



cerebral
palsy
scotland



Scottish Government
Riaghaltas na h-Alba
gov.scot

Framework for Neurological Care 2020 -2025 CP CONNECT FINAL REPORT

Overall Aim: Development of flexible specialist support for adults with CP

Project Start Date: April 2022

Project End Date: March 2023

Report Date: June 2023

Project Summary

Cerebral Palsy Scotland supported 2 HSCPs improve services and referral pathways for adults with CP. Developing the learning from our previous CP Connect work, we worked to ensure the needs of adults with CP are recognised and understood by generic community-based health and social care teams so that they are better able to help adults with CP and access condition specific knowledge from CP Scotland as appropriate.

We worked with 2 HSCPs: Midlothian HSPC and Stirling and Clackmannanshire HSCP.

Timeline of Activity and What Changed

Midlothian:

June – August 2022

- 2 online planning meetings and a further 2 in-person meetings with the community team in Midlothian to facilitate joint working practices and project planning.

September – October 2022

- Joint working to embed Cerebral Palsy Scotland staff within understanding of how adults with CP access services in Midlothian.
- Initial work to develop a CP specific pathway for Midlothian

November – December 2022

- Midlothian appointment of Lead Wellbeing Practitioner for neurological conditions lead to further collaboration of Cerebral Palsy Scotland with Midlothian and the Thistle Foundation to explore the model of general wellbeing practitioners and how this could be adapted for adults with CP.
- Development of CP pathway and referral routes from Midlothian HSCP teams and from GPs. knowledge and insight of CP into their existing pan-neurological work. As a result, the focus of our work with Midlothian was directed towards pathway planning with key link workers and co-ordination with the Lead Wellbeing Practitioner for neurological conditions.

January – March 2023

- Referral form for CP adapted by Cerebral Palsy Scotland and shared with Midlothian team lead
- Launch of Midlothian Neurological Conditions pathway, including specific CP pathway
- Visit to Cerebral Palsy Scotland centre by Lead Wellbeing Practitioner
- Review of project progress with Midlothian team lead

April – June 2023

- Collating feedback, sharing learning and report writing

Stirling & Clackmannanshire:

Whilst there was an initial positive response to the partnership, their lead AHP was slow to respond over the summer period and the first planning meeting did not happen until late September 2022. This led to a further meeting with clinical managers in October but it took until December for HSCP and NHS colleagues to share details of key contacts in the area.

Scoping Exercise:

Aside from our own links with wheelchair services, Cerebral Palsy Scotland did not have links with wider adult services within the region. A scoping exercise was undertaken to identify key services and contacts. Local contacts ranged from social work, SDS Scotland, carers' organisations to review existing support options for adults with CP within Stirling and Clackmannanshire, and in some cases the wider NHS Forth Valley, areas. A project information sheet was produced and circulated to all contacts along with an application for referrals.

Collaboration working:

A total of 7 referrals were received. All were given initial virtual clinical assessments (via NHS Near Me) by Cerebral Palsy Scotland specialist clinical therapists. Each adult was offered 3 further in person session in their own homes. Sessions lasted 1.5 hours. During these sessions carers/family members had the opportunity to practice any specific physical strategies or handling techniques. Advice was given regarding other strategies or actions that would be beneficial for the individual. Advice sheets, with photos, were compiled for one adult to enable all their rota of carers to work in the same way and to practice what they'd learnt between sessions.

Issues addressed from hands on, in person working included:

- Improvement of pain and discomfort
- Postural review to maintain good musculoskeletal health and prevent further soft tissue shortening
- Enable adults with CP to participate in daily activities
- Provision of communication strategies, particularly for situations where adult was becoming distressed
- Identification that review of medication on onward referral to neurologist was required
- Implementation of self-management strategies
- Mental health support from CP Scotland consultant psychologist

Outcomes of in person working beyond therapy included:

- Skills review and development for carers

- Discussion with social care regarding future housing/care requirements
- Onward referral by CP Scotland to other services

Further investigations with local partners often became circular, i.e. being transferred back and forth between services as they endeavoured to identify where referrals sit best according to each service's criteria. Yet again, adults with CP often did not 'fit' neatly into current provision and therefore it was left to CP Scotland to advocate for support on their behalf.

Project Learning

We seek all opportunities to present our work. We shared mid project learning on the importance of annual reviews for adults with CP at our annual Cerebral Palsy Scotland conference on 5th October 2022 and we are currently seeking funding to offer an annual review service to adults from across Scotland. We also presented our work during the Scottish Government Neurological Framework Practice Sharing sessions in December 2022.

During the course of the work we worked with AHP teams within each HSCPS and the Thistle Foundation in Midlothian. We also worked the following services for specific cases in Stirling and Clackmannanshire and throughout NHS Forth Valley:

- Stirling Carers Centre
- Falkirk & Clackmannanshire Carers Centre
- Wheelchair services
- Orthotics
- District Nursing
- GPs
- Disability Sports
- Bowel and Bladder UK

Evaluation and Feedback

Feedback was gathered from participants during sessions and from discussions and meetings with professionals. Questionnaires were sent to all participants at the end of the project.

- All respondents reported a positive outcome from Cerebral Palsy Scotland's input, from simply benefiting from onward referrals, to improving their knowledge about their own type of CP.
- Carers also reported benefits in learning how better to support the person they were caring for.

In summary, the following key themes were identified for adults living with a long-term neurological condition from the feedback:

Carers: difficulties with availability, consistency, and scope (e.g. some cannot drive). This has huge impact on both the clients, and their family who need to constantly juggle things to 'plug the gap'.

Accessing specialist services e.g. being able to speak to someone who grasps the implications and nuances of their condition and future prognosis was greatly valued; not having to continually start process with new professionals each time they are referred back into a service/system/need to reapply annually for respite/carers. Participants

reported feeling more relaxed and that our specialist input was helpful in reducing chronic pain.

Lack of system for routine reviews e.g. equipment & medication. This is a matter of significant concern and could be resolved by the provision of annual reviews (as per the NICE guidelines for adults with CP). People reported that they hardly ever were able to see an NHS physiotherapist

Need for a key overseer particularly in lieu of the above system. Someone who has the ability to recognise when there is warrant for:

- review of equipment/medication/needs
- referral for further assessment or medical investigations
- specialist input from a different service

Discharged, or not referred-on to other services, despite unresolved issues or continued presenting difficulty

It would appear that there are instances where ongoing pain/difficulties/deteriorations are viewed as to be expected as part of the trajectory of having a life-long condition – and are not fully explored. This may be due to lack of understanding of the condition and what could be possible. For example, one GP declined to refer to neurologist as felt the client needed physio not seen by a neurologist. Specialist physio indicated the client's tone was severe enough to warrant medical assessment and trial of appropriate tone medications, before any physio input can be of benefit.

Passive acceptance of difficulties

People living with life-long neurological conditions like CP, often 'get on with' living with pain/discomfort or significant functional challenged. They often believe this is part of their condition, and therefore do not proactively pursue help or initiate contact with others who could do so on their behalf and which could improve their quality of life or prolong their ability to live independently.

Carer fatigue

Many family/unpaid carers have had years of managing life supporting someone with a long-term neurological condition. In addition to any pre-existing conditions they have themselves, they many have developed secondary physical &/or mental health issues in response to the impact of their situation. Consequently, many appear system/situation-fatigued and not in a position to advocate effectively for their family member.

Deviations from Plan

As anticipated, HSCPs do not have robust data on who they currently support in their area with a diagnosis of CP. In Midlothian for example, they could only identify adults with CP who also had a learning disability. In Stirling and Clackmannanshire, it was carers' organisations that most easily identified adults with CP and also that they needed specialist support.

Work with Midlothian HSCPs was spent working with professionals to develop the CP specific referral pathway. No requirement for specialist input was identified through the referral pathway developed with Midlothian HSCP. The reasons for this could be:

- Adults with CP in Midlothian are living well with their condition and therefore do not need or do not wish to seek assistance

- People with CP are not self-managing but are not visible and do not know where they can seek assistance or what might be available to them
- There is not yet sufficient awareness of the pathway amongst professionals within Midlothian who are currently supporting adults with CP.

The 3 months from the launch of the pathway in Midlothian to the end of the project meant there was little time to evaluate the longer term effectiveness of what was developed or make any adjustments in order to ensure that it was fully accessible by all adults with CP. The focus of the referral route through GPs and Wellbeing Practitioners may have meant that the pathway was more aimed at adults living independently and not at those living with carers or with reduced independence. The route for carers to refer was less of a focus in Midlothian and given that it was this group that made up the majority of referrals in Stirling and Clackmannanshire, we would like to see an open referral system developed.

Next Steps

As we stated in our application, success for this project means embedding knowledge and good practice for adults with CP in the community and therefore adults within these areas experiencing improved care. We rely on HSCPs understanding the value of supporting adults with CP and when and how they can access condition-specific support.

Adults with cerebral palsy (CP) are 'not quite fitting in'. Professionals do not know where to refer people and so adults with CP are transferred back and forth between services with little resolution of issues. Cerebral Palsy Scotland would intend to look for further support to enable us to become the condition-specific link to support local services to solve this issue. We have already shared our nascent directory of services with professional AHP leads in Stirling and Clackmannanshire but we would like to build on this experience to develop referral pathways for other HSCPs across Scotland.

We see the longer-term role for CP Scotland as one of condition-specific clinical expertise, support and training, in co-operation with good community services. For example, we currently have funding applications under consideration by trusts and foundations to support us to develop an annual review service for adults with CP.

Directory of Services:

In order to facilitate longer term learning from this work, Cerebral Palsy Scotland has begun to collate a reference directory for our team (and potentially for sharing more widely). Information on local services, contact names and details and referral criteria are being captured on an HSCP basis. This is a live, working document that requires continual updating and revision, but serves as a starting point for our own team to know who to contact regarding a variety of common issues experienced by adults with CP. This document has been sent to the Stirling and Clackmannanshire AHP Lead for cross reference and to check accuracy.

If local statutory service providers are not willing to embrace partnership working, then this work is not sustainable. This funding has been key to demonstrate the benefits for local services of joint working and supporting adults with CP, many of whom are consumers of local support services already, but through being able to access a flexible, limited amount of specialist input can achieve more positive outcomes. However, it was often through co-ordinating with other Third Sector partners (e.g. the Thistle Foundation,

local carers' centres) and not with statutory partners, who although willing to collaborate, could not identify adults with CP or could not identify what support they needed. We pay tribute to Midlothian and Stirling and Clackmannanshire staff for being open to challenge and willing to change.

Scottish Government has a central role to play in ensuring that this population become more visible to service providers through the standardised collection and sharing of clinical coding. We hope that through the government's refreshed Digital Health and Care Strategy, the invisibility of people with CP can be improved. We welcome the Neurological Framework's initial work around prevalence, but note that the population of adults with CP is significantly under-represented in this work and existing data, such as that from the CIPs programme is not being used to transition into adult services. Without being visible to adult services, we can create as many pathways as we like but if local health and care professionals do not understand the condition specific challenges adults with CP face, then care and support will not improve.

Cerebral Palsy Scotland urge Scottish Government to ensure the NICE guidelines for adults with CP are implemented across Scotland. We would also like the support of Scottish Government to ensure that, should this project be deemed successful, other areas are encouraged to adopt the pathways that are developed for adults with CP, based on the NICE guidelines. To date it has taken this specific funding to encourage local areas to take up our offer of joint working as we do not otherwise have the capacity to direct our delivery in this way without funding.

We continue to believe that once a local area can understand the different needs of a population like adults with CP then the lessons learned can translate into many other long term, lesser-supported neurological conditions.

Breakdown of Expenditure

Total Amount Funded: £38,198.00

Spend to date: £65,261.10

Funding for the Framework for Action for Neurological Conditions - CP Connect: Round 3

Budget

	Budget		Spend to End March 23	
Clinical salaries	£	33,606.00	£	32,982.75
Travel	£	1,200.00	£	456.71
Professional Fees	£	5,280.00	£	5,088.20
Therapy/Centre Assistant	£	8,640.00	£	11,233.74
PPE, supplies and equipment	£	500.00	£	642.40
Service charges, heat, light, water, etc.	£	4,592.00	£	4,630.80
Insurance	£	960.00	£	708.10
Maintenance	£	420.00	£	341.90
IT expenses	£	1,200.00	£	1,152.40
Co-ordination/Management	£	8,640.00	£	8,024.10
Total Project Cost	£	65,038.00	£	65,261.10

Income Received from ALLIANCE				
Health and Social Care Self- Management Fund	£	11,840.00	£	11,840.00
Income Received from Agnes Hunter Trust	£	15,000.00	£	15,000.00
Scottish Government Neurological Funding	£	38,198.00	£	38,198.00
Total Income	£	65,038.00	£	65,038.00
Overspend (covered by Cerebral Palsy Scotland)			£	223.10