control the virus and its effect on the delivery of healthcare.

***Table 6:*** *Potential causes for deterioration in physical and functional presentation identified by* participants.

|  |  |  |
| --- | --- | --- |
| **Theme** | **Category** | **Details:** |
| **Impact of social measures used to control the spread of virus** | Carer fatigue | * Relationships have become more fragile through the frustration and fatigue of living together for a prolonged period of time. * Lack of respite care availability. * Some families have taken on care to reduce contact outside bubble and have less paid support. * Feeling exhausted and overwhelmed. * Increase in carer injuries. * Increased anxiety levels due to the pandemic and fear of letting people in to help. |
| Change in routines | * Changes to routine resulting in behavioural changes. * Change to and a lack of consistent postural management * Lack of ‘safe environments’ for mobility |
| **Impact of the virus on the delivery of healthcare** | Hospital prioritisation in light of COVID | * Stopping of essential treatment such as PEG surgery and hip operations * Keeping ventilators free and available for patients with higher chance of positive outcomes. |
| Lack of timely referrals to specialist learning disability services | * Lack of referrals, as people were shielding and did not want health care workers to visit. Followed by a surge post lockdown causing capacity issues |
| Physiotherapy by proxy | * Motivation and confidence of the network of care to deliver programmes and provide activities within the home environment * Capacity of and changes to the network of care due to carers shielding, off sick, etc… |

Next participants were asked to describe any intrinsic or extrinsic characteristics or factors that, in their opinion, increased the risk of adults with a learning disability experiencing deterioration during the pandemic. Participants detailed a vast range of intrinsic characteristics and extrinsic factors which are documented in table 7.

***Table 7:*** *Intrinsic characteristics and extrinsic factors that participants identified that increased the risk of deterioration during the pandemic*

|  |  |
| --- | --- |
| **Intrinsic Characteristics** | **Extrinsic Factors** |
| Hypertonia (spasticity, dystonia, movement patterns and spasms) | Lack of natural and formal opportunities for movement and physical activity  *“Lack of movement due to there being no functional focus to the movement therefore generalised deteriorating in function.”* |
| History of difficulties with mobility and transfers | Lack of access to day centres and colleges for maintenance therapy, movement, equipment and environment. |
| Known risk of falls | Unable to access equipment needed for their mobility or postural management due to constraints of home environments |
| Required regular Botox management | Carer fatigue  “Families lost respite, day service and/or support agency therefore are exhausted and worried so are less able to meet needs of person, follow usual programs and offer meaningful activities.” |
| Mental health problems such as anxiety and fear | No alternative social contact outside family unit.  “Many families have stopped paid care to limit virus spread but then struggle to provide variety, enough stimulating activity and physical activity to maintain health at usual levels.” |
| Behaviours that challenge | Carers (paid or family) not having time, motivation and knowledge on how best to support people to stay active, fit and well at home. |
| Sedentary lifestyle - poor exercise tolerance | Adults with a learning disability and their network of care declining face to face visits from health professionals. |
| Low motivation | Lack of or delays in access to hospital services and appointments |
| Reliance on community activity and involvement as motivating factor for activity | Restricted and reduced access to specialist learning disability physiotherapy. |
| Over weight | Changes to daily routines and continuity of care |
| Pre-existing health problems, multi-morbidities and co-morbidities | Living in a larger residential home  “We found larger residential home were more likely to decline external visitors to reduce risk.” |
| Complex body shape | Lack of support from carers and family - difficulty in following home exercise plans if have limited care input. |
| Known respiratory vulnerability | Elderly and vulnerable carers  “PMLD clients have been shielding at home often with elderly carers and we worry about the mental health issues that a whole family unit are experiencing” |
| Unable to follow guidelines and social restrictions | Lack of access to technology and internet |
| History of pain | Challenging family social situation where direct physical management input from family is limited |
| Weakness | Government guidance  “Blanket assumptions of clinical risk based on diagnosis of an learning disability, increasing the isolation of individuals, whom, with the right protection measures, could have continued to access the community.” |

The results highlight that the intrinsic characteristics are easier to identify and define than the extrinsic factors. Thematic analysis identified that the external factors can be grouped into those relating to the network of care, health and social care organisations, local community and society, environments and social situations (Figure 8). Interestingly, these are the same factors that are often the extrinsic barriers to adults with a learning disability accessing successful healthcare.

***Figure 8:*** *The external factors that increase the risk of deterioration during the pandemic*

The sheer number and complexity of the characteristics identified highlights that a significant number of adults with a learning disability are at risk of deterioration during the pandemic, and makes it difficult to predict who will experience decline. It will also make proactively identifying and re-engaging with specific groups during the recovery phase challenging. One participant sums this up nicely when they comment that *“it is the great variety in people's experience which makes this so complex.”*

80% of participants reported that they are proactively re-engaging with adults with a learning disability who are at risk of deterioration during the pandemic (Figure 9). Most services started this over the summer when the prevalence of the virus reduced, but the second wave has impacted on their ability to continue. This has left many services with difficult decisions because they have uncovered the clinical need but are unable to continue to proactively assess and meet this need. One participant commented that proactively re-engaging with such a vulnerable group of people sits uncomfortably as it is attached to risk. This comment was from someone who provides service in a very high risk area at the time of completing the survey. But now applies to all parts of the UK.

***Figure 9:*** *The percentage of services proactively re-engaging with adults with a learning disability who are at risk of deterioration during the pandemic.*

Where services have been able to proactively re-engage with service users, they have targeted a range of high risk groups (Table 10). The wide variations demonstrates the breadth of adults with a learning disability at risk of deterioration and would benefit from proactive assessment and intervention. Services have used a range of strategies to proactively identify, assess and provide intervention. This includes virtual platforms; training and education; screening by health and social care colleges; bringing forward reviews; and setting up clinics. A number of services have plans for 2021 to be more proactive. A number of respondents stressed that a key tool to proactively re-engaging with people is sending out a clear message that services are ‘open for business’ and accepting referrals. Then reinforcing this message as we move through the next wave of the pandemic.

***Table 10:*** *Groups of adults with a learning disability targeted for proactive re-engagement of physiotherapy assessment and intervention*

|  |  |
| --- | --- |
| **Group of people** | **Specific area** |
| At risk in mobility and/or falls | * Attended physical activity groups * Individuals who have reduced physical activities * BMI>30 |
| Complex physical disability/Profound and Multiple Learning Disability | * Cancelled appointments such as wheelchair, orthotics, spasticity clinic * Due an annual review of posture * Dysphagia * GMFCS 4 and 5 * Outstanding equipment * Pain or discomfort * Postural issues * Pressure areas * Respiratory complications * Spasticity |
| Fragile/limited social situation | * Limited support * Living alone - Socially isolated * Risk of placement breakdown * Living in large residential homes * Those living with family members * Anyone moving provider/home |
| Immediate risk of health decline | * Recent hospital admission * Risk of hospitalisation * Medical unstable patients * Shielding categories |

A number of participants responded that their service is not in a position to be proactively engaging present. This is due to the high priority demand for physiotherapy caused by the pandemic and the change in services delivery from a proactive to a reactive model. Participants regularly use the term ‘firefighting’ to describe their current practice. This is compounded by a lack of resources and capacity to meet this new high priority demand. Many respondents reported that they were under-resourced prior to the pandemic and where unable to proactively manage their local population in line with the recommendations from the standards of practice. Thus, it is not realistic to be proactive in the current situation without additional resources.

The barriers to returning to a proactive service model are likely to continue for the foreseeable future, especially now we are now in the midst of a second wave. The inability to proactively re-engage with adults with a learning disability will further increase the high priority demand. This creates a vicious cycle that will challenge services for many years. Locally there is the same problem and the team is having the same debates about where to target limited resources. The reality is that more staff resources are required to meet the current and emerging demand and to recover ‘normal practice’, let alone recommence service development identified prior to the pandemic.

# **Part 4:** Exploring the **rehabilitation** required to restore physical and functional presentation

Part four of the survey explored the rehabilitation needs of adults with a learning disability, and how services are planning to meet this demand. 87.5% of services are offering rehabilitation, but some are limited in their capacity to meet this need. One respondent highlighted that *“there are very long waits for those who are not urgent due the high priority demand on their service at present”.* And another reported that *“if someone is identified as needing rehabilitation, they would try and see what we could do, but we are a really small team and struggle to provide regular face to face interventions”.* These comments further outline the difficulties services are currently experiencing to meet demand.

Services are using a range of treatments and modalities to deliver rehabilitation to adults with a learning disability to within the limitations of ongoing measures to control the virus; restricted access to clinics and normal treatment environments; and a reduced capacity (Figure 11). Participant’s commented that that they have not been able to offer the group rehabilitation sessions or therapeutic activities, which limits their ability to provide successful rehabilitation. Only three respondents reported that they were able to offer hydrotherapy or rebound therapy which are important modalities used to manage the acute and long term physiotherapy needs of adults with a learning disability.

***Figure 11:*** *Physiotherapy treatments techniques and modalities used to provide rehabilitation during the pandemic*

In addition to the modalities outlined above participants used orthotic devices, Botox injections, special seating, and complex walking aids. Respondents commented that as well as offering physical rehabilitation they would also provide support with mental health problems, anxiety and fears. A number of physiotherapists have been stepping outside their normal practice to deliver successful rehabilitation demonstrating the versatility of the profession. For example, covering for mainstream rehabilitation services where they have been re-organised due to the pandemic.

Most participants reported that they have used remote technology to provide rehabilitation and training to adults with a learning disability and their network of care. They report mixed outcomes. Some have found that virtual modalities have been effective and in some cases *“actually better than face to face as we have been able to get more staff involved”.* Whereas others have not found virtual methods useful because of difficulties engaging services users; lack of access to appropriately technology; inability to utilise ‘hands on’ and holistic observation skills and techniques; and difficulties delegating programmes to carers. It is evident that there are pros and cons to the use of virtual modalities. It is likely that virtual assessment and interventions will remain in some form. Therefore, refining the way it can be used successfully will be an important role moving forward.

The vast majority of respondents reported that they had partially achieved successful outcomes from rehabilitation (87.9%). 10.3% reported that they have been successful, and only 1.7% reported that they have not been unable to achieve the desired outcomes and goals. The results are very encouraging and highlight that individuals can restore their physical and functional baselines with timely specialist intervention. Participants reported that it is mostly extrinsic barriers caused by the pandemic which have impacted on achieving successful outcomes (table 12). These provide an example of the challenges to working effectively in the current climate. Participants commented that these limitations mean that some people are unlikely to return to baseline and will experience irreversible changes to their posture, body shape, mobility and function. These will increase disability and reliance on care. Where rehabilitation has been successful, the challenge will be maintaining this improvement as the pandemic continue to restrict people’s lifestyles and impacts on services capacity to monitor and review progress.

**Table 12:** Theextrinsic barriers caused by the pandemic which have impacted on providing successful rehabilitation to adults with a learning disability during the pandemic.

|  |
| --- |
| **Example of extrinsic barriers to achieving goals during the pandemic:** |
| * Anxiety * Carer capacity - limited opportunity to delegate programmes * Carer fatigue * Closure of or limited access to hydrotherapy, gyms and exercise facilities * Families and care homes refusing staff entry to provide assessment and treatment * Health promotion groups have remained limited. * Lack of access to equipment and appropriate environments * Lack of capacity to deliver services * Lack of therapeutic modalities such as rebound and hydrotherapy * Limited access to community activities used to maintain function and wellbeing * Ongoing pressures and long waiting times for mainstream services * Reduced capacity for face to face visit due to social distancing, shielding and capacity * Restriction placed on carers to manage COVID-19 within the care facilities * Restrictions of home environments * Some services restricting face to face assessment and intervention * Second wave of the pandemic * Service users and their network of care lack access to appropriate technology to engage online * Unable to provide full set of service and interventions |

One participant comments that their service is focusing and devoting resources to rehabilitation, but recognises that as a result they are concentrating their limited resource on a small number of service users which impacts on the management of others. This highlights that specialist learning disability services are not set up in a rehabilitation model and a relatively small number of referrals can significantly impact on the services ability to deliver ‘normal practice’. This is a concern, as respondents are predicting a surge in referrals when people start to re-engage with society and realise the impact of the decline in physical presentation.

# **Part 4:** Case studies

In part 4 participants had the opportunity to write a case study where they had provided rehabilitation to service users who had experienced deterioration during the pandemic. 20 case studies where submitted and can be accessed via the webpage. The case studies support the results of the survey and demonstrate how the views of the respondents translate to real life situations and practice. The case studies represent a cross section from those with a mild learning disability and previously no physiotherapy needs, to those with PMLD and long term physiotherapy needs. The majority have positive outcomes with specialist intervention confirming that, with specialist rehabilitation adults with a learning disability can restore to their baseline and achieve their goals. They highlight the fantastic work completed by participants and services, demonstrating the critical role of specialist learning disability physiotherapy during the different waves of the pandemic as well as managing the recovery period. Two case studies highlight in detail the extreme impact the pandemic has had on the outcomes of some adults with a learning disability. These confirm that it is not only contracting COVID-19 that has resulted in the premature deaths of people. One participant commented that they had 27 adults with a learning disability pass away in the first six months of the pandemic which is a much higher number than usual, and yet only one of these deaths was directly due to COVID-19.

# Recommendations

Specialist learning disability physiotherapy services have an essential role in managing the physiotherapy needs, health and wellbeing of adults with a learning disability during and after the pandemic. Therefore:

* Specialist learning disability physiotherapists must retained capacity to meet the physiotherapy needs of their local population.
* Services should continue to provide direct and indirect assessment, treatment and reviews to adults with a learning disability as clinically indicated.
* Service must take into consideration the indirect impact of the pandemic on the physical and functional presentation of adults with a learning disability when making decisions about service provision.
* Physiotherapists should risk assess the benefit of physiotherapy versus the risk of contracting the virus. This should take into consideration any potential impact of not offering physiotherapy; and the person’s wishes and choice. Where the person lacks capacity to contribute the risk assessment, best interest should be considered.
* Services should be proactive in identifying people at risk of deterioration during the pandemic, and offer physiotherapy to minimise decline in physical and functional presentation.
* Services should maintain capacity to offer rehabilitation for deterioration in physical and functional presentation in a timely manner to restore baseline.
* Service should contribute to monitoring of long COVID (COVID syndrome) in adults with a learning disability, and support the management of the condition either directly or by supporting access to mainstream services.
* Services should work with their local day services and community activities where and when possible to promote opportunities for physical activity, movement and health promotion.
* Service should plan for an expected surge in referrals as the social measures used to control the virus are reduced and society returns to normal.
* Services should recover back to a proactive model of care as soon as possible, whilst maintaining the ability to react quickly to high priority referrals.
* Services should monitor service demand versus capacity to meet this need. Where demand outweighs capacity this should be raised with management and commissioning to highlight gaps and request additional resources to manage this need. This includes highlighting the roles and tasks not being provided as a result of the pandemic.

# Summary

It is evident that the COVID-19 pandemic has had a profound impact on adults with a learning disability. They had a six times higher death rate than the general population from contracting the virus in the first wave (Public Health England, 2020). They have also been severely impacted by the social measures used the control the spread of the virus. The results of the survey indicate that the latter had a greater negative impact with adults with a learning disability experiencing deterioration in their physical, function, cognitive and mental health presentation. In addition, the increased anxiety, fear, stress and load placed on networks of care has caused carer fatigue and impacted on quality of care. These are likely to be exacerbated by the third wave of the virus and the latest lockdown measures.

Specialist learning disability services have had to change their model of care to manage the increased high priority demand. They have been unable to return to ‘normal practice’ and offer the proactive management that is so critical to meeting the physiotherapy needs of adults with a learning disability. Returning to a proactive model of care as soon as possible is essential. However, the extent of the deterioration highlighted in the survey means that services are likely to be reacting to this need for some time. Worryingly, the results suggest the extent of the impact of the virus is not yet known, and will only become apparent as society returns to normal and public confidence returns. Physiotherapy services will need to plan and prepare for this demand.

The range of areas in which adults with a learning disability have deteriorated and the number of factors identified that increase the risk of decline will make proactively identifying and re-engaging with specific groups difficult. Physiotherapy services will need to focus their limited resources on people with known physiotherapy related problems and long term physical disability, such as those with complex physical disability, long term mobility problems, and known fallers. But also, sending out a strong message to encourage service users and their network of care to make referrals for new and acute physiotherapy related problems. Services will need to monitor the demand versus capacity, and seek additional resources where required. Many services were under resourced prior to the pandemic and will struggle to meet the additional need whilst recovering a proactive service model without extra staffing. There is clear evidence about the benefits and potential cost savings of rehabilitation against living with long term disability. There is a growing awareness that the pandemic has caused significant rehabilitation needs across all settings of healthcare. It is critical that adults with a learning disability are not forgotten.

It is important to take note of the findings of the survey as we more forwards into the next phases of the pandemic. It is crucial to strike a balance between the benefits of physiotherapy and the risk of contracting the virus. This is difficult, professionals need to be careful about being a vector for transmission. However, it is important to learn from the experiences during the first wave. We now have evidence of the negative impact of the ongoing restrictions to society; closure of day services and community activities; limited access and delays to healthcare; and the reduced opportunities for movement and physical activity on adults with a learning disability. Thus it is not appropriate to cease specialist learning disability physiotherapy; completely shift service delivery and provision to manage COVID-19, or redeploy staff into acute or vaccination services. It is important to stress that learning disability physiotherapists are specialist in working with adults with a learning disability and should be retained to complete this essential role. Although they have a range of skills that can be useful in the efforts against the virus, not many professionals have the skill set required to successfully work with adults with a learning disability. If we have learnt anything from the pandemic, it is that if you limit access to specialist learning disability physiotherapy and relevant healthcare services; reduced opportunities for physical activity and movement; and remove proactive management from adults with a learning disability many will experience significant deterioration. Therefore, these must remain in place wherever possible during the next and any subsequent phases of the pandemic, and be fully restored as soon as possible.

# References

* Public Health England (2020) People with learning disabilities had higher death rate from COVID-19. Press release. Available at <https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19>