When the Bough Breaks

by Sheila West, BA, CQSW

An Independent Survey into Families' Perceptions of the
ONE HUNDRED HOURS
Model of Service

A One Hundred Hours Publication

BACK COVER –

One Hundred Hours has pioneered a new service in Yorkshire for families who have a new baby with serious brain damage. It offers emotional support and practical help to the parents in their own home as soon as possible after discovery of the problem.

In this independent survey Sheila West has interviewed thirteen families who used the service in its first two years. She finds that the parents feel they have benefited from the service and that the support offered was not available to them elsewhere.

The major regret the parents voice is that they did not learn about One Hundred Hours sooner. Their recommendation for development of the service is that it should be made available to all families at the point of diagnosis.

> *"I found it very hard working with the child in those early months – every time I tried to do something it I was just confirmed that things were pretty grim."*
>
> *"The service helped us clarify the child's needs – because we didn't know anything about the world of disability."*
>
> *"You need someone to contact just to tell them how awful you feel about having a handicapped child."*

- Parents' comments

£4.50

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Contact: peter.limbrick@mailfence.com
Web: tacinterconnections.com

About the Author

Sheila west obtained her Social Science Degree at Lanchester Polytechnic (now called Coventry University). During her final year she completed a major research study comparing provision for people with disabilities with their own perceptions of their needs.

She then worked in Coventry, first as a liaison worker for the charity 'The Association for the Treatment of Brain-damaged Children' and then as a field work organiser for Lanchester Polytechnic's Health Visiting and Social Work Department.

On moving to Yorkshire she worked in a residential home for adults with learning difficulties before taking her social work qualification at Leeds University. After a period as a generic social worker in an area office, Sheila West took a career break to care for her young family. She now lives on a hillside just outside Halifax with her husband, two children and a dog.

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Rock a-bye, baby,
On the tree top,
When the wind blows,
The cradle will rock.
When the bow breaks,
The baby will fall,
Down will come baby,
Cradle and all!

Preface

One Hundred Hours is an independent Yorkshire project helping parents who have a new baby with serious brain damage and consequent multiple disability. We were registered with the Charity Commissioners in January 1992.

Our aim as a charity is to establish an effective new model of service for this client group and to disseminate information about it to professionals and parents across the UK. In our first two years we have worked with families in Bradford, Halifax, Huddersfield, Leeds and Wakefield.

The work with the families was undertaken by two members of staff designated as 'keyworkers'. The first was myself working full-time in the combined role of keyworker and manager of the charity. My past experience is in special needs teaching and in charity administration and includes personal family experience of a baby with brain damage. The second keyworker was Daphne H, a retired Health Visitor who was employed to work with one family in Leeds between June 1993 and January 1994.

One Hundred Hours has focused its attention on that small number of babies who have serious brain damage which can result in a combination of some or all of the following factors:

- a number of significant disabilities, e.g. cerebral palsy, sensory deficit, epilepsy
- impaired respiration and feeding
- the child being frail and subject to frequent illness
- a shortened life expectancy
- the child being difficult to manage

The diagnoses and main special needs of the children of the thirteen families interviewed in this survey are tabulated on Page 9.

One Hundred Hours was founded in the belief that this client group were not adequately served by existing services in either the statutory or voluntary sectors. The major gaps, as we perceived them, were as follows:

i. Parents were left largely to their own devices with their baby during the first months. This left them lacking essential information about their baby's disabilities and needs and about what services were appropriate and locally available.

ii. Parents were not offered proper emotional support either at the time of diagnosis or afterwards. They had no opportunity to talk openly and repeatedly to an experienced person they could trust about what they were feeling now and about their uncertainties and fears for the future.

iii. Parents were not offered sufficient practical help in learning how to manage their baby, how to cope with any challenging behaviour and how to encourage development.

iv. Parents who were given programmes to work on at home were not given adequate support. In our experience there can be many valid reasons why some parents, especially during the first year, will find it difficult or impossible to do these home programmes. The effect of this can be to add to the parents' sense of guilt and inadequacy and reduces the professional's effectiveness. These reasons include:

    - physical tiredness
    - stress
    - lack of time
    - unwillingness to assume the role of the teacher/therapist
    - unwillingness to accept the baby's difference or disability
    - not sharing the professional's aims
    - not understanding the reasons for the activities
    - forgetting what the programmes are
    - unwillingness to make demands on the baby or cause him or her discomfort
    - cultural differences

v. Later on, when more professionals are helping with the various disabilities, there is the danger of the child's many needs being catered for in isolation from each other. The parents are left with the task of integrating these separate programmes and resolving any apparent or real contradiction.

The One Hundred Hours Model

The One Hundred Hours model of service was designed with the following elements:

i. Offering immediate support by visiting the family within two or three days of their request for help. Providing the family with a keyworker who begins work with the family within a few days after the initial meeting.

ii. Working in the family's own home where the parents are in control and where the child feels secure in familiar surroundings.

iii. Being available to the family for one, two or three 2-hour visits each week.

iv. Offering a finite period of intensive work. (100 hours represents 6 hours a week for 17 weeks, 4 hours a week for 25 weeks or 2 hours a week for 50 weeks.)

v. Agreeing with the family a course of action in relation to what they feel are the priority needs and to check continually that they feel the work being done is meeting those needs.

vi. Making contact with and staying in touch with all professionals in the other services who are helping. This can reassure the family that everyone is working together and can prevent real or apparent contradictory information and approaches.

vii. Acknowledging the strengths and skills of the family members.

viii. Being open and honest with the family and maintaining total confidentiality.

ix. Keeping a continuous record of the child's progress in written form and on video tape, both of which stay in the family home and remain the property of the family.

x. Ensuring that One Hundred Hours never offers any service which is already available from another local agency.

The keyworker's role

This is shaped by the needs of each particular family and can include:

- Helping the parents to find answers to questions either of a general nature or specifically about their child.
- Helping the parents to make the best use of all available relevant services.
- Helping the parents learn how best to manage their child and how to cope with any challenging behaviour.
- Supporting the parents with the home programmes provided by other professionals.
- Helping the parents integrate all information and approaches so that they retain a whole picture of their child's abilities and needs.
- Providing emotional support to significant family members.

The Survey

At the end of our first two years of work we wanted to know how the families we had worked with felt about the One Hundred Hours model of service. Did they feel they had benefited? Which of their needs had we met and which ones had we failed to meet? How would they suggest we develop the model in order to help families in the future who have a new baby with brain damage?

We commissioned Sheila West as an independent Social Worker to interview each of the families. We did not brief her in any detail about the model of the service nor did we describe the babies to her beyond telling her that each one had brain damage. The families whose baby had died were identified to her.

Sheila West's survey shows that the families had experienced significant gaps in the services available to them before One Hundred Hours. We welcome this survey because it validates our model of service and provides a clear indication of how we should develop.

Peter Limbrick, BSc
October 1994

	The babies' medical diagnoses and main special needs for care and for learning	**Age at referral**
1	Brain damage after heart surgery at 23 months, cerebral palsy, visual deficit, sleeping difficulties	27 months
2	Cerebral palsy, microcephaly, visual deficit, epilepsy	11 mths
3	Cerebral palsy, microcephaly, profound deafness, eating difficulties	6 mths
4	Cerebral palsy, Microcephaly, profound visual deficit, epilepsy, inability to take food orally, sleeping difficulties, needing to be nursed all waking hours	9 mths
5	Genetic syndrome, severe developmental delay	11 mths
6	Cerebral palsy, eating difficulties, sleeping difficulties, needing to be nursed all waking hours	7 mths
7	Cerebral palsy, microcephaly, profound visual deficit, epilepsy, inability to take food orally, needing to be nursed all waking hours	6 mths
8	Cerebral palsy, visual deficit, inability to take food orally, needing to be nursed all waking hours	7 weeks
9	Lissencephaly, visual deficit, severe developmental delay	20 mths
10	Cerebral palsy, profound deafness, partial paralysis of hips and legs	15 mths
11	Uncertain diagnosis, visual deficit, severe developmental delay, inability to take sufficient food orally	8 mths
12	Agenesis of corpus callosum, genetic syndrome, microcephaly, epilepsy, profound visual and hearing deficit, inability to take food orally, very frail, needing to be nursed all waking hours	13 mths
13	Major heart defect, hydrocephalus, developmental delay, inability to take food orally, visual deficit, hearing deficit	17 mths

Introduction

Aim of the survey

To carry out an assessment of the work of One Hundred Hours (OHH) in order that OHH may develop in a way that best meets the needs of the families with which it works.

Method

To interview all of the families who had received an intensive service from OHH.

Purpose

i. To establish the families' perceptions of the service, if and how it met their needs.

ii. To uncover any criticisms of the service.

iii. To establish ways in which the families feel the service could be improved.

Methodology

I was employed by OHH as an independent Social Worker. My remit was to interview all the families with whom OHH had worked (13 families) with the above aims in mind.

All the interviews were taped, semi-structured interviews, carried out in the families' own homes. I was given no prior knowledge about the family other than their name and address and the name of their disabled child. This enabled each family to have control over the information received.

Acknowledgement

I would like to express my extreme gratitude to the families who agreed to be interviewed. Their co-operation is very much appreciated as I am very aware that one of the direct consequences of having a disabled child in the family is having a constant stream of 'interested professionals' impinging upon one's life and one's family. I can only apologise that one of the things I inevitably contributed was to increase that number by one more.

I also appreciate that for every family their child's disability is a painful fact of life that is not always easy to talk about. I am therefore very grateful that every parent I interviewed spoke with such openness and feeling.

S.W.

Analysis of the Interviews

How families heard about One Hundred Hours

For OHH to have a chance of being effective it has to be accessible to families. This accessibility is largely dependent on families knowing of OHH's existence.

Of the 13 families interviewed, 5 were told about it by a health professional, 2 families were informed by a professional working in a private capacity, 2 families had read an article in a newspaper and the remaining 4 families were told about OHH by a friend or relative.

Just over half of the sample were given the name and telephone number by one of the professional helping agencies and just under half heard about it by chance.

Families' experiences at the diagnosis of brain damage

For a family with a disabled child, the point at which their lives are irrevocable changed, for the most part, is the point at which they are given the diagnosis that their child has brain damage that may result in multiple disabilities. Most of the families interviewed were able to describe graphically this moment and the effect it had upon them. Eight of the families, once given their diagnosis, reported that they were offered no support, either emotional or physical. One family found the staff in the intensive care unit very supportive and were led to believe that a support network would be there on discharge from hospital. However, they found that this was not the case. This family and one other reported that they received support from the outreach nurses but that this support was medically based and therefore limited to those aspects of their problems. Only one family were referred to OHH at this point of their child's diagnosis. This family found this early involvement invaluable, in that support was supplied by OHH when they were first learning of their child's disabilities, even before her discharge from hospital after birth.

The general experiences of the families interviewed seemed to be that they felt abandoned by the medical profession at the point at which they were given their child's diagnosis. The only exception to this was the family who were referred to OHH when their baby was seven weeks old and still in hospital. The successful pattern of support for this family included OHH providing both the major emotional support and the liaison between the professionals involved. There appeared to exist a positive relationship between those working with the family and a good level of communication between the family, OHH and the other professionals. Most other families, however, spoke of being sent home with no back-up. For example, several families whose child was diagnosed as having cerebral palsy were not told about the Spastics Society.

Three families mentioned Health Visitor follow-up which they had not found particularly helpful. Two families were followed up by the Paediatric Outreach Service which they did find helpful. No families reported that the support from Social Services was significant.

Every family had further contact with the hospital in the form of consultant paediatrician appointments with varying frequency depending upon the medical needs of their child. For most families this was their only contact with any kind of helping agency at this early stage. Every family who felt that they should have received more help in these early stages expressed the feeling that input from OHH at this point would have been very beneficial.

The nature of the initial contact with One Hundred Hours

The common theme with every family interviewed was that once the family contacted OHH the response was immediate. One mother said on her initial telephone call to the keyworker,

> *"I was used to people saying they would come and see me in a month's time – he wanted to come the next day."*

Every family's initial contact followed the same pattern. The keyworker arranged to visit the whole family within one or two days of the first telephone call and spent two hours talking to both partners and meeting the children of the family. Within that time he gave the families the opportunity to state how they hoped OHH may be able to help whilst at the same time giving the family some idea of the limits of his remit.

The nature of the work with each family

The overriding impression given by every family interviewed was that the programme of work undertaken with them was designed specifically for them as an individual family. Each reported that during the initial meetings they were given the opportunity to express what they wanted from the service. The keyworker explained clearly what OHH could offer them and in every case they were able to agree on a pattern that met their child's and the family's needs. Each family had an agreed record of aims and objectives which were reviewed as the work was being carried out. Families referred to the flexibility of the approach which was something they did not feel was available from the Health or Social Services.

> *"The problem with Social Services Departments – the services they offered are so inflexible – you can't generalise about the needs of families with special needs children. Every child's needs are different."*

Although the service is individually tailored for each family, certain common elements emerge. From the interviews, the keyworker's role can be summarised as follows:

a. To promote development by designing a programme of education and stimulation, complementing any work being undertaken by any other profession.
b. To record, on paper and video, any work undertaken, particularly any progress made by the child.
c. To provide information about any services available to the family.
d. To liaise between the family and the other (sometimes numerous) professionals working with their child.
e. To provide emotional support.

Twelve out of the thirteen families interviewed reported that the keyworker achieved these aims to a very high level satisfaction. The remaining family expressed a degree of satisfaction with the educational programme in the initial stages but when it appeared that the programme was not appropriate for the child, OHH's input ceased at the family's request.

The basis for the overall finding, that the work OHH undertook was beneficial for the child and the family, can be analysed by taking each of the five strands of the keyworker's role and looking at them separately in detail:

a. Developmental work

Every family with whom the keyworker undertook developmental work spoke of its beneficial effects upon their child. The reasons for the success of this approach were variously given as:

i. The frequency, duration and regularity of the work.

> *"Maybe (the child) wouldn't be doing what he is doing now, because you don't have that time – you don't have three hours in the morning to do what (the keyworker) does."*

ii. The fact that someone other than a parent was taking time to work on the physical programme with the child.

> *"I found it very hard working with (the child) in those early months – every time I tried to do something it was just confirmed that things were pretty grim. In those early days when you're trying to do basic things that you try to do with babies we just weren't getting the right reaction and it made it increasingly difficult to do. I think that it is something that therapists lose sight of – how difficult it is to go home and lie her on her tummy when she is screaming and doesn't want to be on her tummy and do all the thigs that they've suggested."*

> *"The main thing is that he tries to get your child to do things that you don't think they are ever going to achieve."*

iii. The fact that the service is home based.

> *"With hospital appointments you are under pressure because you want them to do the right things and they (the children) pick that up."*

> *"The nice thing about (OHH) is that it is done in your own home, it is done at her pace and I don't feel under pressure."*

> *"It is not fair to ask the child to do things at the allotted appointment."*

> *"Having time to give; you don't feel as if you have a half-hour slot and that somebody else would be waiting outside the door, which you do feel in hospital."*

b. Records and videos

Every family received a record of their child's progress and a video of work undertaken. Every family felt that this was a useful thing to look back on and to remind them that progress had indeed been made, however small.

> *"The use of videos was so helpful because it gives you the chance to concentrate on the child's abilities and you can also involve the partner who can't be there during the day."*

> *"You can take the video into hospital to show them because she doesn't perform well in the hospital setting – she is not a performing dog."*

c. Provision of information

All thirteen families referred to the useful information OHH was able to give with regard to what other help is available to them. Not only did the keyworker seem to provide the family with contacts for help with a variety of specific problems, he also appeared to give them the confidence to ask for, or even demand, that help.

> *"The problem was that unless you shouted you didn't get anything, but with (the keyworker) on your side, he advised us of the right people to shout at."*

> *"(The keyworker) has given me a lot of confidence – before I was nervous – now I just say what I think."*

One mother reported that she felt the keyworker had given her an insight into the system of services for the disabled. He supported them at meeting with other professionals and put them into contact with people and services they would have otherwise not known about.

Another family spoke of the fact that the keyworker provided choices and useful information. When their child was very ill in hospital, he suggested a Neurologist who might be able to help. This Neurologist suggested a different and very effective form of treatment.

> *"If we had not taken her away from the one hospital that was dealing with her to a specialist that the keyworker put us in touch with, I think she would have died."*

One family did not receive the child development service because it was not felt appropriate at that time. The keyworker, however, carried out an assessment of the child resulting in a written report. The family felt this report was:

> *"… very professionally done"* and *"gave us confidence as to what he (the keyworker) felt (the child) needed, what was available and how to pursue it."*

> *"The service (the keyworker) gave us helped us to clarify (the child's) needs – because we didn't know anything about the world of disability. He gave us the backing we needed to enable us to go to speech therapy and ask for weekly appointments."*

d. The liaison role

Part of OHH's role can be to liaise between each family and the other professionals with whom they are involved. This role was undertaken in varying degrees across all the families interviewed. One family did not feel this was a role they needed at all.

Four families had a particular Hospital Trust which would not co-operate with OHH in any way.

The remaining eight families felt that OHH undertook this role to a varying degree. For some of these families the liaison role usually a line of communication between the various professionals involved, the keyworker and the family, so that each knew what the other was doing. This communication also sometimes took the form of OHH attending or even initiating meetings between the whole team of people working with a specific child. In one particular family the OHH worker was to become the central person through whom all communications were channelled as the family felt they could no longer cope with the stress of co-ordinating all the different disciplines working with their child (22 in all). However, this plan never came to fruition as the child died. The family nevertheless spoke in very positive terms about how they felt the system would have worked.

> *"It was what we wanted – to take the pressure of us – to organise appointments – to let other professionals know what was going on without us having to tell them separately. All we wanted was some continuity in (the child's) care."*

e. The provision of emotional support

Eleven of the thirteen families spoke of the value of the keyworker's role in offering support to either or both parents.

Of the two families who did not value this aspect of the service, one family felt that the role of the counsellor may be better filled by someone other than the keyworker. They felt that the keyworker's role should be restricted to fact finding and information giving. For the keyworker to act as emotional counsellor as well would only serve to cloud the issues. The other family felt that there was a danger that the involvement of just one person as a keyworker could become too intensive. They felt that the one-to-one relationship inhibited the family from making any criticisms of the work the keyworker was undertaking. They also recognised that there was an in-built danger that, if the family and the keyworker did not get on well together for whatever reason, there was no one else to whom they would be able to turn. They felt that a second person as a back-up or even alternative, may have helped them to air any difficulties.

All the other families seemed to place great value on the role of the keyworker combined as a 'hands-on' worker with their child and also as a source of emotional support for themselves. None of the families felt that they received the same level of emotional support from any other helping agency.

> *"He sat and listened to you and was always very positive."*

> *"He became a tower of strength for me. He came into the hospital and talked to me as a person."*

> *"He comes some days when I just don't know how I'm going to get through to the end of the day."*

> *"We needed help with things like marital problems. He is not just there for (the child), he is here for me as well."*

"He was a listening ear."

"It (the service) was very helpful, bordering on life-saving for my sanity."

"He is a good listener and never pries. Also you know that whatever you tell him is going to go no further."

"You need someone to contact just to tell them how awful you feel about having a handicapped child."

"He was the only one around."

"(The keyworker) had by this time become an invaluable friend – the one person I could ring any time day or night – he was always there for us – with no other motive – no political motive – nothing else but for our benefit and mainly for (the child)'s benefit. Also the only person who reaffirmed what we believed – that we knew our child best."

"He would sit and listen to all your fears and he wouldn't make any judgement on it, just sit there, take it all in and afterwards you would think 'I feel better now'. You'd talked yourself through rather than him guide you, you would talk yourself through it and make your own decisions. He never made a decision really. He helped you make your own – without opening his mouth."

The effect One Hundred Hours involvement had on families' relationships with other helping agencies

The way in which other helping agencies responded to the fact that OHH was having some involvement with the families varied tremendously. Five families reported that they felt the relationship between themselves and the other professional agencies and between the keyworker and the professional agencies was a good, positive one. This was typified by the keyworker being able to attend meetings and hospital appointments with the families and participate in decision-making about any planned or proposed plans of action.

One family stated that the other professionals and OHH –

> *"… get on very well. They communicate so everyone is working in the same way."*

Another family reported that their Consultant Paediatrician was very positive about OHH's involvement. Initially they felt that he (the Consultant) was worried that the family may be given information that conflicted with the information from the hospital, but the family felt that this potential problem was overcome by everybody working together and communicating effectively.

Two families felt that the keyworker's input into the family had no effect upon that family's relationship with other professionals.

Three families stated that they felt that OHH's involvement was not particularly welcomed by the medical profession. When talking about their response, one of the families said that –

> *"They (the medical professionals) more or less accepted it, but have never been very welcoming; they have never really gone out of their way. (The keyworker) has always gone out of his way to tell them what he is doing. Sometimes they are just being downright rude."*

Another family felt they detected a distinct change in the relationship between them and the medical professionals since OHH's involvement. They felt the medical professionals were very suspicious and defensive and viewed them, as parents, as a threat. A third family felt there was a slight negative 'knock-on' effect, in that the physiotherapist felt that, because their child was receiving help from OHH, she (the child) did not need more physiotherapy. Therefore she did not increase her input beyond once a month. The family felt there was a definite feeling of antagonism and mistrust of what OHH was doing.

The remaining families' experiences were typified by their Hospital Trust's unequivocal refusal to work with OHH. (This was in each of the three cases the same Hospital Trust.) None of the families were given a reasoned argument as to why they would not work with OHH.

> *"I had to relay messages back to (the keyworker). He had to ask me what had gone on so that he could carry on the programme with (the child). I would have liked them to work together like all the other authorities do. The authorities refused to work with him but did not offer an alternative."*

Another family met with silence when they asked why they would not work with OHH.

> *"They did not want to discuss it – they were OK before we first met him (the keyworker) at the Child Development Centre, but I don't know what happened. They don't much talk about it."*

The other family with this experience of non-co-operation felt there was some kind of –

> *"… management policy of not working with OHH. The physiotherapist would not put together a programme for him to follow."*

This family felt that this impasse did not have any detrimental effect on the keyworker's role within the family.

How One Hundred Hours concludes its involvement

Each of the families interviewed had been made aware at the outset that OHH's involvement was time limited. In some instances the 100 hours had been exceeded, in others the time spent with them was less than 100 hours, but every family had a clear understanding that any intensive input would at some stage have to stop.

Of the thirteen families interviewed only four were currently receiving a regular service from OHH.

Of the other nine families, eight felt that the service had been terminated by a mutual consent. The other family, as previously mentioned, requested that the service terminate early, as they felt it was no longer appropriate to their child's needs.

The children of two of the remaining eight families had died. Both these families reported that the keyworker continued to provide emotional support for them for some time after the death of their child.

Each of the other six families felt that the service had been terminated by mutual agreement. They all felt that they, as a family, had reached a stage where they no longer needed what OHH could offer, because of the changing needs of their child. These changes were typically because the child had started either at nursery or school and the education system was beginning to play an important role in their lives. Whilst they all felt that the withdrawal of the work of the keyworker had been handled sensitively, they also felt still in touch with their keyworker and able at any time to contact him to request further help.

"If I rang him tomorrow and needed him for something he'd be over."

Criticisms of the service

Every family was asked if they had any criticisms of the service they had received from OHH. They were also asked to make any suggestions for changes or additions to the service that they would like, or would have liked, to see.

Eight of the families were unable to think of any way in which they could criticise the service they received. These families' responses are typified by the following quotations from their interviews:

"I can't knock him for anything because he was always there when I needed him."

In answer to the question – 'Did OHH offer or suggest anything which was not helpful?' one family replied:

"No, because before he does anything, we talk it through."

A second family's response was:

"No, I cannot think of anything because you come to an agreement between yourselves what you want. You are not forced into anything, it is left to you. You make the decisions."

"If he says he is going to do something, he is there. He supports me at meetings and any major steps forward."

"No, I can't criticise him for anything because he was always the person on our side. He was on our wavelength, but this may not be the case for all families."

This last point was the one major criticism given by the one family interviewed who had any major criticism of the service. They felt there was no recognition within OHH that the family and the keyworker may not be able to work together. They felt that because of the intensive nature of the relationship between the keyworker and the family it was vital that there was no clash of personalities.

> *"If you don't get on – it's pretty serious. With the others – doctors, physiotherapists, etc. it's not so important that you get on, but with OHH it's more important."*

The remaining four families each gave one example, as they saw it, of a minor criticism. Viewing the service as a whole, however, they felt OHH was very effective. The minor criticisms were as follows:

One family felt that the keyworker wanted to be too involved in the family and they cited an incident when the keyworker wanted to accompany the family to a hospital appointment but the family preferred to attend alone. The mother also said, however, that the presence of the keyworker at that particular appointment did give her strength.

In answer to the question 'Did OHH offer or suggest anything that was not helpful?' two families gave examples of being told about services they might find useful. In one case this was a support group for parents with disabled children and the other was a Family Centre with a play group for disabled children. Both sets of parents felt that these were not what they, as a family, needed. One family felt that there was quite a high expectation on them trying the Family Centre, which they did, but found it was not helpful for their particular situation.

The fourth family with a minor criticism had a particular course of action suggested to them which in the end proved not to be feasible. The family felt that perhaps the keyworker should have fully investigated the proposal before bringing it to their attention.

Despite these criticisms each of these families was nevertheless able to talk positively about the service OHH provided. Their feelings are exemplified by the following quotations from their interviews:

> *"I always got what I wanted. I always got an unbiased opinion. It has always been our decision about what we wanted to do."*

> *"With OHH you just get what you want."*

> *"He gives the impression of somebody who knows what he is talking about and is aware of the needs and aware of the issues about disability."*

> *"In terms of handicap, I feel you have to experience having a handicapped child to know what it is like. Only families who live it know what it is like and nobody can imagine anything near what it is like. (The keyworker) understands that and doesn't try to be anything more than an outsider, but he does have an understanding of the issues and shows that."*

Suggestions for improving the service

Each family were asked to make suggestions which could improve the service OHH offers. The overall picture emerging from each family was not one of changes to the service, but of expansion of it.

One family would have liked the service to continue in the school holidays. This was one of the families for whom the service had ended because of the child's attendance at school.

They spoke of their difficulties in maintaining the level of stimulation provided by school during the long holidays without any outside assistance.

At least two families felt the need for some respite care. Most families spoke of severe strain caring for a severely disabled child places on the family. Several families would have welcomed extra help, either in the home or provided elsewhere, when they could be confident that their child was being well cared for. This would enable them to carry out some other aspects of normal family life.

Two families felt the need for the service to have more than one keyworker. Several families commented upon the limitations of the service pivoting upon the work of mainly one person and recognised the limitations that would place upon the service. These limitations would not only be of time but there would also be the restrictions of knowledge and expertise. Two families mentioned the potential difficulty that the family may not be able to interact effectively with the keyworker and that, if he were the only one, they would not be able to seek an alternative within OHH.

Several families' responses took the form that they felt they could not have asked for anything more from the service. They felt that the service met their needs to their total satisfaction. These feelings are summed up by the following quotations:

> *"No, I don't feel there is anything extra OHH could do because I feel I could ask for anything."*

> *"He has covered all our areas of concern more than adequately. If he can't do something himself, he can always find somebody who can. He has provided input and information about things he can't deal with directly himself."*

Other families' feelings about improving the service centred around their regret that they had not heard about it earlier in their child's life. These families felt that their experience of disability would have been made less painful if someone could have made contact with them at the point of diagnosis.

> *"I would have liked more support at the diagnosis, or information about a support group for parents. Not too much all at once, but access to it so that you could choose to contact someone in your own time, or even the chance to talk and ask questions – even just the Spastics Society's telephone number. I had to come home and look it up in the phone book."*

> *"We would have liked to have known about it (OHH) earlier. The Specialist Health Visitor visited and she was good and helped a bit, but her role was limited. It would have been of enormous benefit if we had someone to help us understand what was going on – like a co-ordinator – help us ask some of the questions we didn't feel able to ask or even provide us with the answers before we thought of the questions. Because it's such a maze – dealing with so many different people takes so much time and energy and we had to deal with (the child) as well."*

The Conclusions

1. Referrals

OHH appears to have become known to families on an ad hoc basis. It therefore needs to be more widely publicised.

2. Access to the service

The families felt that they would have gained even more from the service had they known about it as soon as possible after the child's diagnosis. This ties in with the previous point about wider publicity indicating that this publicity should be targeted at those professionals who have the first contact with the newly diagnosed child who is likely to have multiple disabilities.

3. Follow-up

OHH shows an example of extreme good practice in the nature of its immediate response to requests for help.

4. Content of the work

Every family interviewed made positive comments about the various aspects of the service. The overall impression given to the researcher was that the service worked well for the majority of the families for these following reasons:

i. The service is flexible in its approach basing its work on the needs of the child and the family.

ii. OHH provides, if appropriate, someone to assist with or undertake the developmental work with the child designed in conjunction with the therapists. This is carried out on an intensive basis in the child's home, considerably easing the burden of the primary carer.

iii. The written records and videos made by the keyworker provide a permanent record of work undertaken, further work to be done and any progress made, however small.

iv. OHH is a major source of information regarding any other services that may be of use to the families.

v. The keyworker can act as a link between the families and the myriad of other professionals with whom they may come into contact.

vi. The keyworker is able to provide emotional support to the parents at a time when one of their greatest needs is someone who has time to listen to them.

5. Responses from outside agencies

Each family reported on their perception of the various Health Authorities' responses to the service provided by OHH. This, they reported, varied along a continuum from complete communication between all the interested parties, through few or no expressed views on OHH's involvement, to complete refusal to communicate with the keyworker about the family. Whatever the Health Authority's attitude appeared to be, however, it did not affect the family's perception of the value of the service.

6. Terminating the service

Another example of good practice was exhibited in the way OHH terminates its involvement with the family. No family whose intensive input had ceased felt bereft by the cessation of the service. OHH appears to have achieved its aim of being an enabling service, rather than an irreplaceable prop.

7. Criticisms and suggestions for improvement

The overall impression was one of a very high degree of satisfaction with the service offered by OHH.

The suggestions for improvement focused on expansion of the service in various ways:

i. OHH becoming involved at a much earlier stage.

ii. The use of more than one keyworker.

iii. Expanding the service to include respite care.

8. The way forward

It would appear for the most part that OHH offers an example of practice that could well be emulated by other welfare agencies. For OHH to develop further it needs to be cognisant of those aspects of its work which the families found most valuable. However, in order for the work to further expand, the size of the potential client group would need to be assessed and the question of employing further keyworkers would have to be addressed. This clearly has wide-reaching implications for aspects of recruitment and training, establishing codes of practice and, most importantly, funding.