Annual Review 2021•22

cerebral palsy scotland

2021•2022
Joint statement from

Ian Johnstone
Chair of Trustees

Stephanie Fraser
CEO Cerebral Palsy Scotland

Welcome to our annual review of 2021-22. We are proud to be able to report on our progress, reaching more people with cerebral palsy (CP) throughout Scotland.

Our top priority has been to ensure we are open and available to provide support, information and advice for people with CP, their families, carers and the professionals who work with them. Whilst Covid restrictions continued to impact some of our services, we maintained our face-to-face therapy services throughout the year and adapted our children's groups to support primary school aged children. This year also saw the launch of our Better Start programme, primarily in Glasgow, but which will be expanded over the next three years to cover even greater areas of Scotland. We remain committed to embedding mental health and wellbeing support in our service delivery and continue to allocate core funding to support this.

Keeping in touch with people with CP across Scotland has enabled us to gather information on key issues and advocate to service providers and policy makers what needs to change. We continue to strive every day to ensure better services and support for people with CP.

We have all been through challenging times and we are aware there are more challenges still to come. We pledge to continue to do all that we can to be there for people with CP in Scotland. We cannot achieve this without our wonderful donors and supporters, our dedicated staff team and volunteers. We would like to thank everyone who has supported us, inspired us and who help us to continue our vital work.

Thank you.

What is cerebral palsy?

Cerebral palsy (CP) affects a person's ability to control their movement, posture and balance.

No two people experience cerebral palsy in the same way. How someone is affected will depend on the type of cerebral palsy a person has and how much of their body is affected. As well as affecting movement, cerebral palsy can affect other areas of function:

Of those people living with cerebral palsy

- **1 in 4** is unable to talk and uses alternative methods of communication
- **3 in 4** experience pain
- **1 in 4** has epilepsy
- **1 in 2** has a learning disability
- **1 in 4** has bladder control problems
- **1 in 5** has a sleep disorder
- **1 in 5** has saliva control problems
- **1 in 3** is unable to walk

Why our work matters

Cerebral palsy is one of the most common causes of life-long disability.

Around
1 in 500
births result in CP diagnosis

Around
150
children are diagnosed each year in Scotland

Lack of specialist services

We believe there is a huge disconnect between the level of care and support people with cerebral palsy currently receive and what is required in order for children and adults with CP to reach their full potential.

A survey carried out by us in November 2021 revealed that **45%** of respondents felt NHS services were 'not at all' meeting their needs, while a further **20%** said their needs are being met only 'a little'.

Healthcare services for adults with cerebral palsy were of particular concern.

Traditionally viewed as a static childhood condition, life expectancy for adults with CP who have mild to moderate disability is now only slightly reduced, compared with the non-disabled population.

Yet, statutory support for people with cerebral palsy remains concentrated in children's services and education. There is no specialist therapy service for adults with cerebral palsy in Scotland, apart from what is provided by us.

Covid-19 has made existing inequalities worse

It has been well documented that the Covid-19 pandemic has magnified pre-existing inequalities for disabled people.

Our own survey carried out in February 2021 revealed that **60%** of respondents said restrictions had a negative impact on their mental health, while **43%** of people reported that their physical health had deteriorated.

What we do

We're a charity that improves the lives of children and adults with cerebral palsy through specialist therapy, support and information.

We're ambitious for people with cerebral palsy.

For over 25 years our therapists have worked alongside people with cerebral palsy, their families and carers, helping them develop practical skills which transform daily life.

Founded by a group of determined parents whose children were unable to get the specialised therapy they needed close to home, we're the only cerebral palsy charity in Scotland.

As we've grown, the cerebral palsy community continues to be at the heart of everything we do. Our groups reduce isolation, bringing people with cerebral palsy and their families together. Our support service offers a listening ear and advice. We share our knowledge and skills through courses, conferences and working collaboratively. We raise awareness and we campaign for life-long access to knowledgeable, compassionate services and support.

Every day in Scotland, people with cerebral palsy are not getting enough support.

We exist to close that gap, so that every person with cerebral palsy can reach their full potential.

How we supported children and adults

Specialist therapy

In 2021-22 our specialist therapists provided therapy to 140 people with cerebral palsy. We:

- Welcomed **79** children and **61** adults for therapy (compared to **52** adults and **55** children in 2020-21).
- Completed **701** therapy sessions (compared to **552** in 2020-21). That included **626** in-person sessions, **52** virtual sessions and **18** home visits.
- Delivered **88** first assessment appointments.
- Saw **62** new service users, and **78** people returned for therapy.

Psychology support service

Recognising that cerebral palsy can impact mental health as well as physical health, we provided **21** one-to-one sessions with a Clinical Psychologist to support people's overall wellbeing.

Bringing people with CP together

- We ran two groups for primary school-aged children, building life skills and relationships
- On 9 October 2021 our virtual annual conference provided an opportunity for the cerebral palsy community to get together and share information and experience.

Advocating for people with CP

We kept the needs of people with cerebral palsy at the forefront of the minds of statutory service providers and policy makers and continued to play a leading role in policy development.

Sharing information

Sharing information online - via our website, e-newsletters and our social media pages - has been a key element of keeping people updated on news and services relevant to the CP community.

Specialist therapy

Providing therapy using the Bobath concept is at the heart of what we do at Cerebral Palsy Scotland. Our team of specialist therapists have built up many years of experience working with children and adults with cerebral palsy, their families and carers.

- Everyone was offered an initial virtual assessment consultation. In-person or virtual sessions were then provided, depending on people's needs and preference.
- Our CP Connect service ran until March 2022, providing children and adults with a funded programme of intervention at a time when people needed it most.
- Our Better Start programme, funded by The National Lottery Community Fund, provided therapy sessions to 20 children aged 2-14 within Greater Glasgow and Clyde Health Board area. Match funding supported five families from outwith the Greater Glasgow and Clyde area.
- Due to ongoing Covid restrictions we were unable to run our baby group. Instead we offered individual sessions to 10 families with babies (aged 0-2) so that early intervention therapy was available to them at this crucial developmental stage.

Jon

“If Cerebral Palsy Scotland wasn’t available to me I would have such a different life and I really do believe that.

I first came to Cerebral Palsy Scotland when I was two years old. I came regularly up until I was 18, and I have now started to come back again as an adult.

“When I first came for therapy sessions I couldn’t walk but my twin brother could. One of the biggest achievements in my early sessions was that I learned to walk.

Scan here to watch film about Jon & James

The whole family approach was important because it’s not just me that deals with cerebral palsy, it’s the people around me, and I think Cerebral Palsy Scotland helped us as a family to learn to use therapy in fun ways. Plus I learned how I could be more independent around the house too.

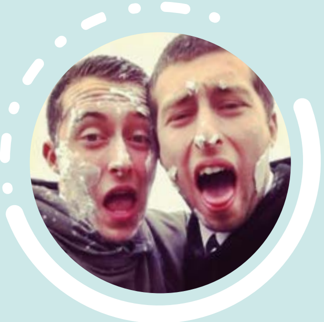
I think as a child being at Cerebral Palsy Scotland was a time when you could completely feel comfortable in who you were, because you’re spending a lot of time trying to hide your cerebral palsy.

As a child I would have some input from the NHS in terms of therapy, but moving into adulthood the services that are available to people with cerebral palsy become extremely limited. The huge benefit of Cerebral Palsy Scotland is that those services do continue as an adult and you can still access intense therapy and support from therapists that concentrate specifically on people with CP.

The lifelong challenges of having CP aren’t just the physical challenges but also the mental challenges. Moving into adulthood was the most difficult time of my life so far. It hits you that you have some limitations and some challenges and at that age I had a picture in my head of what a man should be, and I couldn’t fulfil some of those criteria in my own head and I really, really struggled to cope with that. Coming to Cerebral Palsy Scotland at that age helped me to discuss openly how I was feeling and the therapists really helped me at that stage in my life. You realise that those things are non-essential, and then you can cope with it a wee bit better.

I recently attended Cerebral Palsy Scotland after a two year break and I felt like some of my symptoms of CP were getting worse. Going to university and having a job you sort of lose the motivation for time to work on yourself, and you forget some of the fundamental physiotherapy exercises to do for soreness and tightness. I was playing golf and something happened in my back and I couldn’t feel my whole right leg at all. So in 2021 I contacted Cerebral Palsy Scotland and was allocated some face-to-face sessions to work on the problems in my back - which I don’t have anymore.

The therapists also gave me advice about what exercises to do at the gym, which would be beneficial for my cerebral palsy. Also coming back to therapy you can speak to the therapists for the first time as an adult and speak to them about adult issues, like how you are feeling in general life.



I would say that Cerebral Palsy Scotland has had a massive impact on my life in terms of who I am and of how I have dealt with cerebral palsy from childhood into adulthood because of the level of expertise that has been available to me.

The therapists have encouraged me to strive to reach my potential in everything that I do which is probably why I am doing a PhD now. I don’t think that level of intense encouragement would have came from anywhere else.

Bringing people with CP together and sharing information

Groups

As restrictions lifted, we reintroduced group activities. Our groups are an important way for children with CP to meet each other and foster peer support.

- Vibe Tribe, an after school club for primary school age children, ran from October-December 2021 and provided opportunities to learn skills that aid independence.
- A Crazy Science group in February 2022 supported children that use Augmentative and Alternative Communication (AAC), including high-tech eye gaze communication aids.

Annual conference

Our annual Cerebral Palsy Scotland conference was held virtually on 7 October 2021.

Supported by Digby Brown Solicitors, the event saw **230** delegates register for the day to hear **21** speakers presenting across **12** sessions.

The conference covered topics including the impact of the Covid-19 pandemic on disabled people, ageing with cerebral palsy, postural care, and pain management.

Planned to coincide with World Cerebral Palsy Day, the conference is the only annual event in Scotland focussing on cerebral palsy.

91% **of those surveyed said that the content presented was extremely or very helpful.**

Sharing information

As well as highlighting our own services, our website has general information about cerebral palsy, and a directory of services that support people with cerebral palsy and their families.

- **31,068** individual users to our website and over **68,399** page views in 2021-22.
- **4,000** followers on Facebook, **700** followers on Instagram and **1,000** followers on Twitter.
- **15** e-newsletters issued to over **2,000** subscribers.

Psychology support service

People with disabilities or chronic health conditions are reported to be three to four times more at risk of developing anxiety and depression.

Across 2020-21 our psychology support service offered people with cerebral palsy one-to-one sessions with a Clinical Psychologist, at a time when they need it most.

“

My name is Marion. I am 38 years old and I stay in Renfrewshire. I am a wheelchair user and I use a communication aid.

I have been going to Cerebral Palsy Scotland for physio since 1995. I believe without my physio over the years I would not be able to do all the activities that I can today.

I first heard about the psychology support service from staff at Cerebral Palsy Scotland. At that time I was still coming to terms with a family bereavement and I had just heard I was getting moved into supportive housing which I wasn’t too keen on. As well as all the uncertainty with Covid, it was a worrying time for me.

Joy Nisbet, the Clinical Psychologist, and I met weekly on Zoom. I felt it was very easy to open up about my worries to her and to build a good relationship quickly. Because I can’t speak and use a communication aid some people take a long time to get to know me, but even if our sessions were online Joy was not slow to understand me.

I have benefited a great deal from my support sessions because without the input from Joy I don’t believe I could have coped with everything as well as I did. Even being able to email her in between our sessions helped me a great deal, and she also spoke on my behalf at meetings. I felt more confident too.

The support from Joy was very important to me at a difficult time in my life, and I felt the benefit of having someone who understood CP. Joy was exceptional and just very professional at what she did. If I hadn’t met Joy, I would have been on my own dealing with things.

Amber and Cheryl

“Amber is five years old and an identical twin. She’s just started primary school where she attends with her sister. Amber is severely disabled. She has cerebral palsy which affects all four limbs. She struggles to hold anything in her hands or do anything functional without adult assistance. She’s non-mobile and pretty much non-verbal. So we do a lot of physiotherapy, and she’s learning to use her eye gaze computer forcommunication.

Amber has been coming to Cerebral Palsy Scotland for about three years. And to be honest it’s been an absolute godsend to us.

Going into lockdown and shielding with the girls was really tough. For Amber, not being able to access the therapy and services we normally would, we had the issue of muscles becoming tighter and the treatment options just weren’t there.

Cerebral Palsy Scotland were so helpful in terms of giving advice - we didn’t really have anywhere else that we could turn to for help at that time. We had some sessions online and we got some strategies to help her tight muscles, which were very effective.

Then we got some face-to-face sessions at Cerebral Palsy Scotland at the centre through CP Connect, and that was absolutely fabulous. Amber really needed input by then, she had grown so much and we needed to refresh our strategies. So those sessions were really helpful because that steered us in the direction of what Amber really needed at that point in time. And having not seen anyone or done any of her regular things for so long Amber was just loving going to the sessions. There were some sessions when it was time to finish and Amber got upset and said “no” - she didn’t want to leave!

Therapy sessions at Cerebral Palsy Scotland have shown us how to bring out the ability in Amber to play, how to play with her, and they’ve helped us realise how bright Amber actually is. I think it’s also helped Amber’s engagement with her peers and her sister. Overall it has just helped Amber engage with the world around her. Every time she comes I can see she’s got this spark about her. And as a parent, the therapists have given me confidence and skills to know that I am doing the best I can to help Amber progress.

Through coming to Cerebral Palsy Scotland over the last few years, it’s helped us realise what Amber’s own little milestones are and to take great pleasure in seeing her achieve them. The experience at the centre, it’s not just therapeutic. I can see the difference in her physically while she does therapy blocks, but it’s more than that - she’s excited about things, she’s more vocal, she’s more engaged, she’s more enthusiastic. If it wasn’t for Cerebral Palsy Scotland I don’t think Amber would be getting as much out of life. I would have her in the centre every week if I could!

Jamie and support worker Jane

Jamie:

My name is Jamie and I'm 24. I live in my own flat, but because of Covid restrictions I couldn't go out and do things that I normally did, so it was very challenging for me. It was not good for my body and my mind.

I found out about Cerebral Palsy Scotland through my mum. I wanted to find out what better exercises I can do to make me fitter and stronger. I also wanted to try and play Boccia again. I used to play it a lot and I got fed up with it because I couldn't get my arm working and I was slipping down my chair.

I went to some CP Connect sessions. I worked on exercises. That was good fun, just seeing what you guys can help me with and what I can do in terms of exercising.

Jane:

Jamie wanted us to support him with exercising. I have never worked with anyone with cerebral palsy, so there was a worry in the back of the mind that I could hurt Jamie or push him too hard.

Lesley, the Cerebral Palsy Scotland physiotherapist, gave the staff ideas on different games - things that are fun for all of us and not only Jamie. The exercises were things that we could easily incorporate at home, for example using a broom handle with Jamie to stretch his arms. Lesley showed us how to use things that were inexpensive or that we already had to help Jamie with his exercises, which I thought was really good.

> “Now I know from speaking to Lesley what he can and can't do, and I know the best ways for Jamie to exercise, to move his arms and to build up his strength. So now I can come up with ideas for exercises that me and Jamie can do together which is good.

Jamie:

Lesley also helped me with my wheelchair. I wanted to make it more comfortable for me, and Lesley contacted the wheelchair support service and worked with them on that, so that was very good.

I would recommend Cerebral Palsy Scotland to any person that is struggling with cerebral palsy and anyone who wants to get fitter and stronger. I would definitely recommend it as it is very interesting and it lets you know better ways that you can do your exercises.

Campaigning

As part of our mission, we advocate for the cerebral palsy community to have life-long access to knowledgeable, compassionate services and support.

Campaigning for specialist healthcare

- In November 2021, we undertook a survey of the cerebral palsy community in Scotland that showed health services were failing people with CP. Forty five percent of respondents said NHS services were 'not at all' meeting their needs, while 20% said NHS services were meeting their needs only 'a little'.
- We met with MSPs and civil servants to highlight this issue, and secured press and TV coverage. We continue to campaign for Scottish Government to improve healthcare services for people with cerebral palsy, and are calling for the government to ensure adults with cerebral palsy are given specialist health and care annual reviews.

Advocating on national policy groups

- Our CEO, Stephanie Fraser, chairs the Scottish Government's National Advisory Committee for Neurological Conditions (NACNC). The committee continues to ensure Scottish Government implement the Framework for Action for Neurological Conditions, which covers the period 2020-25.
- Stephanie Fraser is an Officer of the All Party Parliamentary Group (APPG) on Cerebral Palsy in Westminster. The group's purpose is to enable policy makers to better understand the challenges faced by individuals of all ages with cerebral palsy and their families. During the year it published three reports from evidence gathered from stakeholders across the UK – on Early Intervention in the care of Infants and Young Children, Best Practice in Education, and the Barriers for Adults with CP.
- We are also contributing members to the work of the Scottish Parliament's Cross Party Group on Disability, the Neurological Alliance of Scotland and the Health and Social Care ALLIANCE.

Next steps

- We will carry forward our learning and experience from operating during the Covid-19 pandemic and will continue to offer a mixture of therapy services from in-person, multi-disciplinary intensive sessions to online clinical consultations via the NHS Near Me platform.
- We will develop our mental health and wellbeing service, working under the guidance of our Consultant Clinical Psychologist and have invested in further training for all our therapy staff.
- We will re-establish group support and outreach work across Scotland and also develop peer support and opportunities for social events.
- We are recruiting for the new role of Cerebral Palsy Support Co-ordinator to improve our ability to understand the needs of our service users and support them in their journey with us. We will also re-organise our administration functions to support service development and impact reporting.
- We will continue to raise awareness of the experiences of living with cerebral palsy by engaging with policy makers and statutory services so that the needs of people with CP are taken into account in decision-making around rehabilitation and recovery.
- We will raise awareness with families and people with cerebral palsy of the continued support Cerebral Palsy Scotland can offer, as well as ensuring condition-specific information is shared with the CP community.
- We will continue to increase engagement with our beneficiaries so that they are able to feed in information and access the support they need.
- We want to support and train professionals to develop their skills to ensure better services for people with CP.

Fundraising

Our ability to support people with cerebral palsy and their families simply would not have been possible without the people and organisations who continued supporting us through uncertain times to ensure specialist therapy, support and information was available to everyone with CP in Scotland who needed it.

Over **85%** of our income comes from funding we have raised ourselves, over half of which is from charitable trusts and foundations. We are deeply grateful to all those organisations who continued to support us and who share our vision that we needed to be an organisation who could provide a flexible service for people with cerebral palsy at a time when other services were not available. We would like to thank all those trustees, grant making teams and advisors for enabling us to ensure we continued to help people throughout Scotland during this year.

We are extremely grateful to all organisations who have provided strategic grants over the last year including The National Lottery Community Fund, RS Macdonald Charitable Trust, The Health and Social Care Alliance Scotland, The Scottish Government's Children and Young People and Families Early Intervention Fund and the Scottish Government's Adapt & Thrive programme amongst others.

Our individual supporters through donations, challenges and events made a huge difference. The funds that were raised have provided a lifeline for the cerebral palsy community in Scotland.

They included nine year old Jack, who planned a **26 mile** sponsored cycle with his friends. Jack's younger brother Matthew has benefitted from therapy at our centre. Ahead of their ride, Jack said, "I think it will be hard, but I want to do this to help other children like Matthew." They successfully completed their challenge, raising over **£4,100**.

Financial review

Cerebral Palsy Scotland remains committed to matching funding to need. Our aim is to ensure as many people with cerebral palsy from across Scotland have access to our services whenever they need us.

- We ended the year with a planned deficit of **£20,000.**
- Our income totalled **£630,000** and our total expenditure was **£650,000.**
- Over **80%** of our income was spent on our charitable activities, with under **20%** on remaining functions such as charity governance and fundraising.
- The trustees keep a tight control of costs and although financial forecasting remains challenging due to the volatile economic outlook, we are committed to investing in building our staff team, without whom we could not provide our services.

cerebral
palsy
scotland

Chief Executive

Stephanie Fraser

Trustees

Bradbury House,
10 High Craighall Road
Glasgow G4 9UD

Tel: 0141 352 5000
Email: info@cpscot.org.uk
cerebralpalsyscotland.org.uk

Auditors

Bell Barr & Company
2 Stewart Street
Milngavie
G62 6BW

Bankers

Bank of Scotland
836 Crow Road
Glasgow G13 1ET

Clydesdale Bank
30 St Vincent Place
Glasgow G1 2HL

Solicitors

Mitchells Roberton
36 Hanover Street
Glasgow G1 2AD

Photography

Sean Purser

Design

dmu design
dmudesign.co.uk

OSCR
Scottish Charity Regulator
www.oscr.org.uk
Registered Charity
SC022695

WE'RE COMMITTED
TO GOOD FUNDRAISING
goodfundraising.scot

Registered Charity number
SC022695

follow us on