

**An exploration to 'demystify'
the management programmes
provided by the Brainwave
Centre.**

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INTRODUCTION

Historical Perspective

The Kerland Foundation was established in March 1982 by two employees of the British Institute for Brain Injured Children (BIBIC), which was an off shoot of the Institute for the Achievement of Human Potential (IAHP), based in Philadelphia, USA. They had been trained at the American Centre where they learned the principles of the Doman Delacato approach to cerebral palsy and it was this that they chose to use at the Foundation. The decision to create a new foundation arose from the differences they were having with the founder of BIBIC in terms of the amount of time and the level of commitment required by the families at BIBIC to carry out their programmes. When the Kerland Foundation first began operating it recommended that families carry out the programme with their children, on average between 12 and 18 hours per week. The IAHP often recommended that families carried out the programme every single day, but between 6 to 8 hours.

From 1986 onwards, the Charity employed a number of staff to work as "developmental therapists" with backgrounds in human movement, teaching and caring for special needs. None of the staff recruited in the 1980's had a physiotherapy qualification. In the late 1980's and early 1990's some of the staff began to question some of the techniques being carried out at the Centre and the amount of pressure being placed on families to carry out the programme however, the founder members refused to engage in discussion.

The therapy staff became increasingly frustrated with this situation, and involved the Trustees in their concerns. The result of these discussions was the removal of the founder members from their posts in October 1993. A new Head of Therapy Services and a Centre

Manager were appointed, with a Trustee's brief to review both the Charity's therapeutic practices and its approach with respect to its families. This resulted in the Charity changing its name to Brainwave in early 1995 and with the appointment of a new Chief Executive later in 1995; the Charity radically began to change its approach in terms of therapy, recruitment and philosophy. During the 25 years that Brainwave has been running, it has moved from positioning itself as complementary and it now regards itself as being able to provide an integrated mainstream provision for families who wish to provide a home-based therapy programme for their brain injured children. It is this vision that underpins all the activities within the Charity and they do not associate themselves in any way with the Doman Delacato method nor do they refer to their approach as "patterning".

The Centre believes that many therapists have not heard of Brainwave and that those who have think that Brainwave's approach still uses the Doman Delacato method, or at the very least, perceive that they use a great deal of patterning within their therapy programme. The staff at Brainwave perceives that they have inherited a rather negative legacy from the Kerland Foundation and their experience is that there are a wide range of attitudes and perceptions regarding Brainwave and its therapy team. These include:

Therapists within the NHS are concerned with encouraging families to follow therapies with outside agencies in case "something goes wrong".

Therapists have a rather cautious attitude as they are not entirely sure what Brainwave does.

Many therapists within the NHS do not realise that there is a team of qualified physiotherapists working at Brainwave, who follow standard movement principles and practices. There would appear to be some resistance to anything that is different or outside of the NHS, without a full understanding of the exact situation.

Brainwave has employed State Registered Physiotherapists for a number of years, but this message is still proving difficult to communicate to therapists within the NHS. It is their intention to work alongside all other health professionals involved in the care of any child that they see and not to replace them, although they are not convinced that this is how they are perceived in the outside world.

The Centre are constantly reviewing and evaluating their practices and it is part of this need to evaluate practice that resulted in their approaching the University of the West of England, to discuss a small pilot study initially to explore parents' perceptions/experiences of the Brainwave approach.

Purpose of the study

- To identify the programmes provided by the Brainwave Centre
- To identify the strengths and weaknesses of the programme as perceived by families who are attending or have attended the Centre
- To establish how these programmes differ from other 'mainstream approaches'
- To promote a positive way forward for future developments at Brainwave

METHODOLOGY

If we are to promote a move towards a model of health care, which includes recognition of an individual's right to autonomy in making decisions around their children's care then we need to understand how people make sense of their lives. To explore people's experiences and to interpret these experiences in a meaningful way requires a qualitative, phenomenological approach to research (Van Manen 1997). The methodology of choice was a focus group to facilitate discussion amongst the parents who have experienced Brainwave's approach. Focus groups are a suitable way of collecting rich data within a familiar setting, which is non-threatening (Krueger and Casey 2000). They are also an economical way of generating data from a group of people without too much time being involved (Bloor 2001). Easton et al (2000) suggest that one of the main advantages of focus groups is that the facilitator has the opportunity to interact with the participants and clarify any points raised from the information being obtained. Ethical approval for this study was gained from the University of the West of England Ethics Committee.

a) Focus group

Participants

Letters, inviting parents to participate in a focus group, and consent forms were sent to 102 families who have attended the Brainwave Institute in the last eighteen months.

Inclusion criteria

- Families who are still on the programme following initial assessment
- Families who have dropped out of the programme prior to completion

- Families who attended for initial assessment and chose not to join the programme

Take up for the focus group was very poor with only 3 parents agreeing to take part. Despite the small number, it was decided to continue with the focus group in the hope that themes arising from the group may be used to produce a questionnaire that could then be distributed more widely. Open-ended inductive questions were used to facilitate discussion (see appendix1)

The focus group was tape recorded and transcribed and the transcript was then analysed using the framework for analysis described by Smith et al. (2001). In seeking to establish credibility we want to know whether the researcher has established confidence in the findings of the study. To ensure rigor within the analysis the transcript was analysed by both researchers independently and a third blind analysis was done by an independent person. Sandelowski (1986) cited in Krefting (1991) suggested that:

'Qualitative research is credible when it presents such accurate descriptions that people who also share the experience would immediately recognise the descriptions'
(p.216).

A summary of themes was therefore sent to the participants of the focus group for comment on the truth value of the researcher's findings.

b) Questionnaire

Following further discussion and approval by UWE Ethics Committee a questionnaire was compiled using the main findings from the analysis

of the focus group transcript (see appendix 2) and this was sent to 102 families. These families met the same inclusion criteria as those approached to take part in the focus group. 45 questionnaires were completed and returned, (44%).

FINDINGS

a) The Focus Group

The main themes / sub-themes to arise from the analysis of the transcript were:

Service delivery

- integrated care package
- practical issues
- timing
- cost
- commitment

Communication

- professional discord and impact on the family
- information

Issues around parental Involvement

- empowerment
- lifestyle
- choices
- perceptions
- emotional issues

Assessment and treatment

- whole child
- family

- long term maintenance
- key workers/ lead professionals

b) The Questionnaires

These were designed using the themes/sub-themes that emerged from the focus group to produce a series of questions. The questions addressed both the importance of specific issues to do with their child's management and how they rated the actual Brainwave experience. Participants were asked to rate their responses 0-5, where for some questions this addressed degrees of agreement and for others it was rating how appropriate the Brainwave responses were. These were then compared to determine whether expectations around important issues identified by families were being met.

It is important to highlight those areas which were particularly positive. Here the percentages have been produced by adding together ratings of 5 and 4 (in the scale of 0-5 where 5 is the most positive).

AREAS OF QUALITY TO BE COMMENDED

Service delivery

97% of respondents were happy with the commitment of Brainwave staff

97% of respondents were happy with the initial assessment

95% of respondents were happy with the initial exercise programme

89% of respondents were happy with the length of assessments

Communication

93% of respondents were happy with communication between Brainwave staff and parents

90% of respondents were happy with the communication between Brainwave staff and their child

Issues of parental involvement

77% of respondents were positive about the programme fitting with their lifestyle

84% of respondents felt most of the time they were able to make choices about their therapy provision

Assessment and Treatment

79% of respondents felt they received an holistic approach to their child's care

77% of respondents felt they received an holistic approach to the family/siblings

85% were happy with the continuity of care

Commenting on the following statements:

Brainwave gave us hope for the future 83% agreed with this statement

Brainwave was cynical about other therapies 96% disagreed with this statement

Brainwave was very flexible in their approach 78% agreed with this statement

AREAS OF CONCERN

There were however, areas that would appear to be of some concern and here the results have been established by adding together ratings from 2-0 at the negative end of the scale:

Communication between Brainwave and local therapy services

27% had little or no communication with a further 20% responding not applicable.

Communication between Brainwave staff and the child's school

44% had little or no communication with a further 40% responding not applicable

Communication between Brainwave staff and lead

professionals (other than therapists) 35% had little or no communication with a further 7% responding not applicable.

Although these findings indicate room for improvement in communications in these areas, the qualitative findings show that in some cases it is parental choice influencing the levels of communication. Below are a few of the direct quotes from the participants (Q denotes questionnaire, FG denotes focus group):

'We are very happy with the programme and value the structured way in which it is delivered. However, we as parents do not inform our local HSE (Health Service Executive) that we are attending Brainwave as they can be defensive about outside influences. We feel also that it may damage relations between us and the HSE. It would be preferable if the HSE and Brainwave could liaise with each other and share their experiences and expertise with each other for the future development and benefit of the child. Maybe this is something for Brainwave to consider'
(Q)

NHS therapists understanding of Brainwave's programme

The most significant negative finding was the response to the statement 'NHS therapists have a good understanding of Brainwave's

programme' only 8% rated this at 5 or 4 with 80% disagreeing with the statement. These findings were also reflected in the focus group and the open-ended questions on the questionnaire:

'Many NHS practitioners are not fully aware of how Brainwave works and sometimes withdraw treatment. As Brainwave is complimentary I feel it would be beneficial to families to educate the NHS as much as possible about the Brainwave service.'(Q)

'.....actually I have had a couple of therapists have actually said 'oh you are doing Brainwave so you don't need anything from me' and they always say 'oh there you are off you go you' You can go from one extreme to the other can't you?' (FG)

'.....the one NHS worker I have spoken to about Brainwave had heard good things but didn't know a huge amount about them' (Q)

These findings begin to address the first aim of the study which was to identify strengths and weaknesses of the programme as perceived by the families.

The second aim was to establish how Brainwave is different from other approaches. We have established how Brainwave perceives they are different and we can compare their views with those of focus group / questionnaire participants. However, one must bear in mind the limitations of questionnaires in probing deeper and the small numbers of participants involved.

HOW ARE WE DIFFERENT?

(This section includes information from Brainwave (B), findings from the data (**D bold**) and quotes from participants (*P in italics*).

B. We offer parents the chance to be more proactive in their child's therapy so that they can carry out exercises with their child on a daily basis to help them improve their functional ability. As parents choose to come to the Centre, we can explain exactly what we provide so that the parents know precisely what to expect, with no surprises. This helps parents to feel more in control and empowered before they even arrive at the Brainwave Centre.

D. 89% of respondents did feel they were able to make choices about their child's care although the questionnaire did not specifically address parental empowerment specifically

P. 'We as a family have always had a positive experience as we have felt empowered upon our return home. The staff has always instilled us with confidence.' (Q)

P. 'the staff empowered us as parents from the moment we walked through the door.' (Q)

B. As an Initial Assessment takes place over two days, we have plenty of time to listen to parents and take on board the needs of the whole family and it also gives us a greater time scale in which to assess their child, resulting in us achieving a much fuller picture rather than just a snapshot of the child's abilities. We often hear of reports from parents that their therapists can only see their child at certain parts of the day,

which is not always the best time for the child him or herself; e.g. around lunchtime or at a time when a child needs a nap.

D. 98% of respondents were happy with the initial assessment

P. The initial assessment is OK but pseudo quantification/graphing of results is misleading and unnecessary'. (Q)

Those families who were not happy with the initial assessment expressed it thus:

P. 'At the initial assessment F was made to go through exercises 3 times this was too much and F would not comply in the end this turned into a fraught experience for all concerned. I knew from experience that no amount of persuasion would work and would of liked to stop trying. Second visit was more relaxed as only went through once'. (Q)

B. The programmes that we provide for families are very specific and only include exercises that we feel parents can carryout at home successfully and the whole of the second day of the assessment is spent teaching the parents how to carryout the programme.

There were mixed views on the 'do ability' of the programmes. Although 97% were happy with the initial exercise programme maintaining this over time could be a problem for some families.

P. 'Child does not enjoy programme. It is a constant battle to get her to do it.' (Q)

P. 'We attended the initial assessment and one follow-up visit, we then cancelled the second follow-up visit. We had been doing the exercises religiously though it made all our lives a misery as F has always fought against them.' (Q)

B. In addition to this we also provide the necessary equipment (e.g. wedges, rolls, Physiotherapy balls) as well as a DVD of the child carrying out the programme and a written description of every exercise or technique included within the programme.

D. 92% of the respondents were happy with equipment provision.

B. We can also give the parents advice on handling their child to help decrease tone and prevent contractures, as often the feedback we get is that therapists come to the home to “work” with their child, but the parents are left not understanding the principles behind the therapy, or what they are trying to achieve. As our therapists work in teams made up of physiotherapists, cognitive and developmental therapists, there is a slightly different perspective during an assessment, which leads to a more holistic programme.

D. 79% of participants felt their child’s assessment and treatment took an holistic approach

HOW ARE PROGRAMMES PLANNED?

B. Children are assessed with respect to their physical and cognitive abilities, taking into account the range of movement, quality of movement, joint alignment and any variation in muscle tone. We also listen carefully to the parents in terms of what their main concerns are and design a programme of exercises to maintain joint range, facilitate function and to help the child achieve its next developmental milestone; e.g. if a child has poor head control, then we would encourage lots of work in a prone position. When planning the exercise programme, we incorporate the principles of “normal movement” and depending on the age and needs of the child, the exercise programme has a duration of between 20 and 30 minutes. Parents are normally asked to carry out the programme 5 or 6 days a week and working on the principles of neural plasticity, programmes will include all aspects of a child’s functioning including gross motor function, fine motor control, balance and co-ordination as well as cognitive and sensory input. Children are reassessed every 4 to 6 months, as this is an achievable time frame for parents rather than it being an ideal time frame for the therapy team at Brainwave.

The findings of this study do establish a link between Brainwaves’ perceptions and parents’ perceptions of how they are different from the NHS in what they offer. However, it has not been possible to identify and explore the different approaches to assessment and treatment that may be provided to these families through their local NHS therapists and therefore to compare these with those offered by Brainwave in a more objective manner. This potentially could be addressed through a separate study comparing parents understanding of the approaches and evaluating their perceptions of ‘do-ability’ and efficacy of each approach

REGIONAL FAMILY CO-ORDINATORS

B. There are seven Co-coordinators currently in post covering families living in the West Midlands, Norfolk, Suffolk, Cambridgeshire, Devon, Dorset, Cornwall, Essex, Greater London (E), Surrey, Kent, Berkshire, Wiltshire, Herts and Bucks.

All our Co-coordinators are employed from backgrounds largely in social and health care which gives them a proper understanding, not only of family dynamics, but also the knowledge and research ability of how to access help from mainstream and independent sources.

They provide a listening ear and a tangible link to the community and to the Brainwave Therapy Team. Co-coordinators organise social events at local venues for Brainwave families which connects them with one another and gives families the chance to meet up, share experiences and information, and have a great time.

For many families, the Co-coordinator's visit is the rare and pleasurable experience of a professional entering their home without complicated forms to be completed, or who carry out judgmental assessments, or who leave them with a greater problem than they felt they already had. What they enjoy is the visit of friendly, understanding, uncomplicated, and informed people whose sole purpose is to help and support them.

D. 53% of respondents were happy with the support they received from local co-coordinators and 52% of respondents did feel it was important to have the support of a local co-

coordinator. However 33% said it was not applicable to them and we have wrongly or rightly assumed that this means they do not actually have access to a local co-coordinator.

This may be an area to consider for future development as the qualitative feedback indicates that they have an important role to play in support and motivation to stay on the programme.

P. 'B could maybe contact parents once a week to enquire if all is going well. This would encourage parents to stick at the programme giving some moral support, helping to rejuvenate their enthusiasm as the programmes are not just hard work for the children'.(Q)

The third initial aim of the study was to identify the programmes provided by the Brainwave Centre. On reflection this was probably not an aim we could achieve through this particular approach and methodology. What would be required is further information from Brainwave about the philosophy underpinning their treatment/management programmes and specific techniques used. How they determine the appropriate programme for each child and how these are progressed and how they measure improvement both physically and cognitively.

The final aim of this study was to consider ways of promoting a positive way forward for future developments at Brainwave. We include the following action points and suggestions for further research

ACTION POINTS

1. To increase communication with external agencies, e.g. NHS therapists, schools etc.

Our final report clearly identifies this as an area of major concern highlighting issues around communication between Brainwave and local therapy services, schools and lead professionals as compounding this problem.

It is therefore important that Brainwave addresses the communication issues and considers ways in which this could be improved. Suggestions/ comments from the participants in this study in addressing these problems include:

'As Brainwave is complimentary I feel it would be beneficial to families to educate the NHS as much as possible about the Brainwave service.'(Q)

'What would really benefit the children would be for all the professionals involved to work together and communicate. There are some children who just don't slot into the average textbook....this is where the NHS stumble' (Q)

'Brainwave staff to liaise with the child's school and therapists' (Q)

Our suggestions in this area:

- Brainwave need to explore further the NHS therapists' perceptions and understanding of their (Brainwave's) work.
- Brainwave could consider establishing some structured framework for educating/involving NHS therapists in their work, e.g. Workshops to inform NHS therapists of their philosophy and approach to the management of children with cerebral palsy.
- Invitation to therapists to attend their child's assessment/follow ups at Brainwave.
- Brainwave to establish links with the child's school, where this is appropriate, and ensure information about their physical, emotional and cognitive needs are clearly communicated to the teaching/therapy staff of the school.

ACTION POINTS

2. Underpinning philosophy

'There seems to be some sort of er disparity between the therapists from the NHS and Brainwave they don't seem to be on the same wavelength as each other and what I found was that between the programme that Brainwave offered and the programme that was offered by the NHS therapists they didn't seem to have any conformity with each other and I found they were almost at loggerheads and our therapist in the NHS would be critical of what Brainwave were

*providing as a programme. Brainwave not being critical back
Brainwave just offering an alternative view of their thoughts.'* (FG)

Part of the communication problem would appear to stem from the lack of understanding of the Brainwave philosophy that underpins their rationale and justification for the approach that they promote. As researchers we believe this may be a crucial area to address, indeed it may not be possible to deal with communication issues until your philosophy is clearly established and in the public domain.

Our suggestions in this area:

Brainwave need to reflect further on their philosophy and rationale and consider publishing an article to increase the understanding for healthcare professionals who work in this field.

ACTION POINTS

3. To be more proactive in marketing the services of Brainwave

'more newsletters, greater info on website. We found out about Brainwave by sheer accident/luck!'(Q)

There were a number of comments from participants about how little is 'out there' as far as information and marketing of Brainwave's work is concerned. Our many years of clinical experience have enabled us to understand and recognise parents' needs to seek the best approach for their child. To this end they often do much research, reading and website searching in an attempt to find alternative therapies that may

offer their family more than the traditional NHS approach. It is therefore vital that Brainwave consider ways of increasing public awareness of their work and the support they can offer.

Our suggestions in this area:

- Consider increasing and updating the information on your website and ensure that it is user friendly and easy to access for parents.
- Publish regular newsletters to which parents can contribute their experiences, ideas and in so doing provide support systems for other parents.
- Provide workshops for parents to share experiences first hand (these could be regional service user groups).
- Newsletters to Trusts and Primary Care Trusts (PCTs).
- Disseminating information to GPs through promotional in-service sessions

4. The role of the Coordinators

Families who did have access to a regional coordinator felt this was a great benefit and provided them with very positive support. However, many families did not have any contact with a regional coordinator.

Our suggestions in this area:

- Consider increasing the number of regional coordinators
- User groups who can link with the coordinators

5 Practical issues

Equipment

Our suggestions in this area:

- Increase equipment library both centrally and regionally

SUGGESTIONS FOR FURTHER RESEARCH

1. To define Brainwave's philosophy
2. To explore NHS therapists perceptions of Brainwave
3. To explore the different approaches to assessment and treatment that may be provided to these families through their local NHS therapists and therefore to compare these with those offered by Brainwave
4. To evaluate the role of the local co-ordinators

Our thanks to all the Brainwave staff and the families for their commitment and co-operation in this research

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APPENDIX 1

Suggested questions that may be used to facilitate discussion in the focus groups (Brainwave)

The aim of these groups is to facilitate discussion around the therapy programme provided by Brainwave and to demystify their approach.

Areas we would like to explore with the parents include:

Prior to attending Brainwave were their children receiving therapeutic input?

If yes what type of input,
where,
how often
funded by?

If no why not?

How did the parents 'discover' Brainwave?

What does Brainwave offer your child?

What are your expectations of this approach?

If have experienced other treatment approaches why the move to Brainwave?

How does it differ from other approaches?

To parents who have sustained the programme for a long period of time:

- What is your role as parents in the Brainwave approach?

- What benefits do you perceive?
- How does your child respond to the programme?

To parents who feel Brainwave provides extra to the mainstream therapy they also receive:

- How do you manage to combine two different approaches to care?
- How do those providing 'mainstream' approaches respond to your involvement with Brainwave?

To parents who have given up the programme:

- How long did they maintain it?
- Why did they give it up?
- What therapy approach are they now adopting?
- How does it compare/contrast with Brainwave?
- How does your child respond to the programme?

APPENDIX 2
Questionnaire

AN EXPLORATION TO 'DEMYSTIFY' THE MANAGEMENT PROGRAMMES PROVIDED BY THE BRAINWAVE CENTRE

QUESTIONNAIRE

SERVICE DELIVERY

1. WHAT VALUE DO YOU PLACE ON THE FOLLOWING ASPECTS OF SERVICE DELIVERY?
(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

Aspect	0	1	2	3	4	5
COMMITMENT OF BRAINWAVE STAFF						
INITIAL ASSESSMENT						
INITIAL EXERCISE PROGRAMME						
FOLLOW UP ASSESSMENT						
MAINTENANCE PROGRAMME						
EQUIPMENT PROVISION						
LENGTH OF ASSESSMENT						
LENGTH OF TIME BETWEEN VISITS						
SUPPORT FROM LOCAL COORDINATORS						

2. WITH REFERENCE TO YOUR EXPERIENCE OF BRAINWAVE, HOW DID YOU RATE THE FOLLOWING?

(Please TICK one box for each aspect; 0 = POOR, 5 = JUST RIGHT)

Aspect	0	1	2	3	4	5
COMMITMENT OF BRAINWAVE STAFF						
INITIAL ASSESSMENT						
INITIAL EXERCISE PROGRAMME						
FOLLOW UP ASSESSMENT						
MAINTENANCE PROGRAMME						
EQUIPMENT PROVISION						
LENGTH OF ASSESSMENT						
LENGTH OF TIME BETWEEN VISITS						
SUPPORT FROM LOCAL COORDINATORS						

COMMUNICATION

3. WHAT VALUE DO YOU PLACE ON THE ASPECT OF COMMUNICATION WITH THE FOLLOWING PEOPLE?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

Aspect	0	1	2	3	4	5
BRAINWAVE STAFF AND PARENTS						
BRAINWAVE STAFF AND CHILD						
BRAINWAVE STAFF AND LOCAL THERAPY STAFF						
BRAINWAVE STAFF AND CHILD'S SCHOOL						
BRAINWAVE STAFF AND LEAD PROFESSIONALS (KEY WORKERS)						

4. WITH REFERENCE TO YOUR EXPERIENCE OF BRAINWAVE, TO WHAT EXTENT DID EACH ASPECT OCCUR?
(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time)

Aspect- communication between	0	1	2	3	4	5
BRAINWAVE STAFF AND PARENTS						
BRAINWAVE STAFF AND CHILD						
BRAINWAVE STAFF AND LOCAL THERAPY STAFF						
BRAINWAVE STAFF AND CHILD'S SCHOOL						
BRAINWAVE STAFF AND LEAD PROFESSIONALS (KEY WORKERS)						

ISSUES OF PARENTAL INVOLVEMENT

5. WHAT VALUE DO YOU PLACE ON THE FOLLOWING?
(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

Aspect	0	1	2	3	4	5
HAVING A PROGRAMME THAT FITS IN WITH YOUR LIFESTYLE						
BEING ABLE TO MAKE CHOICES ABOUT YOUR THERAPY PROVISION						

6. With reference to your experience of brainwave, to what extent did each aspect occur?

(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time)

Aspect- communication between	0	1	2	3	4	5
HAVING A PROGRAMME THAT FITS IN WITH YOUR LIFESTYLE						
BEING ABLE TO MAKE CHOICES ABOUT YOUR THERAPY PROVISION						

ASSESSMENT & TREATMENT

7. HOW DO YOU RATE THE FOLLOWING?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

Aspect	0	1	2	3	4	5
HOLISTIC ASSESSMENT & TREATMENT APPROACH TO CHILD						
HOLISTIC APPROACH TO FAMILY & SIBLINGS						
CONTINUITY OF TREATMENT						

8. With reference to your experience of brainwave, to what extent did each aspect occur?

(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time)

Aspect	0	1	2	3	4	5
HOLISTIC ASSESSMENT & TREATMENT APPROACH TO CHILD						
HOLISTIC APPROACH TO FAMILY & SIBLINGS						
CONTINUITY OF TREATMENT						

9. PLEASE COMMENT ON THE FOLLOWING STATEMENTS

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = STRONGLY DISAGREE, 5 = STRONGLY AGREE)

Aspect	0	1	2	3	4	5
BRAINWAVE GAVE US HOPE FOR THE FUTURE.						
BRAINWAVE WAS CYNICAL ABOUT OTHER THERAPIES						
BRAINWAVE WAS VERY FLEXIBLE IN THEIR APPROACH						
BRAINWAVE MADE US FEEL THAT IT WAS OUR FAULT WHEN WE COULDN'T KEEP UP						

THE EXERCISE PROGRAMME						
NHS THERAPISTS HAVE A GOOD UNDERSTANDING OF BRAINWAVE'S PROGRAMME						

10. WITH REFERENCE TO YOUR TIME AT BRAINWAVE, ARE THERE ANY AREAS WHERE YOU WOULD LIKE TO FEEL MORE EMPOWERED AS PARENTS/CARERS?

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.....
.....
.....

11. IF YOU ATTENDED THE INITIAL ASSESSMENT AT BRAINWAVE ONLY AND THEN DIDN'T FOLLOW THE PROGRAMME, COULD YOU PLEASE EXPLAIN WHY?

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.....
.....

12. IF YOU ATTENDED THE INITIAL ASSESSMENT, FOLLOWED THE PROGRAMME FOR A PERIOD UNTIL THE FOLLOW UP, THEN STOPPED, COULD YOU PLEASE EXPLAIN WHY?

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.....
.....
.....

13. PLEASE FEEL FREE TO ADD ANY FURTHER COMMENTS WHICH MIGHT ASSIST BRAINWAVE IN IMPROVING THEIR PROGRAMME.

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.....
.....
.....

THANK YOU VERY MUCH – LESLEY & KATHY

APPENDIX 3

Questionnaire results

= 45 IN TOTAL

SERVICE DELIVERY

1. WHAT **VALUE** DO YOU PLACE ON THE FOLLOWING ASPECTS OF SERVICE DELIVERY?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

2. WITH REFERENCE TO YOUR EXPERIENCE OF BRAINWAVE, HOW DID YOU **RATE** THE FOLLOWING?

(Please TICK one box for each aspect; 0 = POOR, 5 = JUST RIGHT)

	Value	Rated
Commitment of brainwave staff	93% = 5 7% = 4	84% = 5 13% = 4 3% = 3
Initial assessment	91% = 5 7% = 4 2% = 3	76% = 5 22% = 4 2% = 3
Initial exercise programme	82% = 5 18% = 4	73% = 5 22% = 4 5% = 3
Follow up assessment	76% = 5 20% = 4 4% = 3	16% = N/A 64% = 5 16% = 4 4% = 3
Maintenance programme	29% = N/A	37% = N/A

	44% = 5	49% = 5
	24% = 4	7% = 4
	3% = 3	7% = 3
Equipment provision	2% = N/A	2% = N/A
	60% = 5	64% = 5
	22% = 4	28% = 4
	16% = 3	2% = 3
		4% = 2
Length of assessment	2% = N/A	2% = N/A
	49% = 5	76% = 5
	36% = 4	13% = 4
	9% = 3	8% = 3
	4% = 2	2% = 2
Length of time between visits	49% = 5	4% = N/A
	27% = 4	73% = 5
	20% = 3	13% = 4
	4% = 2	6% = 3
		4% = 1
	Importance	Rated
Support from local coordinator	29% = N/A	33% = N/A
	38% = 5	38% = 5
	14% = 4	15% = 4
	6% = 3	6% = 3
	11% = 2	4% = 2
	2% = 1	4% = 0

COMMUNICATION

3. WHAT **VALUE** DO YOU PLACE ON THE ASPECT OF COMMUNICATION WITH THE FOLLOWING PEOPLE?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

4. WITH REFERENCE TO YOUR EXPERIENCE OF BRAINWAVE, TO WHAT EXTENT DID EACH ASPECT OCCUR?

(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time)

	Importance	Extent / Occur
Brainwave staff and parents	91% = 5 9% = 4	87% = 5 19% = 4 2% = 3 2% = 2
Brainwave staff and child	84% = 5 14% = 4 2% = 3	82% = 5 12% = 4 4% = 3 2% = 2
*Brainwave staff and local therapy	4% = N/A 53% = 5 20% = 4 20% = 3 3% = 0	20% = N/A 27% = 5 7% = 4 18% = 3 9% = 2 2% = 1 16% = 0
*Brainwave staff and child's school	18% = N/A 38% = 5 18% = 4	40% = N/A 14% = 5 2% = 4

16% = 3	9% = 3
4% = 2	11% = 2
2% = 1	24% = 0
4% = 0	

Brainwave staff and lead profs.	2% = N/A	7% = N/A
	53% = 5	31% = 5
	11% = 4	7% = 4
	22% = 3	20% = 3
	5% = 2	5% = 2
	2% = 1	9% = 1
	5% = 0	21% = 0

ISSUES OF PARENTAL INVOLVEMENT

5. WHAT VALUE DO YOU PLACE ON THE FOLLOWING?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

6. With reference to your experience of brainwave, to what **extent** did each aspect **occur?**

(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time).

	Value	Extent/occur
Having a programme that fits with 5 your lifestyle	96% = 5 4% = 4	53% = 24% = 4 16% = 3 2% = 2 5% = 0
Being able to make choices about 5	71% = 5	60% =

Your therapy provision	18% = 4	24% =
4		
	9% = 3	11% = 3
	2% = 2	5% = 0

ASSESSMENT & TREATMENT

7. HOW DO YOU RATE THE FOLLOWING?

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = NOT IMPORTANT, 5 = VERY IMPORTANT)

8. With reference to your experience of brainwave, to what *extent* did each aspect *occur*?

(Please TICK one box for each aspect; 0 = not at all, 5 = majority of the time)

	Value	Extent/occur
Holistic assessment and treatment	80% = 5	2% =
N/A		
Approach to child	13% = 4	67% = 5
	5% = 3	12% = 4
	2% = 2	12% = 3
		5% = 2
		2% = 0
Holistic approach to family & siblings	69% = 5	5% =
N/A		
	22% = 4	64% = 5
	7% = 3	13% = 4
	2% = 2	8% = 3
		4% = 2
		4% = 1
		2% = 0
Continuity of care	85% = 5	69% = 5

13% = 4

16% = 4

2% = 3

9% = 3

3% = 1

3% = 0

10. PLEASE COMMENT ON THE FOLLOWING STATEMENTS

(PLEASE TICK ONE BOX FOR EACH ASPECT; 0 = STRONGLY DISAGREE, 5 = STRONGLY AGREE)

Brainwave gave us hope for the future 2% = N/A

57% = 5

26% = 4

13% = 3

2% = 1

Brainwave was cynical about other therapies 80% = 0

16% = 1

4% = 2

Brainwave was very flexible in their approach 2% = N/A

51% = 5

27% = 4

9% = 3

6% = 2

5% = 1

Brainwave made us feel that it was our fault 51% = 0

when we couldn't keep up the exercise prog. 14% = 1

5% = 2

5% = 3

11% = 5

4% = N/A

NHS therapists have a good understanding	49% = 0
Of Brainwave's programme	16% = 1
	15% = 2
	12% = 3
	6% = 4
	2% = 5