Understanding the Impact of COVID-19 Restrictions for people with Cerebral Palsy September 2020

Context

Cerebral Palsy Scotland carried out a survey in May 2020 to understand how lockdown restrictions were currently affecting people in Scotland with cerebral palsy (CP) and their families and carers. The survey gave us an extremely helpful, if concerning, picture of the issues faced by this population during this time. The headlines of which were:

- 70% of people with CP, and their Carers, believed that lockdown was impacting negatively on their physical health.
- 54% reported that lockdown was impacting negatively on their mental health and 49% responded that the mental health of their carer was being impacted negatively.
- 69% of respondent had medical appointments cancelled.
- 15% reported that planned surgery had been cancelled.
- 58% reported that both shielding and practicing social distancing was affecting their lives "a great deal" or "a lot".
- 42% were either finding it hard to make contact with health professionals or didn't feel they were getting enough support.
- 41% had equipment needs that required attention and adjusting.
- 56% of people reported that they had not been able to access PPE.
- 34% of respondents reported that they were happy with the level of support they were receiving from health professionals.
- 69% of respondents felt they were getting enough support from Cerebral Palsy Scotland.
- 75% valued the weekly email update of cerebral palsy related issues.

Now that shielding measures have been paused, schools have returned for the new term and health and social care services are looking at how to resume Cerebral Palsy Scotland felt it was appropriate to track the changes (or not) experienced by people with cerebral palsy, their families and carers. Our second survey was open from 18th August – 1st September 2020 and was accessed via Survey Monkey. 44% were responding on behalf of children under 18, 48% were adults between 18 and 60 years old and 8% were adults over 60. Responses were received from all health board areas in Scotland (except for Orkney and Shetland). There was a 78% completion rate for the survey, with an average time of 9 minutes spent by respondents.

Key Statistics in September 2020:

- 76% said that the Covid-19 situation had put more pressure on family life
- Over 50% said that their family was more isolated as a result of the restrictions.
- 71% reported that any care arrangements they had in place previously were not yet back to the levels they were pre-Covid.
- 55% responded that their physical health had declined

- 53% responded that their mental health had declined
- 30% of the survey classed themselves as "shielding" although only 8% reported that they had received an official letter, reflecting how vulnerable people felt as a result of their condition.
- 58% reported difficulty in accessing support from physiotherapy, occupational therapy and speech and language therapy with 51% only able to access healthcare services online or via telephone.
- 79% of families have sent their children back to school but of those who haven't, 20% felt that their school or nursery would not be safe and 20% reported that the school or nursery could not currently accommodate their child.
- 82% of respondents were happy with the level of support they had received from Cerebral Palsy Scotland.

Main Themes

Shielding

30% of the survey classed themselves as "shielding" although only 8% responded that they had received an official letter. This reflects how many people with cerebral palsy felt vulnerable during this time and therefore chose to shield themselves which led to an increased sense of isolation, anxiety and impacted on all members of the household, not only the person with CP. Many people did not understand the logic of who was or was not meant to shield or who to go to in order to find information. The picture reported is one that illustrates there were many variations across the country and that people themselves did not always feel equipped to take their own decisions about their own level of risk.

"I still don't really understand why I was shielding when mostly all my friends who are the same as me did not get an official shielding letter. I really found that difficult to cope with."

"I didn't get any information on shielding but as a person who catches every bug going, I chose to stay indoors."

"We spoke to our son's consultant and he added us to the list"

"I am surprised at this [that he wasn't shielding] *as he's on weekly antibiotics for chest infections"*

"Had to contact my GP to be added to the shielding list"

"Received official letter on 31st July, COVD advice changed to include developmental disability and swallowing difficulties"

"We were told by occupational therapist that because we are not sure, shielding would be for the best"

"With my son having disabilities and myself being pregnant, we've shielded from the beginning"

"We shielded as best we could as a family but were not advised to shield officially."

Care Arrangements

71% of respondents reported that any care arrangements they had in place previously were not yet back to the levels they were before Covid-19. Over 40% were totally reliant on family carers. 12% reported that they did not want people coming into their house at this point because they remain concerned about the virus. Some reported that care had been restored only at the end of August 2020. Others pointed to the lack of respite care, day centres and support groups not opening and resuming.

"All support was cancelled, support groups cancelled and are still cancelled. Still do not feel it's safe to go outdoors"

"My brother no longer attends his regular day centres meaning his now isolated at home with family"

"We stopped care completely during shielding and have only allowed one carer back at the moment, meaning I am the second person required for personal care, moving, handling, hoisting etc."

"Respite service still not open"

"Friends are helping me"

"Really struggling with the uncertainty of my care situation and not being able to go out"

"My mum had to look after me every day" (adult respondent)

Others had issues with transitions in housing or care arrangements being paused and not fully completed still.

"I am in the process of moving out and getting new support workers so didn't start my care back up. My mum is still having supporting me."

For parents of children with CP the re-opening of nurseries and schools was important in helping them with care arrangements.

Health and Wellbeing

During lockdown over 70% of our survey reported that they feared a deterioration in their physical health. In our follow up 55% reported that they HAD seen that deterioration in their physical health. 53% reported that their mental health had deteriorated. 23% reported that nothing had changed. Access to community facilities and being able to keep active was an important factor in how well people managed to cope.

"Lack of physical exercise and isolation"

"I'm on edge all the time"

"Increased anxiety and little opportunity to exercise"

"Huge stress caused by an unsupported employer"

"No physio was available during lockdown and his normal everyday life in and around the community vanished leading to boredom and lack of routine."

"I'm stiffer and more wary of people around me"

"Isolation and not being able to leave home or to have family and friends visit me"

"The worry about leaving the house, plus the stress of not having transport either"

"As his carer, my mental health has been negatively impacted"

"I have scoliosis, depression and anxiety which isn't the easiest to deal with but due to COVID-19 its gotten worse especially as my son with cerebral palsy isn't able to go out due to worry and concern about the virus. It makes things harder to deal with as we haven't had any support throughout from my son's physiotherapist, occupational therapist, orthotic doctor and paediatrician. Just a phone call to see how we were doing at the start of COVID-19 lockdown from his physiotherapist and pediatrician. We feel neglected in a way and it's sad."

"Unable to access massage therapy resulted in extra tension in all four limbs plus neck and back. Increased use of painkillers caused constipation aggravating difficulties."

"More leg tightness and spasms due to working from home and change in exercise can't do normally like horse riding, basketball and swimming."

Those who were already well connected with community support, such as Disability Sport programmes fared better.

"Involved in para sport so have trained at home through lockdown. While it's been hard having my training disrupted, I wouldn't say my mental health has deteriorated although it has emphasised the challenges of my disability."

"My son's physical health is probably better than pre-lockdown. He used his running bike every day out on the street. He can now move in the bike independently and wasn't able to do that before. His reciprocal movement (Stepping rhythmically) has improved hugely. This has been great for his physical and mental health. He loves using the bike. However, he did miss the stimulation and friendships of school, so there were downsides too for him."

Accessing Healthcare

57% of the respondents reported that they were able to access healthcare advice either for their CP or for another issue. 51% said that access was either virtually or via telephone, only 12% had accessed healthcare in person. 17% reported that they had not been able to see or speak to their GP or other healthcare professional.

The largest issue for people was access to support for their physical health (physiotherapy, occupational therapy and speech and language therapy). 58% of people reported difficulty in accessing support from these services. 47% said that appointments with the health professionals they normally see about their CP have still not resumed. In addition:

- 28% have been unable to resolve equipment issues
- 21% said that they had difficulty accessing mental health support
- 17% reported that they are still waiting for planned surgery that was cancelled to be rearranged

"Other than Cerebral Palsy Scotland who kept us up to date, no other health care bodies have been in contact."

"Hospital appointments cancelled, mental health worse because I can't socialise"

"Written to consultant asking for advice. Still awaiting reply."

"Yes [I can access healthcare services] *but get fobbed off"*

"The GP was very reluctant to come out. The hospital was helpful but have a low threshold for admission."

"Not able to access spasticity service which is at hospital. I can call my GP but they are not specialists in spasticity management."

"We have not had and still don't have any input from physiotherapy"

"Virtual contact with OT and physio has not been particularly successful"

"Not able to access steroid injections to relieve pain in shoulder and other joints"

"We have accessed Botox but still no physio, OT or SLT apart from very occasional email check-ins"

"I now have a pressure sore and anemia which is delaying surgery"

"No physio or hydro due to social distancing. No support whatsoever from GP surgery as we didn't get a shielding letter"

"No access to orthotics. Cancelled appointments with psychologist and also dental surgery cancelled (non-emergency).

"I desperately need advice from neurologist but appointment has been changed from October 2020 to January 2021. I have had no reply to written communication."

"We were fortunate in that my child's consultant still scheduled my child's routine 6 monthly appointment towards the end of May which allowed a very sensible and pragmatic discussion on practically interpreting shielding policy. I feel that all parents would have benefited from such a visit as a planned strategy rather than 'by chance'."

"Our community physio is brilliant, kept in touch by phone throughout and did a few virtual sessions with us which were great. We also accessed two virtual physio sessions via Cerebral Palsy Scotland which were really useful."

"My son hasn't worn his splints for 3 or 4 months now as he has outgrown them. He has also totally outgrown his wheelchair. We have just received an appointment but only after our physio intervened."

"Experience is dependent on the quality of your local team and on parents being able to intervene… appointments and equipment shouldn't be allocated on the basis of who shouts loudest, but sadly they always are. The system needs to be better than this as it ends up failing the most vulnerable."

"I can't seem to get any help with my mental health. They don't understand CP"

"A very mixed response from healthcare, Botox cancelled, was rescheduled, but physio etc. have not been able to adjust any equipment since early March and new equipment has been put on hold."

Family Life

76% reported that the Covid-19 situation had put more pressure on family life. Families with children were struggling to cope with the demands of physical care needs in addition to educational needs, the requirements of non-disabled siblings and potentially trying to work from home as well. Adults with CP reported relying on their own parents and family to provide care. The lack of access to the usual community supports and respite care was a significant factor in adding to the stress of family life during this time. For some this stress had specific physical health consequences. Many others reported feeling exhausted and unsupported.

- Over 50% said that their family was more isolated
- 44% said that lockdown had negatively impacted on the mental health of other people in the family
- 37% reported that the person with CP in their family was experiencing more problems than usual and 22% reported that the person with CP did not understand the social distancing rules.

"Strengthened us because we have got through it and enjoyed a lot of it, when not too worried, but we are exhausted and feel unsupported"

"It has affected by whole family as I chose to shield so it has restricted what my family can do"

"My PAs were unable to provide my usual support and this meant that my immediate family had to take over. My father was unable to go to work as he and my mother were now my sole care and support providers 24 hours per day. This has led to my parents being exhausted and with no contact from social work services it has been extremely difficult."

"Live on my own. Very stressful, muscle atrophy and lack of eating during lockdown"

"We were struggling. It just became really challenging trying to give my son all the support and care he needs and do our own work at the same time. Our non-disabled child was also feeling really abandoned."

Schooling

The majority of respondents on behalf of children sent their children to a mainstream school. 79% reported that they had sent their child back to school. That meant 21% had not sent their child back to school. 20% of these felt that school or nursery would not be safe for their child. Another 20% reported that the school or nursery could not currently accommodate their child. Others are still waiting for a start date to be agreed or else they are waiting to assess the Covid impact of the re-opening of schools and nurseries before sending their child back.

"Nurseries being shut was tough on two very young children"

"Trying to work from home, provide full time care for my child and provide care and supervise school work for her sibling single-handedly was extremely challenging and I believe my child with CP suffered as a result due to lack of time to carry out physio or activities during the day."

"I am a highly sociable individual, I don't understand why I can't go to school, the park or shop."

Support from Cerebral Palsy Scotland

82% of respondents felt they were getting enough support from Cerebral Palsy Scotland which was an increase from 69% in the May 2020 survey.

"As has been our family's good fortune over our son's lifetime, we have received outstandingly beautiful support from Cerebral Palsy Scotland."

"I really liked the virtual appointments. Just a couple of sessions gave us a lot of new ideas and sensible advice about tackling some day-to-day problems."

Some people commented that they were unaware of the services that Cerebral Palsy Scotland offered or associated the organisation as only helping children or felt support should be accessed through the NHS.

"I associate Cerebral Palsy Scotland as being there only for children and young people and adults with severe CP."

We asked what people wanted from Cerebral Palsy Scotland at this time. An overwhelming response was a cry to support people to stay active and able to move to the best of their abilities.

"Many adults with CP are struggling with chronic fatigue and it is not addressed by clinicians. Remember that as we age we start to feel the effects more of CP and Cerebral Palsy Scotland needs to look at this"

Support for *"physiotherapy and help to keep moving and active".*

Conclusions

In conjunction with our survey in May 2020, together with the results from our follow up in September, we can see that the implications of the restrictions imposed to combat COIVD-19 have been particularly challenging for people with CP and their families. In addition to increased isolation and feeling that they are unsupported, there is evidence of physical and mental health decline.

It is worrying to note that in September access to health services is still too difficult and that levels of care experienced pre-lockdown have not yet been restored. There is also evidence that the decline experienced in their condition is not being recognised or understood by professionals, (difficulty in accessing physiotherapy, appointments postponed).

COVID-19 has provided an opportunity to create new ways of working. Building on the lessons learned during the last 6 months, Cerebral Palsy Scotland is exploring ways in which we can respond directly to the identified needs of people with CP at this time. We are working to ensure that the needs of people with CP are included in the Scottish Government's Framework for supporting people through Recovery and Rehabilitation During and After the Covid-19 Pandemic as people with CP directly fall into two of the populations outlined in the scope of the Framework:

- Those who have experienced a negative impact as a consequence of the lockdown restrictions
- Ongoing support for those with a long-term condition who have been impacted from the pausing of scheduled treatments due to the pausing of non-critical health services.

We are looking to provide "Post-Lockdown Flexible Support Sessions" to address the identified mental health, wellbeing and physical needs for the CP population to directly tackle the impact of lockdown and shielding, to reconnect them with their communities and to rebuild strength, mobility and confidence.

For more information please contact: info@cpscot.org.uk