

## What's the Evidence?

# 'Family Hope Center for improving speech, movement, or independence in children and young people with neurodisability'

### Key findings

- Family Hope Center is a commercial American company that provides therapy for parents of children and young people with neurodisability. Family Hope Center staff travel to the UK periodically to hold seminars for parents, offer assessments and recommend treatment for children and young people.
- The therapy involves a training programme for parents to follow with their children. Typically, this therapy aims to improve speech, movement, and/or learning. Treatment recommended is different for each child.
- We did not find evidence from rigorous research that the Family Hope Center programme is effective for improving speech, movement, or independence in children or young people with neurodisability beyond what would be expected due to development or recovery from brain injury alone, or with standard therapy.
- Family Hope Center therapy programmes are not delivered by staff regulated by the General Medical Council or Health and Care Professions Council in the UK.

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#### **What were we asked?**

Two parent carers asked about the evidence for Family Hope Center (FHC) programmes. One has a child with cerebral palsy and wanted to know whether FHC might help to improve her child's independence in the future. The second parent carer has a child with learning difficulty and hypotonia (weak muscles) and wanted to know whether the FHC treatment is effective for improving speech and movement.

#### **What did we do?**

First, we carried out a general Internet search to find out about the FHC. We then searched [publically accessible databases](#) including NHS Evidence, The Cochrane

Library, TRIP, NICE, and PubMed. We looked for studies that evaluated the effectiveness of the FHC for children and young people with any neurodisability.

#### **What did we find?**

##### *What is the Family Hope Center?*

Family Hope Center<sup>1</sup> is a private American limited liability company. It provides therapies of intensive stimulation that are often considered to be the 'alternative' to conventional approaches.<sup>2,3</sup> Parents are trained in the techniques to deliver at home. It aims to improve speech, movement, and learning in children with neurodisability.

Family Hope Center founders and current directors are not licensed or board-certified medical practitioners. One member of their team is a medical doctor with board certification in the United States. Some of the certifications and professional affiliations listed on the website are with organisations that we were unable to verify. No one on their team is regulated by the General Medical Council or the Health and Care Professions Council in the UK.

### *What does the programme involve?*

It is difficult to determine exactly what the programme involves. Following a three-day seminar for parents and a two-day assessment, a customised programme is developed for each child. This may include educational stimulation using flash cards, movement stimulation (patterning, see below), training in daily living activities, social training, a nutritional plan including supplements, breathing exercises, craniosacral therapy (see below), purchasing of equipment, and recommendations to discontinue medications. The training plan is revised twice per year by FHC staff.

The FHC programme requires that the recommended stimulation and exercises are carried out by parent carers over several hours of every day.

Much of the theory behind the programme is based on the concept of neuroplasticity. This is the ability of the brain to reorganise its structure, function and connections. Neuroplasticity can be both positive, improving function, and negative when function is impaired.

There is still a lot that is unknown about neuroplasticity. Current understanding is that neuroplasticity is greatest in children. However, it is also understood that the brain does not have limitless potential for plasticity. Different areas of the brain have

different functions. This means that some areas of the brain are not able to take over the function of other areas.<sup>4</sup>

There is a lot of interest in using therapies to use neuroplasticity to promote functioning. However more research is needed to understand exactly what types and doses of therapy are effective to achieve this, and the best time in development for this therapy to take place.<sup>5, 6</sup>

The FHC programme is also heavily based on a type of treatment called “patterning”. Patterning comes from an idea that if children with neurodisability are assisted to repeatedly move in ways that are similar to how typically-developing children progressed in their early development, such as crawling, their motor function will improve.

Concerns have been raised by the American Academy of Pediatrics that interventions using patterning, that are of uncertain benefit, may place considerable stress on parents and lead them to neglect other family members. They also state that, *“Treatment programs that offer patterning remain unfounded; i.e., they are based on oversimplified theories, are claimed to be effective for a variety of unrelated conditions, and are supported by case reports or anecdotal data and not by carefully designed research studies.”*<sup>7, 8</sup>

Another key component of the programme is craniosacral therapy. Craniosacral therapy is a form of alternative therapy that involves a practitioner touching the head and spine. We were not able to find evidence that craniosacral therapy is effective for any outcome for children with neurodisability. A [randomised controlled trial](#) of craniosacral therapy for children with cerebral palsy found no significant effects on general functioning, pain, sleep, or carer’s quality of life.<sup>9</sup>

The South African Society of Physiotherapy has also issued a position statement warning that techniques used in the FHC programme may pose a risk to the safety and outcomes of children.<sup>10</sup>

### *What's the evidence that Family Hope Center programmes are effective?*

Family Hope Center claims to be an “evidence-based practice”, however in order to assert this claim, the FHC should be able to provide robust, independently published research which demonstrates this evidence.<sup>11, 12</sup> We found no robust evidence from scientific evaluations of FHC programmes demonstrating effectiveness to improve functioning beyond what would be expected due to development and recovery, or standard treatment.

Their website includes graphs seeming to show greater gains in functioning for their patients compared to patients at other facilities.<sup>13</sup> However, we are not convinced this is a fair comparison. Children in the two groups are not necessarily similar to each other in terms of ages, ability, and duration or dose of therapy. It may be that children in the FHC group have been followed for a longer period of time than those in the national average group and could therefore have made more gains purely through development over a longer time.

The FHC website also has a page titled “Important Real World Evidence of Neurological Development in Disabled Children”.<sup>14</sup> This page describes a study conducted in Denmark. The study only follows children in the FHC programme with no comparison group. It also only reports results from an assessment of functioning that FHC themselves created. No results from a second, independently developed assessment are reported. It is not clear that any of the reported increases in functionality would be more than what

would be achieved through the child's development without intervention or through standard treatment. This study has not been published in a peer reviewed journal.

A Norwegian and Danish study compared children receiving either the FHC programme or a similar programme called the Institutes for the Achievement of Human Potential (IAHP), or usual treatment in the community.<sup>15</sup> They found few differences in changes in motor function, cognitive function, language, and behaviour between the groups. All groups in the study showed developmental progress. The only area in which the FHC groups showed greater improvement was in fine motor skills after one year, but this difference disappeared after two years. Children receiving usual community treatment showed greater improvement in social, cognitive, and emotional outcomes than those in the IAHP/FHC group after one year, but not after two years.

A cost analysis of four therapies including FHC in Norway found that these intensive interventions are costly. The authors concluded that public funds should not be spent on them until their effects are established in scientifically sound studies.<sup>16</sup>

A more recent Norwegian review found three small controlled trials assessing FHC compared to standard treatment.<sup>17</sup> None of the studies found FHC to be more effective than standard care for improving functioning in children.

### **What do we think?**

- There is no evidence from research that the FHC provides interventions that are effective for improving functioning in children with disability beyond what would be expected due to development and recovery, or standard treatment.

- We advise caution as the FHC programme is expensive, time intensive, and is not delivered by clinically-qualified health professionals regulated in the UK.
- More research is needed to understand how, and when, the brain can respond positively to therapy-induced neuroplasticity.<sup>5,6</sup>

### Signposts to information

Scope have a list of questions to ask before starting a therapy:

<http://www.scope.org.uk/support/families/therapies/faqs>

CanChild have a video of a webinar discussing alternative therapies for cerebral palsy on their website:

<https://www.canchild.ca/en/resources/24-2-complementary-and-alternative-therapies-cams-what-are-the-issues-and-why-are-they-so-heated>

Contact provides online information about conditions and support available across the UK and has a helpline for parents:

<https://contact.org.uk/>

Cerebra provide a range of resources for help and information including a lending library, equipment, guides for parents, and support: <http://www.cerebra.org.uk/help-and-information/>

Note: the views expressed here are those of the Peninsula Cerebra Research Unit (PenCRU) at the University of Exeter Medical School and do not represent the views of the Cerebra charity, or any other parties mentioned. We strongly recommend seeking medical advice before undertaking any treatments/therapies not prescribed within the NHS.

We welcome feedback – please email us at [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk) if you have any comments or questions.

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