Peninsula Cerebra Research Unit PenCRU Childhood Disability Research

What's the Evidence? Brainwave and Footsteps for children with neurological or developmental conditions

Key findings

- Brainwave and Footsteps are separate organisations that provide physiotherapy based treatment programmes.
- We are not aware of any scientific evidence of the effectiveness of either programme to improve children's functioning.
- We think children's lives are about more than 'treatment and therapy' and we advocate that sufficient time should be given to all kinds of recreational activities.

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What were we asked?

Parents asked whether there was any research that therapies provided by *Brainwave* and *Footsteps* are effective, especially as they had heard they were expensive. These are two separate services that offer therapy and advice outside of the NHS.

What did we do?

In 2011 we searched the Cochrane Library, TRIP database, PubMed, NHS Evidence, and guidance issued by the National Institute for Health and Clinical Excellence (NICE). We contacted the Brainwave and Footsteps centres and asked about their programmes, any differences with NHS therapy provision, and whether there was evidence to support the improvements that they claim; we also asked the cost and time required for assessment and therapy.

What did we find?

Brainwave and Footsteps are separate organisations that provide physiotherapy based treatment programmes. Brainwave devises a programme to be carried out at home. Footsteps provide their therapy within their premises in Oxford. The programmes provided by these organisations appear to involve 'mostly' mainstream rather than 'alternative' interventions. Both organisations operate as registered UK charities and therefore seek to overcome any financial barriers to accessing their treatments.

Brainwave are a multidisciplinary team of health and education professionals who assess children with a variety of neurological and developmental conditions, and give advice on a therapy programme which parents are then encouraged to carry out at home. Brainwave costs £500 for a two day initial assessment at one of their centres, their advice and any equipment. One day re-assessments are recommended every 4 - 6 months at a further cost of £300.

Footsteps offer hands-on physiotherapy, at their premises in Oxfordshire, for children and young adults with neurological conditions. *Footsteps* use apparatus for simulating standing as part of their therapy, the so-called spider, which distinguishes their treatment from conventional physiotherapy. We are not aware of any scientific study of the effectiveness of this apparatus. The cost of therapy at *Footsteps* is charged at a rate of £50 per hour. The required number of hours depends on the therapists' recommendations. Programmes are delivered over three-week periods, with 2 hours of therapy a day, over this period costing £1,500.

We are not aware of any scientific evidence of the effectiveness of either programme to improve children's functioning. An evaluation we understand to have been commissioned by Brainwave suggested families appreciated the additional and individualised support. However the intensity of therapy was often difficult to incorporate into family life and therapy ceased once the child started school.¹

What do we think?

• We think that *Brainwave* and *Footsteps* seek to offer a higher 'dose' of therapy than might be provided by the NHS. While therapists at *Footsteps* deliver their therapy directly, *Brainwave* encourages parents to carry out therapy at home. Some children will be advised to follow a structured programme of a maximum 30 minutes a day, whilst others do not follow a programme but are advised on how to incorporate the techniques into their daily lives. Does the dose of therapy make a difference? Well, the optimum dosage of therapy is not really known, and would best be evaluated in well-designed research study.

- Parents want the best for their children, and families with disabled children may want to seek additional therapy even without knowing if it will help.
 Similarly, some parents employ the services of private physiotherapists not allied to these organisations. Children affected by neurological conditions are often late developers; typically they are developing all the time. Therefore it is difficult to determine whether any improvement is above what would be expected to happen in due course with less therapy or even no treatment.
- A controlled clinical trial is required to assess whether the intensive therapy programmes suggested by *Brainwave*, carried out by families at home, improve children's functioning and whether any benefit is maintained over the long term.
- A controlled clinical trial is required to assess the contribution of the 'spider' standing apparatus to any improvements gained through intensive physiotherapy provided by *Footsteps*.
- A controlled clinical trial is required to assess whether increasing the frequency and/or intensity of physical, occupational and speech and language therapies improves children's functioning and any benefit is maintained over the long term.

• Lastly, we think children's lives are about more than 'treatment and therapy' and we advocate that sufficient time should be given to all kinds of recreational activities.

Signposts to other information

We have provided links to these organisations for reference only; as can be seen from our comments, in no way do we endorse the products offered by these organisations. <u>www.brainwave.org.uk/</u> <u>www.footsteps.ltd.uk/</u>

If you are seeking private physiotherapy for your child then this link may be helpful: http://apcp.csp.org.uk/information-parents

We would like to hear your feedback on this summary – please email us at <u>pencru@exeter.ac.uk</u> if you have any comments or questions.

References

1 Heidari et al. (2002). Giving hope in brain injury. An exploration of families' experiences with the Brainwave organisation and therapy. *Children & Society*. 16 (1); 182-194

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