

## Framework for Neurological Care 2020 -2025 Funded Projects

### FINAL REPORT

**Project Title:** CP Link Directory  
**Overall Aim:** To provide a cerebral palsy (CP) specific link for adults with CP and local services  
**Organisation/NHS Board:** Cerebral Palsy Scotland  
**Project Lead:** Milly MacKinnon, Centre Manager  
**Project Start Date:** September 2023  
**Project End Date:** March 2024  
**Report Date:** April 2024

#### Project Summary

*Provide a brief summary of project progress against key deliverables. Please indicate if there are any significant risks that may impact on successful delivery of the project. If everything is going to plan one sentence should be sufficient. This section should be no more than half a page.*

Cerebral Palsy Scotland have built a consolidated bank of knowledge and expertise of services, referral pathways (per HSCP) for adults with CP. This is a collaborative, living resource, curated by our clinical specialists and CP support service providers. The directory enables Cerebral Palsy Scotland to advise adults with CP on what is available for them in their area, ensuring adults with CP receive timely intervention. It also supports local professionals to identify appropriate pathways for this population within their HSCP and beyond.

#### Project Shared Learning

*Provide a brief summary of how you intend sharing project outcomes and what you have learned with others (please include the organisations/networks you will be sharing this with).*

Cerebral Palsy Scotland is the only specialist centre in Scotland dedicated to supporting this population. Our core remit is to help people with CP build skills, knowledge, confidence and relationships and make the most of their abilities. We have a Scotland-wide remit and therefore we are committed to supporting the building of networks across areas and sharing learning from one area to another. We do this through the course of the professional networks our staff are involved in and through our training.

We host cerebral palsy information sessions for community professionals throughout the year in person and online. We host the only conference dedicated to cerebral palsy in the UK. This co-created event has grown and attracts 250 delegates and 30 exhibitors annually. The conference programme appeals to a wide range of delegates and exhibitors include other relevant organisations

We continue to proactively seek out and connect with other organisations that align with our mission. These are shared on our online support directory. This includes reaching out to support groups, advocacy organisations, and community services to create a collaborative network. We are part of the Neurological Alliance of Scotland, The National Advisory Committee for Neurological Conditions and the Cross Party Group on Disability. We work with other organisations regularly most recently inviting Include 2 Me to our co-production morning and hosting a training session with Euan's Guide.

We aim to develop our cerebral palsy support service. This is the first point of contact with us and enables people to access advice and information with ease. We continue to actively engage with local disability activity and sports organisations to expand opportunities for children with CP. By connecting with organisations like Paragon Music, Riding for the Disabled and the Scottish CP Football team, we aim to encourage participation in a variety of enriching arts, leisure and sporting activities.

Through these initiatives, we will strengthen existing connections and develop new relationships with professionals and organisations.

*What support can Scottish Government provide in helping you to share learning from the project?*

We would also like the support of Scottish Government to enable us to work collaboratively with local areas on an ongoing basis to highlight areas of good practice and to remove some of the barriers to services that our staff have encountered in the process of this work and that adults with CP encounter on a regular basis.

### **Sustainability**

*Provide a brief summary of how the achievements of the project will be sustained after funding ends. This could refer to how you hope to ensure adoption by other service providers, or continuation within your own service*

Cerebral Palsy Scotland has committed to build in continual updates and regular reviews of information. This will ensure that the resource remains a “living project” and our staff will continue to edit/expand/update through the course of our core service delivery on an ongoing basis. We hope also that the shared learning as outlined above will also help raising awareness of the need for services for adults with CP to be more accessible and co-ordinated.

*What support can Scottish Government provide in helping you to replicate or extend this project?*

We would like Scottish Government to consider further work to explore the regional differences in access to services for adults with CP that are being illustrated by the Link Directory. We hope to work with Regional Co-Ordinators and the results of the self-evaluation assessments to layer onto their work the learning from the CP Link Directory.

## Progress and Deviations from Plan

*Outline achievements of key milestones or other significant measures of progress. Provide a brief report on any areas not progressing as planned and what is being done to address this.*

The CP Link Directory is a live resource. For now, it is an internal resource for Cerebral Palsy Scotland with 110 services listed and new services being added on an ongoing basis. It would not be feasible to share all of this information with service users as some services require clinical or social work input for a referral to be accepted. Where we can share services, we do, both on a case by case basis when responding to enquiries and via the directory of services on our website.

Clearly not every area has been covered and each of the different areas have different services. Often each area can use different language for their services (for example Falkirk's Central Locality Learning Disability Social Work services operate a "domi physio" model that will address home adaptations or equipment needs, but not for owner-occupied properties, which are overseen by the local locality teams). Some services (e.g. South Lanarkshire Counselling and Wellbeing Service) allow self-referrals, whereas others (e.g. Glasgow City Council) will need to be assessed by social care services before further assistance can be provided. All of this information is being captured on a service by service basis. We have therefore spent far more time than originally estimated tracing named contacts and confirming the individual service remits and referral criteria.

We have worked with the adults with CP who have been referred to the centre between September 2023 and March 2024. We have seen 52 adults during this time. Where they live has dictated therefore which areas we have prioritised for the CP Link Directory.

It remains our intention to share our information with HSCP areas, however, this has not always been possible, for example in areas where it has not been possible to identify a named lead and a generic referral to the service has been advised (e.g. West Dunbartonshire Learning Disability and Social Work teams). In order to ensure this resource remains relevant and up to date we have shared and continue to check information on a regular basis through the day to day work of our centre administration team.

## Metrics

Please detail the metrics being used to track project progress.  
*(As data becomes available please provide appropriate non-identifiable patient data demonstrating progress)*

We can report on the following metrics:

- Number of different services covered

We have added 110 different services to the directory

These include:

ReACH teams (rehab and assessment in the community and home), integrated care services, learning disability services, neurological outpatients, orthotics, social work services, tone management clinics, specialist nurse services for co-existing conditions (e.g. epilepsy), respite, carers' support, independent living centres, continence and bowel management services, equipment and adaptation services, wheelchair and seating services, hydrotherapy pools, disability information officers, day centres, counselling and wellbeing services, sport and leisure, employment and training support, benefits and financial advice, community connectors, Self-Directed Support Scotland.

- Number of HSCPs engaged

15 HSCP areas:

Ayrshire, Dundee, Clackmannanshire, Stirling, Falkirk, Glasgow City, East Renfrewshire, Inverclyde, East Dunbartonshire, West Dunbartonshire, North Lanarkshire, South Lanarkshire, City of Edinburgh, Moray, Fife

- Number of enquiries Cerebral Palsy Scotland successfully signpost to local services

We have dealt with 212 enquiries and signposted to local services, either through onward referral from our clinicians or through directing people with CP to local services (as appropriate).

Our public directory of services is here: <https://cerebralscotland.org.uk/directories/>

Input and feedback:

We have run regular surveys with the CP community during this period. People with CP continue to tell us they want services for people with CP to be more accessible and co-ordinated. Adults also speak of feeling isolated and that there's nothing available for them and so being able to speak to them about different options ensures that they feel more supported.

It has been difficult to gather specific input from partner organisations that we refer people onto, however, we have evidence from a care home worker that they were supported to try new activities with an adult with CP they were caring for.

### Financial Status

**Total Amount Funded: £33,980**

**Total Project Spend: £**

**CP Link Directory**

**(September 2023 - March 2024)**

**Budget**

**Spend to end March 24**

Clinical input time over 6 months	£	16,080.00	£	18,821.85
Therapy Assistant	£	2,500.00	£	2,379.75
Co-ordination/Management	£	9,000.00	£	8,654.05
IT support	£	300.00		
Design	£	500.00		
Office costs	£	5,600.00	£	5,600.00
<b>Total Project Cost</b>	<b>£</b>	<b>33,980.00</b>	<b>£</b>	<b>35,455.65</b>

NB – Due to the additional staff time spent on this work, the project has gone over budget by £1,475.65.