

Survey exploring the role of Specialist Learning Disability Physiotherapy services during the COVID-19 pandemic.

National Executive Committee of the Association of Chartered Physiotherapists for Adults with Learning Disabilities (ACPPLD)

COVID-19 is a type of virus (Novel Coronavirus). As a group, coronaviruses are common across the world. Typical symptoms of coronavirus include fever and a cough that may progress to a severe pneumonia causing shortness of breath and breathing difficulties. Generally, coronavirus can cause more severe symptoms in people with weakened immune systems, older people, and those with long-term conditions like diabetes, cancer and chronic lung disease. Novel coronavirus (COVID-19) is a new strain of coronavirus first identified in Wuhan City, China. COVID-19 has since become a global pandemic.

The first confirmed case of COVID-19 was identified in the UK on the 31st January 2020 and the first death was confirmed on the 5th March 2020. The outbreak started to spike in March and on the 23rd March a partial lockdown of the UK was announced to help contain the virus and to prepare the NHS. This included introducing strict social distancing; shielding of people who were clinically extremely vulnerable*; postponing all non-urgent operations to free hospital beds; and ceasing all non-essential health and social services so that staff could be redeployed to help fight the virus.

***Definition of 'clinically extremely vulnerable'**

Expert doctors in England have identified specific medical conditions that, based on what we know about the virus so far, place some people at greatest risk of severe illness from COVID-19. Disease severity, medical history or treatment levels will also affect who is in this group.

Clinically extremely vulnerable people may include:

- *solid organ transplant recipients*
- *people with specific cancers:*
 - *people with cancer who are undergoing active chemotherapy*
 - *people with lung cancer who are undergoing radical radiotherapy*
 - *people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment*
 - *people having immunotherapy or other continuing antibody treatments for cancer*
 - *people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors*
 - *people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs*
- *people with severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic obstructive pulmonary disease (COPD)*
- *people with rare diseases that significantly increase the risk of infections (such as severe combined immunodeficiency (SCID), homozygous sickle cell)*
- *people on immunosuppression therapies sufficient to significantly increase risk of infection*
- *women who are pregnant with significant heart disease, congenital or acquired*
- *other people who have also been classed as clinically extremely vulnerable, based on clinical judgement and an assessment of their needs. GPs and hospital clinicians have been provided with guidance to support these decisions*

<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

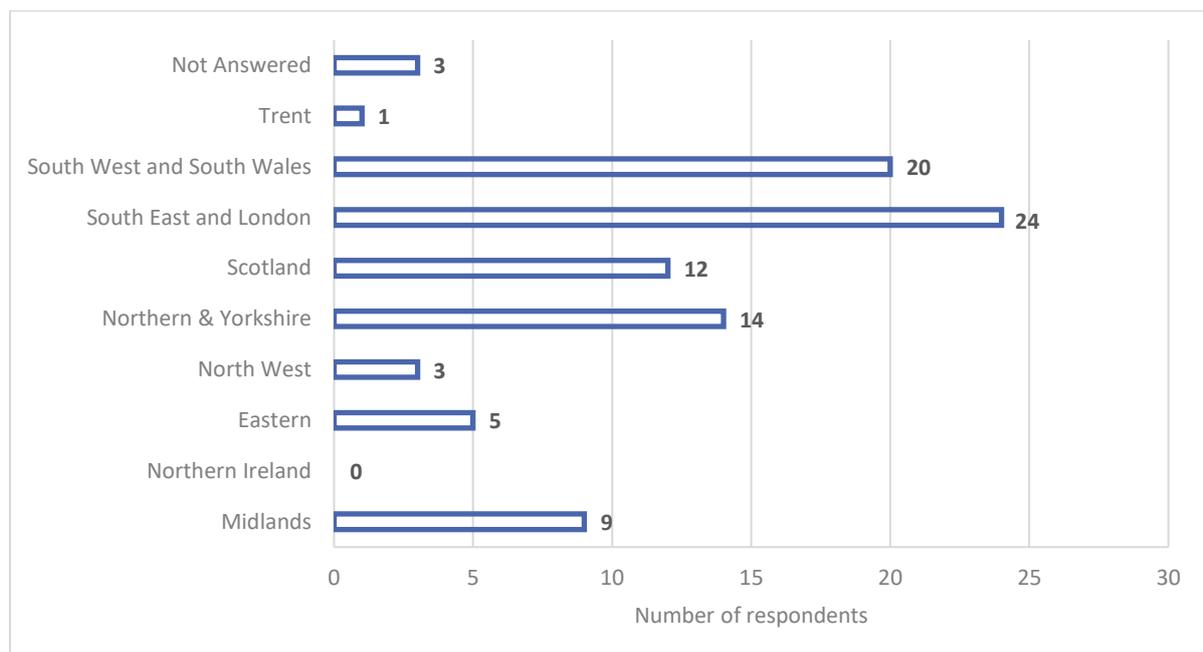
The response required of the NHS needed a complete re-organisation of the way it delivered services. Specialist learning disability services were significantly affected by the pandemic. Firstly, because adults with a learning disability were identified early on as vulnerable and at high risk of

serious illness from COVID-19, thus either officially shielded or followed strict social distancing advice. Secondly, because non-essential health care was postponed, and day services and community activities were closed. And thirdly, because professionals from non-essential services were redeployed into acute hospitals or discharge to assess teams into the community. This led to uncertainty about the role of the specialist learning disability team during the pandemic, especially in the early stage.

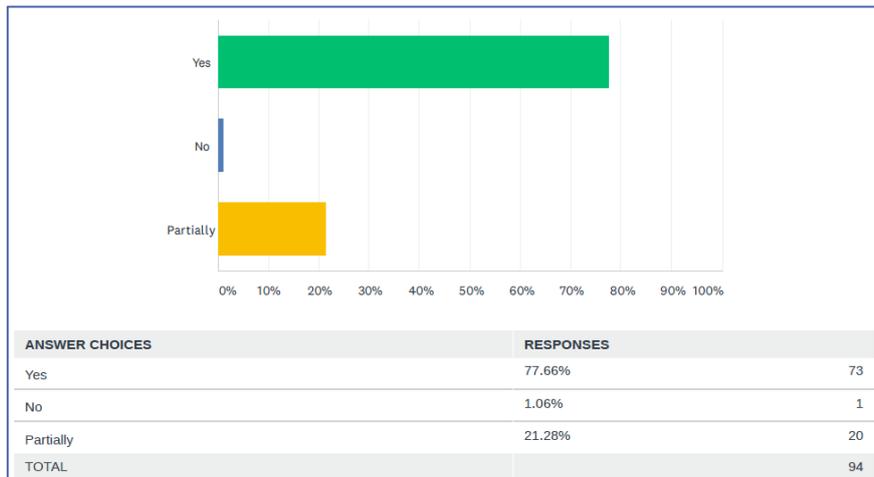
In response the ACPLD National Executive Committee (NEC) published their recommendations for the role of specialist learning disability physiotherapist during the COVID -19 pandemic (<https://acppld.csp.org.uk/news/2020-04-06-acppld-national-executive-committee-response-covid-19-pandemic-march-2020>). To assess how specialist learning disability physiotherapy services responded to the pandemic and followed the guidance, a short survey was developed. The questions were based on informal feedback and enquiries to the NEC. The data extrapolated from the survey was a combination of quantitative and qualitative. Quantitative data was analysed using SurveyMonkey and is represented as descriptive statistics. The qualitative data was analysed thematically, is presented as the themes discussed and is supported by examples.

94 people responded to the survey from across the UK (Graph 1) between 5th May 2020 to the 3rd June 2020. The vast majority of people were employed by NHS foundation trusts (67); six were employed in integrated NHS & Social Care teams; eight by Mental Health Trusts; four by Community Interest Companies; and two worked in special education colleges.

Graph One: Region of respondents



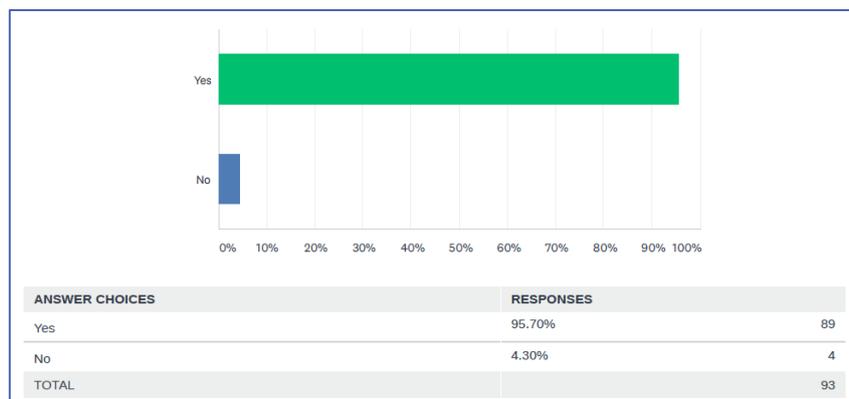
Question Two: Has your service retained specialist learning disability physiotherapy staff during the COVID-19 Pandemic?



The vast majority of services retained specialist learning disability physiotherapy during the pandemic either full time (77%) or partially (20%). A number of respondents reported that they were preparing and ready for redeployment but the pandemic did not reach the predicted levels and staff were not needed to be redeployed into mainstream services. Where physiotherapists were redeployed they covered a range of different roles including:

- Case workers
- COVID wards
- Discharge to assess supported discharge teams
- Healthcare assistants
- Inpatient assessment and treatment unit
- Respiratory wards
- Duty Social Worker
- Support workers in NHS learning disability specialist residential sites.

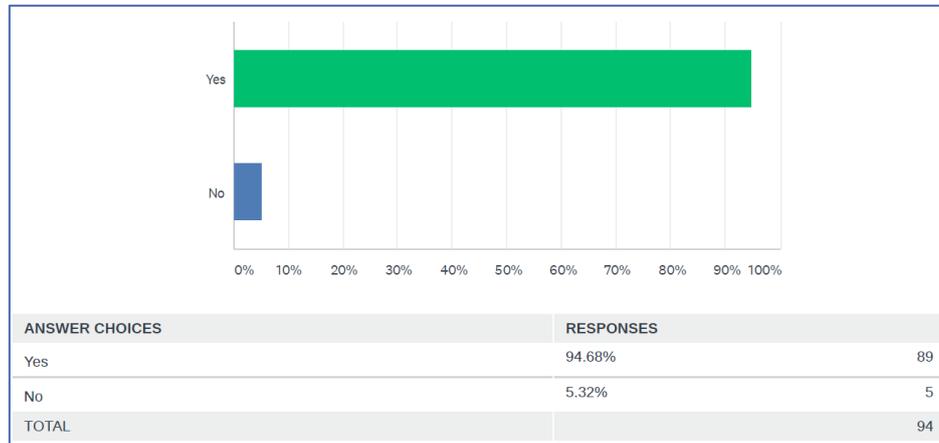
Question Three: Has the physiotherapy team ceased all non-essential physiotherapy to minimise the risk of spreading the virus?



95% of participants reported that their services ceased all non-essential physiotherapy to adults with a learning disability. Two community learning disability physiotherapy teams reported that they had developed a traffic light system to document their roles and responsibilities during the pandemic using the Standards of Practice for Physiotherapist working with Adults with a Learning Disability;

their referral priorities; and their competency framework. In both cases, red represents the essential roles that must be delivered throughout the pandemic; amber the roles that are likely to be required during the recovery phase; and green the roles that will be re-started once the pandemic is over.

Question Four: Has the physiotherapy team identified and is monitoring adults with a learning disability who are at high risk of serious illness from COVID-19?



95% of respondents identified adults with a learning disability at high risk of developing serious illness from COVID-19. Most services use a RAG rating to identify service users either:

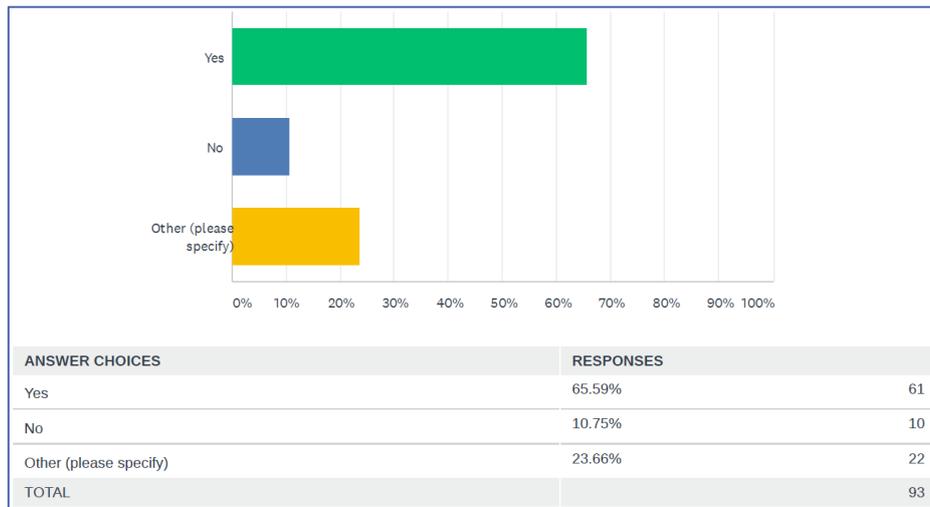
1. At high risk directly from the virus
2. At risk of deterioration due to the social measures put in place to control the spread of the virus
3. Would struggle to manage during the lockdown.

Many identified service users with a complex physical disability, especially those with associated respiratory problems; and people living in vulnerable settings such those living with elderly parents, or complex social situations.

Once identified, most services maintained regular contact during the pandemic through welfare calls either via telephone or video consultation. Welfare calls aimed to:

- Support service users and their network of care to follow government guidance. Including the correct use of personal protective equipment (PPE) and interpreting the messages coming from the department of health and other sources.
- Offer advice on how to support physiotherapy and health needs within the home environment.
- Support the appropriate use of and access to health services.
- Promote physical activity and exercise at home.
- Provide reassurance and help to manage anxieties caused by the pandemic.

Question Five: Is the physiotherapy team supporting hospital admissions and timely safe discharges?

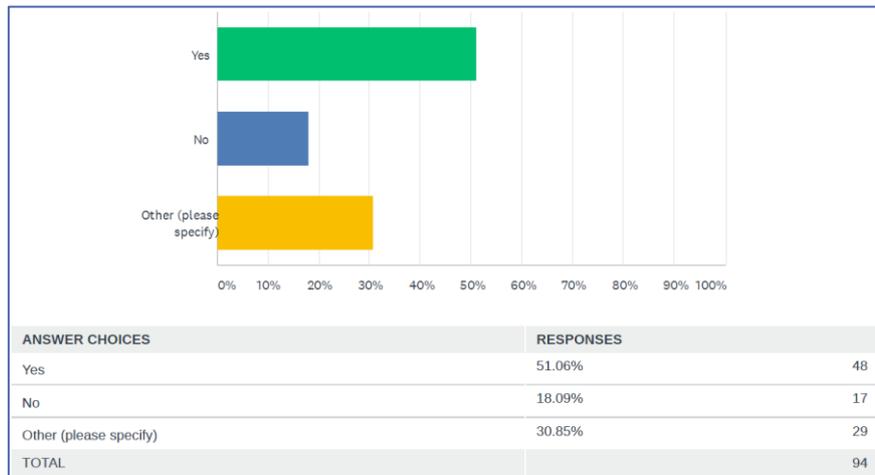


Specialist learning disability physiotherapists have a key role in supporting hospital admissions to improve compliance with and outcomes from therapy as well as facilitate discharges. This is particularly important during the COVID-19 pandemic where there is increased demand and pressures on acute services; hospitals are following a discharge to assess model; hospital visitors were limited; and hospital staff are wearing PPE which covers their faces. All of which reduce the likelihood for poorer outcomes for adults with a learning disability.

Approximately two thirds of services have been supporting admissions and discharges from hospital during the pandemic. Either, indirectly by advising mainstream colleagues about specific cases or developing supportive documents such as hospital passports and advance care plans; or directly by offering in-reach services into the hospitals. Participants reported that they have adopted a multidisciplinary approach to supporting hospital admissions and discharges in liaison with the local learning disability liaison nurse.

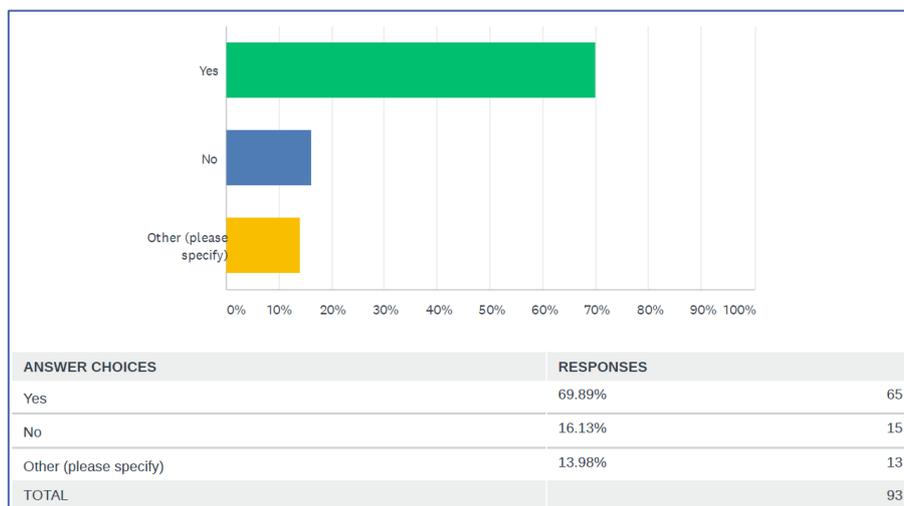
A number of participants commented that they are often not informed about admissions and discharges which has then led to poor outcomes for the individual. 13 people reported that at the time of completing the survey (5th May – 21nd May 2020) there was no known admissions to their local hospital but would offer support if and when the situation arise.

Question Six: Is the physiotherapy team providing rehabilitation to adults with a learning disability post hospital discharge?



Half of participants reported that their service has been offering rehabilitation to adults with a learning disability post hospital admission with COVID-19. Participants also commented that they provided rehabilitation to service users discharged from hospital with non-COVID-19 related problems in order to support local re-organised mainstream rehabilitation services. Similar to the response to question five, 19 people reported that they were not aware of any hospital discharges at the time of completing the survey, but would offer rehabilitation when required. One person commented that they are currently working under the discharge to assess model were they visited a few times to ensure the situation is safe but were not offering rehabilitation.

Question Seven: Is the physiotherapy team providing face to face treatment to adults with a learning disability where there has been a significant deterioration/changes in physical presentation and/or function?



Two thirds of participants reported that their services continued to offer direct assessment and intervention to adults with a learning disability where there is an essential need. Participants commented that they would try to manage the problem using remote methods in the first instant, but would complete face to face assessment if unsuccessful. Participants reported that they would complete risk assessments and use appropriate PPE for all visits to minimise risk. One participant commented that some service users have been apprehensive of masks and visors therefore have

been using "this is me" photographs tags.

Participants would consider the following physiotherapy related problems as essential, thus warrant a face to face assessment and intervention:

1. Deterioration in the person's posture
2. Respiratory complications and concerns
3. Falls prevention and management
4. Pressure ulcer management
5. Multidisciplinary management of dysphagia
6. Pain management, where the cause of the pain may be related to a physiotherapy related problems
7. Supporting hospital discharge and rehabilitation
8. Equipment provision
9. Hospital and care home admission avoidance

Question Eight: What other physiotherapy interventions is your service providing during the COVID-19 pandemic?

Participants highlighted a range of physiotherapy interventions that their services provided during the pandemic other than those described above. Table 1 details these activities.

Table 1: Physiotherapy interventions during the COVID-19 pandemic in order of frequency discussed

<p>Develop and disseminate physiotherapy programmes on platforms such as YouTube, DVD, and photographic documents. These include programmes on:</p> <ul style="list-style-type: none">• Exercise and activity suggestions during lockdown• Healthy lifestyle• Positioning and postural management• Respiratory management techniques such as active cycle breathing with percussion and vibrations, lung volume recruitment, and oral suctioning• Seated and standing exercises• Yoga
<p>Remote assessments, interventions and reviews via media platforms such as Near Me, Attend anywhere, Zoom and Skype.</p> <p>Sessions include:</p> <ul style="list-style-type: none">• Adjusting equipment• Breathing techniques• Chest physiotherapy• Exercise sessions (one to one or group sessions)• Falls and mobility assessments and intervention• Joint mealtime assessments• Positioning and postural management• Mobility and rehabilitation programmes• Respiratory management• Reviews of postural equipment• Seating assessments• Training and education• Triage new referrals• Troubleshooting

Supporting primary and secondary healthcare to deliver services during times of increased demand. This includes:

- GP liaison
- Screening before escalating to primary and secondary healthcare
- Hospital liaison
- Linking with safeguarding lead re: DNACPR decisions
- Developing information to support hospital admissions such as hospital passports and advance care plans
- Information sharing to support hospital admissions
- Expanding role to reduce demand on community services

Non-clinical and strategic roles including:

- Network meetings
- Service delivery planning for post COVID 19 interventions
- MDT planning and working (complex cases)
- Co-ordinating service response and developing new pathways and standard operating procedures adapted for the pandemic
- Development of national college guidelines
- Crisis management
- Support trust policy and procedure
- Established virtual methods to continue team functions
- Managing PPE supplies

Review care plans to ensure that they reflect COVID 19 pandemic management strategy and keep them up to date as advice changes.

Contributing to or leading on the development of advance care and escalation of treatment plans.

Equipment provision to ensure people have access to equipment to maximise mobility, function and posture such as walking aids, wheelchairs and standing frames.

NB: One services commented that they leave the equipment with information leaflets left at door rather than face to face contact then follow up with telephone support.

Specialist learning disability physiotherapy performed a range of roles to support adults with a learning disability and their network of care to prepare for and during the pandemic. They minimised the risk of people contracting the virus as well as supporting people to manage during shielding and social distancing. They also had a role in the strategic and practical delivery of the government guidance on an individual, local and national level. They played a key role in supporting mainstream health services either by taking on roles that reduced the demand on services; or by providing advice and documentation to improve outcomes for adults with a learning disability when they accessed services.

The wide range of roles and tasks specialist learning disability physiotherapists adopted during the COVID-19 pandemic illustrates their versatility and flexibility when faced with new challenges. For example, one participant commented that they supported work colleagues to adapt to new working environments by recommending on the ergonomic set-ups for home working environments and providing posture and exercise advice.

Question Nine: What is the physiotherapy team doing to raise the awareness of and manage the impact of coronavirus, social distancing and shielding on physiotherapy related problems such as falls, posture and respiratory health?

Participants detailed a range of measures their services had put in place to raise the awareness of and manage the impact of coronavirus, social distancing and shielding on the physiotherapy related problems that adults with a learning disability may develop. These measures targeted the individual and their network of care as well as mainstream services to highlight that adults with a learning disability are high risk for serious illness from contracting coronavirus.

The large number of participants reported that they provided regular welfare calls to adults with a learning disability and their network of care during the pandemic. During these calls they would take the opportunity to raise the awareness of the potential impact of COVID-19 on people's physical presentation and offered advice.

A number of services either developed or shared existing accessible advice on a range of topics aimed at minimising the impact of the pandemic on the person's presentation. These included, advice on:

- Postural management such as Your posture matters (NHS Scotland publication).
- Falls, strength and balance exercises such as CSP get up and go leaflet.
- Engagement and activity to maintain physical and mental health.
- Individual social stories to help with understanding and compliance with restrictions.

Two participants commented that their services would review advice leaflets coming from different sources before disseminating them.

A number of services provided training and education to people's network of care and mainstream professionals via remote conferencing technology. Three participants used social media platforms including developing a YouTube channel to share a number of physiotherapy interventions; and posting on teams Facebook and Twitter accounts.

A number of participants reported that they were unable to work proactively due to either an increased workload or reduced capacity due to re-deployment of staff. One person commented that in these circumstances that they found it important to be honest and open about the limitations of pandemic on delivering physiotherapy services.

Two participants commented that they were working at a national and regional level to influence policy development and to advocate for adults with a learning disability during the development of government COVID-19 legislation and guidance.

Question 10: Do you have any other comments about the role of the specialist learning disability physiotherapist during the COVID-19 pandemic?

Participants mainly used question 10 to raise concerns they had about the impact of the COVID-19 pandemic on adults with learning disability and specialist learning disability services moving forwards. Table 2 details the common concerns raised from the data.

Table 2: Concerns raised in Question 10 about the impact of COVID-19 pandemic of adults with a learning disability.

Specialist learning disability physiotherapists have a critical role in providing advocacy and support to people with a learning disability and their network of care. Therefore, the redeployment of specialist learning disability professionals increases the risk of adults with a learning disability being exposed to

further health inequalities and poor outcomes. This feeling was compounded by the relaxation of critical legislation that protects the right of people such as the Care Act 2014; the use of inappropriate frailty assessment tools to support decision about escalation of treatment; and the remodelling of community rehabilitation services to a discharge to assess model.

Concerns about the impact of the re-organisation of health and social care services; postponing of non-essential services such as wheelchairs, orthotics, falls, and spasticity; and stringent social distancing or shielding on the pre-existing and ongoing physical health needs of adults with a learning disability. In particular the impact on the person's mobility, falls and posture through leading more sedentary lifestyle and a lack of access to health services and community activities. For example, the closure of day services means people are not accessing physical activity, exercise or 'maintenance' programmes which is likely to result in the development of secondary complications.

People with a learning disability and physiotherapy needs (either pre-existing, or caused by or exacerbated by the COVID-19 pandemic) require ongoing access to specialist learning disability physiotherapy services. This is to prevent the need to access primary and secondary healthcare services; and to manage their posture, respiratory health, mobility and falls. Therefore, services need to develop methods to provide safe and effective physiotherapy throughout the COVID-19 pandemic. This includes developing an effective method to complete assessment and intervention remotely; and offering face-to-face assessment and interventions where required.

People with a learning disability can require extensive and intensive rehabilitation post discharge from hospital with COVID-19. This rehabilitation needs to be delivered by specialist learning disability physiotherapy services because many individuals require adjustments that go beyond what is possible for mainstream rehabilitation services at this time. Many services have been reorganised to a discharge to assess model which limits their ability to offer the flexible and adapted interventions over an extended period of time. Key to delivering successful outcomes to people with a learning disability.

A number of people have not received a shielding letter therefore they required support to get recognised as clinically extremely vulnerable and eligible for additional support.

Physiotherapy intervention for adults with a learning disability is usually delivered by proxy through the delegation of programmes and tasks to the person's network of care. Therefore, physiotherapists must provide training and education to develop competence before the task can be handed over. During the COVID-19 pandemic it is not possible to provide face to face training to hand over skills. Therefore, services need to develop methods to deliver training and assess competence virtually to ensure programmes continue to be completed safely and effectively.

There is limited knowledge and understanding about the long term impacts of COVID-19. Adults with a learning disability are often poor reporters of health problems and are reliant on their network of care to recognise often subtle changes and then appropriately seek medical assistance. Therefore the lack of understanding increases risk of misdiagnosis, delayed assessment and treatment, and diagnostic overshadowing.

Lack of understanding from service managers about the essential role of specialist learning disability physiotherapy services had during the pandemic. This led to the redeployment of staff; professional completing administrative roles rather than supporting adults with a learning disability; or staff having to promote their role to management to ensure that they are not redeployed. One participant commented that their role was to support their trust and service management to respond to the pandemic rather than deliver services to adults with a learning disability.

The challenge of recovering specialist learning disability services back to standard practices, roles and functions whilst:

1. Many adults with a learning disability and their network of care remain fearful of returning back to 'normal' life and having face to face contact with professionals.
2. There is likely to be an increased service demand as adults with a learning disability come out of

- lockdown.
3. Managing the backlog of work on waiting lists and caseloads with reduced capacity to complete face to face visits.
 4. Maintaining capacity to provide rehabilitation to adults with a learning disability post hospital admissions with COVID-19.
 5. Health and social care services are recovering from the pandemic with large waiting lists and not being able to run at full capacity.
 6. Many day services and community activities remain closed or running at significantly reduced capacity.

For some participants, the pandemic provided the opportunity to reflect on service delivery; for change; and for development. This mainly came about in areas where coronavirus was not prevalent in the early stages of the pandemic. Participants commented that some of the positives to come from the pandemic were that services and staff embraced technology and established remote methods of working; worked flexibly and innovatively to continue to provide services during a constantly evolving situation; and improved collaborative working with social care and mental health professionals.

Conclusion,

The survey highlights the different ways that specialist learning disability physiotherapy services worked during the pandemic to support adults with a learning disability. The approaches adopted, were broadly consistent across all participants and were in line with the ACPPLD national executive committees recommended response to the pandemic. It is encouraging that the vast majority of services retained physiotherapists to meet the needs of adults with a learning disability and their network of care. It is also positive to hear that some services did not see any cases of adults with a learning disability contracting coronavirus.

The results demonstrate the broad skill set; innovation and versatility of specialist learning disability physiotherapists. Most services have embraced remote technology to support team functions as well as to perform direct assessment and interventions. Although the jury is still out for many people about its effectiveness in providing physiotherapy to adults with a learning disability.

Since March 2020, the UK has moved through the peak of the pandemic. Society is being unlocked and health and social care is being asked to consider how it recovers. This is a complex task. Indeed, recovering from lockdown is likely to be much more complex than entering it. Whilst health services recover they must develop new ways of working to continue to follow social distancing measures, and to consider the economic cost of the pandemic. In addition, there is always the fear of further waves of the virus and the potential for local, regional and national lockdowns.

The ACPPLD NEC plan to explore this through another survey in due course.

Please do not hesitate to contact David Standley (david.standley@gstt.nhs.uk) if you have any questions about this survey. And remember that you can contact the NEC directly with any issues or feedback you may have that relates the physiotherapy needs of adults with a learning disability (<https://acppld.csp.org.uk/contact-acppld>).

