

# family support

## the Keyworker a practical guide

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Gudrun Limbrick-Spencer

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**the  
Keyworker  
a practical guide**

This guide provides a comprehensive description of the practicalities of providing a keyworker service for the families of children who have a disability. The model and its rationale are explained and case studies illustrate how it can be put into practice.

One Hundred Hours, an independent agency in West Yorkshire developed and used the keyworker model throughout the 1990s. *The Keyworker* includes a comprehensive evaluation of the model in action from the perspective of parents who used it.

Comprehensive protocols, developed over a ten-year period, detail how an effective keyworker service is provided from the initial meeting with a family, including reviews and key documentation.

*The Keyworker* is an essential guide for any service wishing to offer effective family support through the keyworker model. It has been written for service planners, managers and keyworkers, whether a keyworker model is already in place or in the planning stages.

**The Keyworker  
£16**

**ISBN 1 903210 10 0**

## **The Keyworker - a practical guide**

Published in 2001 by WordWorks in association with The Handsel Trust

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Printed in the UK by Westpoint, Birmingham

ISBN 1 903210 10 0

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## Acknowledgements

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The author, One Hundred Hours and the Handsel Trust owe an enormous debt of gratitude to those 120 families with whom One Hundred Hours worked. This was a pioneering service and these families took it on wholeheartedly. They also talked to us honestly about the service and what it meant to them - through many informal conversations and through formal evaluations. It is their honesty and candidness which enabled us to develop the keyworker model as it now exists. They enabled their experiences, and our experiences of working with them, over a ten year period to become a working model for use with other families following in their footsteps.

Right up to the present day, they have continued to give their experiences and views for us to use to demonstrate the need and the model throughout the rest of the UK and beyond.

The author would also like to thank Peter Limbrick and Sheila West of the Handsel Trust both for their written contributions and their advice and support in the writing of the remainder of *The Keyworker*.

# Foreword

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## **A personal experience of a keyworker service**

When he was eight months old, our son Matthew was seriously ill in hospital, suffering from pneumococcal meningitis. This left Matthew with brain damage, autism and epilepsy. In the months after Matthew came home from hospital we were finding it extremely difficult to deal with his complex medical problems. We were also noticing significant delays in his development.

As the time passed and our concerns were being dismissed, we began to feel increasingly isolated, not knowing which way to turn next for help. Then we made contact with the charity, One Hundred Hours. Our immediate impression was that at last we had someone who would listen to our concerns for Matthew however long it took and whenever it was, and genuinely sympathised with them.

One Hundred Hours began helping us to find the right people to contact. They then supported us at the subsequent meetings to ensure that we were getting a proper response to our concerns. Very soon we were able to obtain a diagnosis on Matthew's development, which, although heart-breaking for us, enabled us, with One Hundred Hours' considerable help, to identify what would be the best and most appropriate help that we could get for Matthew. This culminated in us very quickly obtaining a place for Matthew at the local Mencap nursery.

The next initiative suggested to us by One Hundred Hours was to arrange a meeting with both Matthew's doctors and the nursery staff who were looking after him. This ensured that there was a co-ordinated approach and that everyone involved with Matthew was aiming for the same objectives. It was only after this that we began to start seeing some improvements in Matthew's development.

One Hundred Hours continued to work with us providing 'a shoulder to cry on' during our many low points. Finally they assisted us in completing Matthew's Statement of Special Needs, helping us to ensure that we obtained a place for Matthew at the school most suitable for his needs.

We know that if we hadn't discovered One Hundred Hours when we did, Matthew would probably not have made the progress that he has so far achieved and for that we cannot thank them enough.

Mr and Mrs Firth

*Parents with whom One Hundred Hours worked in the 1990s*

## The organisations and people involved

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*The Keyworker* is published by WordWorks in association with the Handsel Trust and has learnt heavily on the work of One Hundred Hours.

**The Handsel Trust** is an independent UK charity, established in 2000, to promote and encourage the support of families with children who have a disability.

**One Hundred Hours** was an independent organisation which worked throughout the 1990s to offer support to the families of children with complex needs in West Yorkshire.

### About the author

Gudrun Limbrick-Spencer worked with One Hundred Hours since it first began, initially as a trustee and then as a paid worker before becoming one of the founding trustees of the Handsel Trust. In 2000, *Parents' Support Needs* was published by The Handsel Trust which is Gudrun's account of her research into the needs of families in the UK who have a child with a disability.

Gudrun also works as a voluntary sector consultant - focusing on advising small to medium-sized charities about management, publicity and funding issues - and has worked with a wide array of such organisations over the last 11 years. Having attained her first degree from Oxford University in 1989, she is currently working towards an MA in Research and Social Policy at Birmingham University.

### Peter Limbrick

Peter was the founder of One Hundred Hours and subsequently worked as director and keyworker for the organisation. His background is in special education and he now works as a service development consultant to UK statutory services in addition to being a trustee of the Handsel Trust.

### Sheila West

In 1994 Sheila researched and wrote *When the Bough Breaks*, the first independent user-evaluation of the One Hundred Hours keyworker service. She then joined the organisation as a keyworker. Sheila now works in a local authority Children's Disability Team and is the social worker attached to the Child Development Centre.

# Introduction

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*The Keyworker* aims to document the One Hundred Hours experience of providing a keyworker model of support for the families of children with disabilities. One Hundred Hours amassed important experience in supporting such families which will be invaluable for other services also wishing to provide such support in the most effective way possible.

## Definition of keyworker

The term keyworker is now commonly used in all fields of care and education. With its popularity as a term comes an ever-increasing number of usages and definitions.

Keyworker can mean anything from a named individual within a team solely for the convenience of providing a named contact to a dedicated individual who is the source of service provision.

Even within the narrow field of offering support services to the families of children with disabilities there are different meanings for the term keyworker. The lack of consensus on what is meant by keyworking brings its own set of problems to service providers who struggle to find clarity and consistency where little exists. With confusion over what is meant by keyworking, the pace of service development is undoubtedly slowed.

The definition of keyworking used throughout this book, and in the One Hundred Hours keyworking model described, is very clear:

***the keyworker is both a source of support for the families of children  
with disabilities and a conduit by which  
other services are accessed and used effectively***

Thus, the keyworker is not only an end in itself - a source of support - but a means to an end - effective services for the child and his or her family. The impact of the work of the keyworker, in this manner, goes way beyond the work they do with the family and instead supports and augments the roles of other existing services.

Importantly, the role of keyworker is not designed to replace the work of other services. It is an additional link with the family which can potentially reduce the burden on other service providers of taking on roles which are not really in their job descriptions, such as emotional support or care co-ordination.

To do this effectively, it is argued, the keyworker needs to be able to offer the family specific services - such as emotional support, information, advocacy and co-ordination of services - and needs to operate under specific principles such as being parent-led, being 'dedicated' (focusing solely on keyworking), independent and operating in partnership with the parents. These elements are each covered later in this book.



## The need for a keyworker

*“If someone had asked me how I felt instead of concentrating solely on my daughter’s problems, I believe it would have released the stress that built up and led to severe depression six to seven months later. My husband and I felt as if it was us against the world.”*

A respondent in the UK SOFTY Survey  
(Published as *Parents’ Support Needs*, 2000)

While it is not the purpose of this book to justify the need for a keyworker support system, that role has been more than adequately taken on by other researchers and publications, it is worth briefly looking at the topic for those new to the concept.

It is well-documented that parents of a child with a disability need support (see Limbrick-Spencer 2000 and Sloper et al 1999). Without support they are liable to feel isolated and lost. The SOFTY Survey demonstrated parents can feel grief for the able-bodied child that didn’t arrive or that they have lost, at sea in a new world of disability, unsure of which advice to follow when opinions conflict, and they can feel more like a nurse than a parent. Parents experience relationship breakdown, depression, the loss of a job or home and the struggle to maintain normal relationships with other children or other members of the family when the child with the disability needs so much of their time and energy.

The SOFTY Survey found that what parents wanted was:

- emotional support
- information about their child and about disability
- information about services
- support in accessing services
- co-ordination of services
- help to maintain a whole picture of the child within the family

Davis (1993) outlines very clearly the common-sense approach to supporting parents which is borne out by talking to families whose children have a wide range of conditions. The way a family adapts has less to do with the specific condition than it does with the people themselves. Thus the first step towards supporting a family has to be to get to know a family and learn about their own strengths and needs. This is a fundamental tenet of effective family support.

It is now reasonably well-documented that a way forward for providing this support is a keyworker role (see publications listed on page 55) – an individual working with a family to provide elements of support and act as a link between the family and some of the services on offer to those families. However, the exact role of the keyworker, who takes on that role and the relationship between them and other services varies between different commentators and has been put into practice in different ways.

The One Hundred Hours keyworker model is a specific way of implementing a keyworker service and an ideal means of supporting families based on practical experience of working with families during the 1990s. The model has been reinforced by current research.

# **The development of the One Hundred Hours keyworker model**

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*Peter Limbrick, the founder of One Hundred Hours*

## **The beginnings of One Hundred Hours**

One Hundred Hours started life in 1991 as a keyworker-based early intervention project for children with multiple disabilities. I had long experience as a teacher of children with multiple disabilities of all ages and, at that time, recent experience of pre-school children with cerebral palsy and associated conditions. In this latter role, I frequently met with parents who seemed to have been offered no real help, either for their child or for themselves, during the first months and years after diagnosis. They had been told very little about their child's condition (and certainly nothing positive) and had been offered no early intervention programmes to do at home. Parents were ill informed, frightened and confused and their children were lacking effective developmental and learning experiences.

Given this background, it was natural to establish One Hundred Hours as an approach for babies and pre-school children that would focus primarily on the child's needs but at the same time offer a listening ear and relevant information to parents.

In our view at that time, to be an effective early-intervention keyworker for the child would require meeting any professionals (therapists, pre-school teachers, nursery nurses, etc) who already knew the child, to learn from them about their goals for the child and the approach they were using to achieve them. The keyworker's task would then be to join these various activities together into a whole approach that was enjoyable and relevant to the child and understandable and relevant to the parents. The aim was to integrate all learning activity into normal daily routines which the parents could do as often as they wished between sessions with their professionals or keyworker. In this way the child's opportunities for learning would be much more frequent, enjoyable and relevant.

As would be expected, we met different needs, interests and skills in parents and different levels of trust and co-operation from professionals. The latter could vary from eager co-operation (from professionals who recognised the child's and family's need for more support than they, as over-worked professionals, could provide), through more or less willing co-operation, to actual hostility and a withdrawal or reduction of a particular professional's service to the child and family.

## **The development of the model**

Despite this mixed response One Hundred Hours persisted and prospered and gradually won over those many professionals who were willing to trust us after seeing how we worked. From the start we worked in equal partnership with parents, on the basis that we had a different expertise from them but shared objectives with them, and made sure our role as keyworkers was led by the parents. This overriding principle of being responsive to needs as

keyworkers and as an organisation led us, over the years, to gradually refine and adjust our objectives with children and families as follows:

**a. the needs of the family**

Whereas our focus had initially been first on the child and then on the parents, we gradually responded to the needs of the families we worked with by focusing first and foremost on the needs of the parents. We could see that many parents had very great needs for general help and support and we felt that by helping to meet those needs we were contributing significantly to the well-being of the child and the whole family.

**b. parents working with the child**

We met many parents who were at first unsure how to play with their child and then later lacked confidence in carrying out suggestions and programmes provided by helping professionals. We supported parents as they learned how to give their child play, development and learning activity.

**c. emotional support**

We recognised that a major need of the majority of parents was to have someone they could trust to talk to on a regular basis. Acknowledging this as perhaps the most important keyworking role with a majority of families, keyworkers became ‘active listeners’ (using Professor Hilton Davis’ model, Davis 1993) and we saw this as an essential service to parents with therapeutic benefit. By providing a regular and non-hurried listening ear we were able to meet many parents’ need for emotional support during the first months after disclosure.

**d. accessible information about disability**

We recognised parents’ need for clear information about their child’s condition and their right to know as much as the helping professionals knew. The keyworker would help parents frame questions for their professionals and could attend consultations with them. Also, by supporting professionals to be open and honest with parents about what they, as professionals, did *not* know about the condition, we could help relieve parents of the anxiety that things were being kept from them. We found many families experienced anger and resentment at being ‘kept in the dark’.

**e. accessible information about services**

We also recognised the parents’ need for accurate and clear information about all relevant services. Finding out what is available is an extremely demanding task for parents and for keyworkers. We found that keyworkers could build up a good working knowledge of all local services in time. Often it was a case of learning with the parent. But information is essential to parents who are struggling to get the best for their child. Parents are disempowered by any council, health authority or service that does not make good information easily available.

**f. accessing services**

We learned first-hand how many parents have to struggle to get services in place for the child. Many parents report how they soon learned to shout and we certainly saw the reality of the popular perception that ‘if you don’t shout, you don’t get’. We acknowledged that One Hundred Hours keyworkers should help parents get relevant services in place and take some of the struggle off their hands.

#### **g. co-ordinating services**

We observed that families suffer additional stress when the various helping services (health, education, social services and the voluntary sector) make no attempt to collaborate or co-operate with each other to provide a joined-up or co-ordinated service. The result of this disjointed and fragmented approach could mean:

- families being subjected to repetition of information gathering, of assessment procedures and of review processes
- giving the family a chaotic regime of appointments to various departments around the locality and a procession of visitors to the home
- families being overloaded with helpful suggestions and home programmes from professionals who were ignorant of which other professionals were also giving 'home work'
- because there was no coherent view of the pattern of service to the family there could be gaps in service, leaving the child or family with unmet needs

With some families, the One Hundred Hours keyworker would take on the role of a service co-ordinator. Success in this role was heavily dependent on the willingness of professionals and their agencies to co-operate.

#### **h. a whole approach**

Because of the nature of the disabilities of the children with whom we were working, there would typically be more than one professional providing development and learning programmes for the child and actually working with the child. At parents' request, keyworkers could promote a holistic approach to the child. At the most basic level it meant arranging for particular professionals from within the same agency or from across agencies to do a joint session with the child and parents. This at least ensured they were aware of what each other was aiming for and, even better, might result in a consistent approach with shared goals. With help and encouragement from the keyworker, it could result in an integrated programme.

In later years we able to define the menu we could offer as:

- emotional support for parents and other key family members
- helping parents get information about the child's condition
- helping parents get information about relevant services, benefits and equipment
- helping parents get all relevant services at the time when they wanted them
- helping co-ordinate services and integrate programmes
- helping parents to be equal partners in the care of their child

The above account shows that this model was developed in response to actual work with families in which their needs were allowed to determine the role of the keyworker and the role of the organisation. It was not a research-based model. It is true that when we called our style of working 'keyworking' we had in mind various reports over the previous years which advocated keyworkers but we had no outside guidance about what a keyworker should be or

what a keyworker should do with these families.

## **Early doubts about our model**

In the early days we were severely warned by various professionals that if parents were given this degree of support they would rely too much on us and would never willingly let go, or in fact ever be able to manage without us. We did not believe this at the time and saw it as a negative view of parents. Nor was it borne out by experience. We found parents were stronger than this and not seeking long-term dependency. It was often parents who suggested we should move from the intensive phase to a less intensive phase. Parents frequently gave as their reason that there were other families who needed us more than they did now. For many families the reduction of our input was a part of getting life back to normal. Many parents spoke of being empowered by their support from One Hundred Hours. They spoke of having increased confidence in pursuing a good service and being more able to assert themselves.

Another warning was: ‘don’t give your home phone number to parents!’ As we all worked from home, we did give our phone number to parents. And this was no problem; we were not swamped with unwelcome phone calls. Perhaps parents who do have a support system which they know is at hand do not need to make much use of it. Perhaps it is the parents who feel abandoned who are pushed into the position of making frantic calls to anyone and everyone. In my time as One Hundred Hours keyworker I can recall only one call for help during a weekend. This was from a teenage mother who had her new baby home from the special care baby unit for the first time. She had run out of gas cards and money and the house was getting cold. She had tried social services, she had tried the police and then she tried me. Fortunately I was free that Sunday morning to collect her card and then put some money on it for her.

# The One Hundred Hours keyworker model

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Families are offered a free support service during the first year or two after they have learned that their child has, or might be going to have, disabilities. The parents are provided with an independent and dedicated keyworker who develops a trusting relationship with them and offers general support as they sort out their emotional response to the child's condition, learn all about their child's abilities and needs, negotiate the maze of services and start the process of adjusting the family's thinking, routines and finances to this new situation.

The model recognises that families are likely to have similar needs during this time regardless of the nature of the child's disabilities and therefore keyworker support is not dependent on any particular diagnosis.

**The keyworker is both a source of support for the families of children with disabilities and a conduit by which other services, including treatment, therapy, education, respite and benefits, are accessed and used effectively.**

The role of the keyworker can be summarised as offering support, information, advocacy and co-ordination. Specifically, the keyworker will make available the following elements of support:

- giving **emotional support** to parents and other key family members. Counselling skills are used but the keyworker is not providing formal counselling. The major element of this support is 'active listening'
- helping the parents get **answers to their questions** about the child's condition
- helping the parents get **information** about all relevant services and benefits
- helping the family get **all relevant services**
- helping the family to **promote the child's well-being**, play and development
- helping parents **co-ordinate the professionals** and agencies involved so that
  - appointments are rationalised
  - professionals know what each other is doing
  - parents are not overloaded with things to do
  - duplication and contradictory advice is avoided
  - services provide collectively for the whole child and family
- helping parents **integrate all interventions** so that
  - they have a holistic picture of the child's abilities and needs
  - there is a whole approach which embraces all developmental activities, learning programmes and goals
- promoting parents as **equal partners** in all services to their child

Importantly, the precise nature of the input, ie. which elements are selected from the above list, is decided by the parents in consultation with their keyworker. Thus parents are not given a predetermined service but are enabled to design the service that is right for them and their individual circumstances at the time.

The framework in which help is offered includes:

- being available to families from the time the parents first know, or suspect, their child has complex needs
- being needs-led
- offering regular proactive contact
- visiting the family in their own home and in hospital when necessary
- allowing sufficient time to listen
- developing a trusting relationship based on honesty and respect
- being positive about the child
- recognising the parents' past and present work with the child
- acknowledging strengths within the family
- acknowledging and facilitating parents' central role in all provision
- not being yet another 'expert' who knows best
- being flexible with contact times to meet working partners and grandparents
- being supportive to siblings
- continually finding out, formally and informally, if the service is useful to families
- guaranteeing real confidentiality to the parents (within child protection legislation)

The keyworker service is time-limited, both to reduce dependency on the service by the family and to enable a realistic caseload for the keyworker. The nature of the service provided is to enable the family to find their feet and access services which will support them in the future.

With some families it is possible to agree a set of clear objectives during the first or second meeting, with others this can take many meetings over several weeks, and with some families it will not happen at all. With these families the general help and support is valued but cannot be crystallised into clear aims to meet specific needs. The keyworker has to be able to adapt to each situation without imposing a preferred structure on the family.

The keyworker model has been used to good effect with families of younger children. For older children, the key element has to be their own views, needs and wants and thus the nature of the partnership between keyworker and family alters.

## **The four phases of support**

It is made clear from the start of a relationship with a family that the service is time-limited and that it will follow the following pattern:

### ***Introductory phase***

The keyworker and family begin to get to know each other and the family learns whether the service is one that they want. The foundations are laid for a trusting relationship and an effective partnership. The keyworker starts learning about the child, about the family and

about what their immediate needs might be. If there is a team of keyworkers available then families might have some choice about which keyworker they have. It is necessary that some families can opt for a female keyworker. It is probable that choice will be very limited and all keyworkers will need to have skills in establishing a trusting relationship very quickly with new families. Because keyworkers will likewise have little choice which families they work with, it is important for keyworkers to be able to form a sincere and effective relationship with families with whom they might have very little in common.

### ***Intensive support phase***

The keyworker visits, usually weekly or fortnightly, to offer support in the way agreed with the family. The intensive phase could last three months, a year, or longer. During times of particularly high levels of need visits can be two or three times a week. A typical session with a family will last in the region of 90 to 100 minutes. When it is necessary, the session can be extended to help during a crisis. Other families who then lose their appointment that day are usually understanding and can appreciate that the same flexibility might benefit them in their time of need.

Clear agreed appointment times and punctuality are very important. This is a part of a respectful relationship. There were occasions when a parent might delay the child's mealtime or another activity so that we could observe it. To be late on these occasions would be very unfair. Parents need phone calls about any changes to arrangements, last minute or otherwise.

During the visit, the focus of attention can change easily between the child, the parent or parents and other family members. When conversation moves from 'active listening' to discussion of any plans of action, there needs to be clear agreement about anything the keyworker commits to doing before the next meeting. A main feature of the sessions during this phase is that the parent has a real need to talk and there are real issues which need discussion. When sessions start to lose this sense of usefulness and purpose it is time to consider moving to the next phase.

### ***Winding down phase***

When the family comes to recognise that their need for this type of support is lessening the intensiveness of the support reduces by negotiation between the keyworker and the family. The criteria for moving into the winding down phase include:

- the parents are starting to 'find their feet' after the initial shock, confusion and fear of the disclosure
- the relevant services are more or less in place for the child and family
- the parents have a sense of where they are going and some confidence in achieving it

### ***Keeping in touch***

The family must know they can initiate contact at any time should they feel the need. Contact through this period may be by telephone or through occasional visits arranged by negotiation between keyworker and the family. During this phase, the family may decide they wish to return to intensive support through periods of crisis or transition.



# **The principles of the keyworker service**

## **1. The helping relationship**

The keyworker operates in very close association with the family at a time when its members are very vulnerable. This can only succeed if the keyworker can develop a relationship based on trust, honesty, respect, and confidentiality. All work with and for the family will succeed only to the extent that this helping relationship has been established.

## **2. Partnership**

The relationship between the keyworker and the family is based on partnership. The keyworker is not there to tell the family what is best for them but to work with them in finding answers to their questions and meeting their needs.

## **3. Parent-led**

The parents dictate the nature of the service they want from their keyworker, within the agreed parameters of the job, and negotiate with their keyworker how and when what they want is carried out. In this manner, the parents have control over the service and can ensure that it is meeting their needs at any given time.

## **4. Home-based**

The service is designed to be offered mostly in the family home to reduce their need to travel and to ensure that the keyworker gets a picture of family life and the family situation. The family home is the place where parents are in control. However, at times when the child is in hospital, the meetings can happen there or at any other venue at the request of the family or suggestion of the keyworker.

## **5. Flexibility**

Through the constant contact with the family and its parent-led nature, the service can respond to the family's changing needs and circumstances. It is likely, for example, that emotional support will be a major need at the beginning of the relationship, or at the time of diagnosis or trauma, but practical support may take precedence later on.

## **6. Time-limited**

One of the aims of the keyworker is to enable the parents to become confident partners with other services and get on with family life. It would be counter-productive to offer a family keyworker support forever. The ending of the service is carried out when the parents feel ready and the manner of the ending - a gradual reduction in intervention for example - is agreed by negotiation between parent and keyworker. With some families the major needs at a particular time can be expressed in terms of specific goals they want to achieve. When they have been helped to achieve these goals the future role of the keyworker can be reassessed.

## **7. Empowering**

Everything the keyworker does must have the dual function of offering support at times of need and helping parents acquire the knowledge and confidence to deal with future issues.

## **8. Positive**

The approach of the keyworker is positive and honest. The keyworker has a role in discussing sensitive issues and this is carried out in a non-patronising manner which, as the keyworker gets to know the family, is relevant and timely to them. Because the keyworker empathises with the parents and is 'on the family's side', a major part of the keyworker's

role is to generate positive attitudes as follows:

**a. valuing parents**

The keyworker openly acknowledges the contribution the parents have already made to the child's well-being and development. Their central role in all future work is acknowledged and valued as is their love for their child. For many parents this can be the first time they feel recognised and valued.

**b. being positive about the child**

It is important for the keyworker to be positive about the child. Many parents say they have not, until this point, heard any professional say anything positive. Many parents are afraid that their child is so disabled that only family members could value him or her.

**c. being positive about the family**

The keyworker can be in a position to encourage professionals to see the parents in a positive light. From the position of knowing the family well such negative judgements as 'non-compliant', 'in denial', 'non-attending', 'overprotective', etc. can be countered with some background and explanation without betraying confidences.

**d. focusing on the child's strengths**

At meetings and in written reports the child should be referred to in positive terms, encouraging others to do so too. It is important to focus on ability rather than disability, on strengths rather than weaknesses.

**9. A whole picture**

Unlike other workers with the child who may specialise in particular areas, the keyworker has a role to maintain a whole picture of the child, of the family and of family life. No child exists in isolation and their welfare is as much dependent on the well-being of the rest of the family as the family's well-being is dependent on that of the child. The keyworker looks at the whole family picture and the child's well-being within that.

**10. Immediate help**

Families deserve support from the first moments when they know or suspect their child might have disabilities. This should not wait for a formal medical diagnosis. Families need support while they are learning about possibilities, waiting for test results or waiting for symptoms to appear. If it should happen that a keyworker has supported a family whose child turns out not to be disabled this is a cause for celebration. The keyworker's time has not been wasted. Also, when a family in turmoil turns to an agency for support they should not be told to wait three weeks, three months or a year. Within the resources of the agency they must be offered some level of support at the time of asking even if full keyworker support is not available at that time.

## **Documentation associated with the model**

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To have effective partnership with parents, it is vital that documentation is developed in such a way that it is accessible to parents, and useful to them as well as to their keyworker. For this reason, very specific means of documenting the work of the keyworker were developed by One Hundred Hours alongside the development of the model:

### **The family file**

Included in the family file are notes dictated after each visit by the keyworker and a record of any communication about the family to or from any other professional involved with the family. This file is held confidentially by the agency. The file is given to the family periodically to read and they have access to it on request. It is otherwise only available to the keyworker and the keyworker's supervisor.

### **The keyworker's logbook**

This is a record of the date, time, duration of each keyworker visit. It also records who else was at each meeting, what type of session it was, where it occurred and a record of agreed action. This is held by the keyworker but known about by the family and available to them should they want to see it at any time.

### **A 'whole-picture book'**

Additionally, parents may want to keep a record of their child and his or her progress, together with any information about services or any other matter that the family wishes to keep a record of. Anyone involved with the child can contribute to it - at the request of the family - and is kept and used however the family wishes. Typically, the whole-picture book may include:

- a list of all people involved with their contact details
- a note of any questions for any forthcoming consultation
- a diary of all significant events
- a list of agreed goals for the child with space for comment to enable any teacher, therapist or family member working with the child on a particular goal-oriented activity to leave a short record of what they had done and how the child had responded.

### **Video tape**

Video can be a very valuable resource. Over the months it shows the child's progress when otherwise it can be hard to discern. It enables teachers and therapists to give the family a visible record of their work with the child and their suggestions for the family to carry out at home and it enables parents to take clear evidence to professionals about the child's activity at home.

Importantly, all documentation is explained to each family at the start of their relationship with their keyworker. The aim is for families to be aware of all information that is being held about them, why it is being held and how they can access it. All the files are kept confidentially and the contents are only shared with others with the full knowledge and consent of the family concerned.

# Examples of keywork in action

## Mini case studies

The following pages give brief details of two families who used the keyworker model and the manner in which it worked for them. These very personal stories give an indication of the different situations in which the model was used successfully. The stories were first published in the One Hundred Hours document *Who supports the parents?* in 1997. We are indebted to the families who contributed. All names have been changed.

### Working with John and his family

#### About John

John's needs are very complex. He has quadriplegic cerebral palsy, he is registered blind, has hydrocephalus and he has naso-gastric tube feeding.

#### John's mum and dad

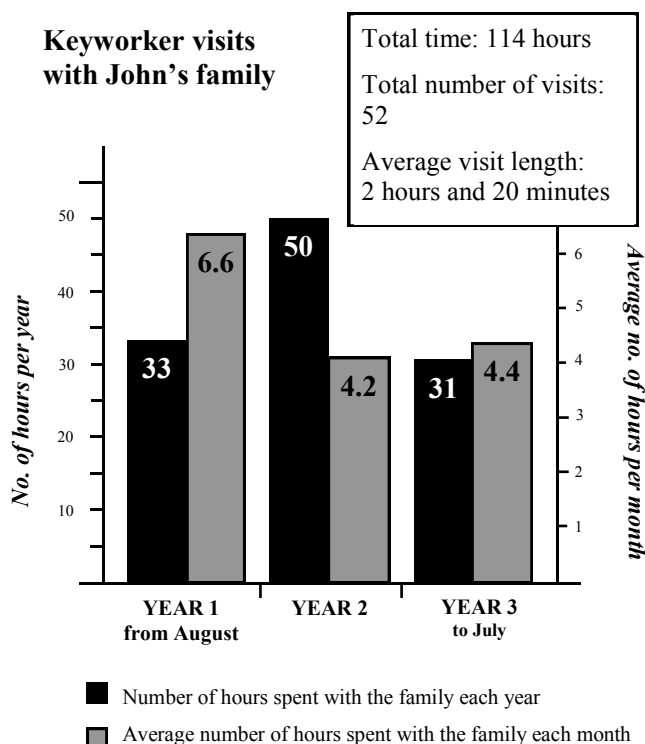
*"We met One Hundred Hours the day we brought John home from the neonatal ward after he had spent five months fighting for his life.*

*"With the help of our keyworker, we started to understand John's problems and our confidence grew. Thanks to all the information and ideas, we became confident partners with other professional services and could articulate John's needs and best interests.*

*"Our main needs are to overcome our 'disability as parents' and discover ways of recharging our limited batteries. We need to maintain our relationship as husband and wife and not lose our self-esteem, confidence and the ability to enjoy our life or the courage to try new challenges. The value of One Hundred Hours is that it helps parents find a way forward using our own strength and the love in the family."*

#### The keyworker service

During the time the One Hundred Hours keyworker visited the family, his role was very flexible and varied. The first few months were traumatic. John was in and out of hospital, the precise nature of his problems were unknown and his parents were getting very little sleep. They wanted emotional support and advocacy to access services. After the first few months, the service became less intense although there were times when it regained some of its initial intensity such as during John's mum's pregnancy with the family's second child and during John's educational statementing process.



## Working with Isobel and her family

### About Isobel

Isobel suffered severe birth asphyxia leading to neurological damage. The following list comprises just some of her regular needs: daily chest physio, an eye patch to prevent further sight loss, regular suction to prevent choking, naso-gastric tube feeding, a nebuliser and an inhaler.

### Isobel's parents

*"We met One Hundred Hours when Isobel was seven weeks old and still in hospital. I was really worried about taking her home for the first time so I phoned One Hundred Hours. Our One Hundred Hours keyworker arranged a visit straight away."*

*"The good thing about One Hundred Hours for us was that it got involved right from the start, before Isobel came home from hospital."*

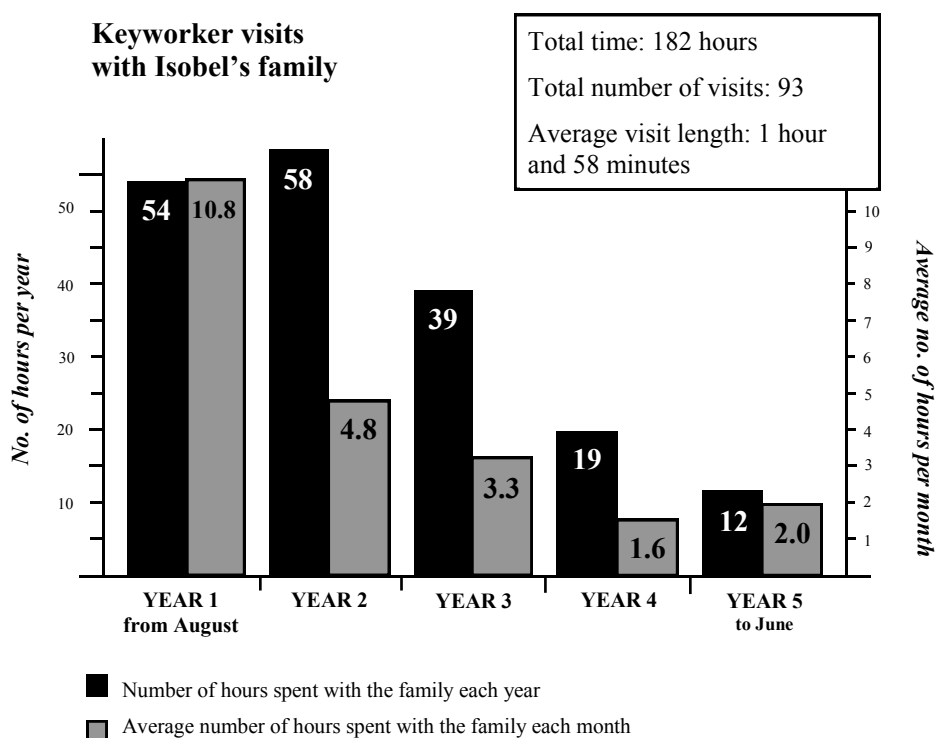
*"What I remember most about the early days is having no sleep, Isobel constantly crying and not knowing if she was still going to be there in the morning. Our keyworker was there a lot - he didn't interfere; he came round and asked us what we wanted. He communicated with all the people involved with Isobel. Knowing that someone was there was a great help. He was a professional but not medical - some of them talk to you as if you are stupid."*

### The keyworker service

Isobel's mum got in touch with One Hundred Hours at the suggestion of the hospital's Liaison Health Visitor. Over the next month, the One Hundred Hours keyworker visited the family regularly at the special care baby unit. He attended a pre-discharge case conference in which a support system was agreed with the family including the GP, the Liaison Health Visitor and the One Hundred Hours keyworker.

The One Hundred Hours input was to be the most intensive of the three, primarily to support Isobel's mum. She was very anxious that Isobel might die once she was at home and very apprehensive about coping with naso-gastric tube-feeding and the suction machine used to keep Isobel's airways clear.

Isobel was four years old and attending school when we were winding down. The keyworker provided support at the time of educational statementing and supported the family at review meetings at the school.



## **Working with Simon & his family: a case study**

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*Sheila West, keyworker with One Hundred Hours*

This is an account of a case study of one keyworker's involvement with a child and his family. It details the keyworker's involvement from her perspective and is an illustration of the One Hundred Hours model in practice. This written account is a combination of information taken from the keyworker's records kept at the time and personal recollections of the keyworker's experiences of working with Simon and his family. All names have been changed to preserve the family's privacy.

### **Referral**

Simon was born at 38 weeks' gestation, the birth being induced due to the mother's pre-eclampsia. A long and unproductive labour resulted in an emergency caesarean. There were no apparent concerns when he was first born then an hour or so later he began to have fits. There followed a series of scans and tests over the next few days and eventually the parents were told that there had been an eight minute lack of oxygen to the brain at birth and that the brain was so damaged that he would not live. Further scans showed that the only part of the brain not damaged was the part controlling the heart and lungs.

Simon was discharged home at three weeks with a naso-gastric tube to enable feeding although he was also being fed orally. The advice given by the hospital was to take Simon home and 'love him for the time he will be with you.' In these early days the family had the support of three consultant paediatricians and the outreach nurse as well as their own GP and health visitor.

The paediatric outreach nurse, based at the hospital, recognised that this was a family that might need more support, particularly emotionally, than she was able to give so she referred the family, after discussing it fully with them, to the One Hundred Hours service when Simon was six weeks old.

### **Introductory phase**

The response from One Hundred Hours was made within a day of the referral by a telephone call to the family and a visit arranged five days later at a time when both parents could be present. This first visit was an information exchange - gathering information about Simon and his family, including other family members such as grandparents - and giving information about the potential involvement I could offer. This included additional, independent support to either parent individually, and the grandparents as well if required.

We acknowledged that they would have a great deal of new experiences, questions and new things to learn about Simon and I would be able to support and help them through this process. I explained that I would also be able to offer them support at the time of his death and afterwards. We agreed the pattern and frequency of visits which, in this case, would be

fortnightly initially with each visit lasting about an hour and a half with the proviso that this could be altered as need (or lack thereof) arose.

## **Intensive support phase**

The focus of the first few visits was dictated by Simon's mother's (Alison's) need for exploration of words and concepts that were new to her. This ranged from terms like brain damage to the role of a physiotherapist and speech and language therapist. I was introduced to key members of the family - both Simon's grandmothers - and we made plans for the way we would manage the introduction of the first new professionals in Simon's life.

We agreed that I would accompany her on visits to the hospital to meet the physiotherapists and occupational therapists and would therefore be able to help take in any information they might be giving her and also be an extra pair of hands - so vital with a small baby with a buggy, car seat, nappies, feeds and a naso-gastric tube. We also agreed that the use of a video during the therapy sessions would be useful to enable Simon's dad (Russell) to know what was happening to Simon: he was unable to attend daytime appointments as he was working.

Also during this time it was becoming apparent that Simon's vision was not functioning as it should. This was not a surprise to the family as they had been given a very honest picture of Simon's likely abilities and difficulties from the outset. I referred the family to the local Service for the Visually Impaired who could carry out play activities with Simon at home to stimulate whatever vision he had. Other information given was of a practical nature - ensuring that the family was in receipt of the Disability Living Allowance and associated benefits and referring them to the Family Fund for additional support for essentials like a washing machine and tumble drier.

During this time I also accompanied Simon and Alison to the consultations with the paediatrician - which often included input from the other therapists working with Simon. Due to the extent of Simon's disabilities, the concentration of their work tended to be promoting good posture and preventing contractures rather than promoting development. These consultations therefore were often a painful experience for his mum as they brought into focus the reality of the prognosis for Simon, and whilst she was well aware of these facts, having to face them in the consulting rooms at the hospital was always a painful and emotional experience. My role therefore was not only to support her during these discussions but also to give her the time and opportunity afterwards to talk about her feelings.

When Simon was four months old, it was proposed that his care be transferred from the hospital team to the community team. This would involve a change in all the medical professionals currently working with Simon and would also involve a full, formal assessment by the new team. These changes in some of the professionals working with Simon would not be the first that the family had experienced as Simon had by this time already had one change of occupational therapist and two changes of physiotherapist. During this next transition I was again able to offer some consistency of care - being the one person who had known Simon and his family since he was six weeks old who was still involved with him on a long-term basis.

Simon was formally assessed at the age of five and a half months – a process that Alison found anxiety-provoking and my role was thus to act as support for her during the assessment and afterwards. She did however feel after it that she had a better and more positive sense that the future for Simon may not be as bleak as she had been led to believe. Each family who is assessed by this Child Development Team has a named keyworker and in this instance I was named as Simon's keyworker.

My involvement over the next few months continued in the pattern described above. I visited regularly to listen to the family - parents and grandparents as well. I continued to use video recordings, both of therapy sessions as well as ones of Simon at home being played with, fed, bathed and sometimes just sleeping. I liaised as much as possible with all the others involved with Simon's care, supported an application for a housing transfer to a house more suited to Simon's needs and referred the family to the social services department for a review of any adaptations to the house that would be needed once the re-housing application was successful. At this time Simon also had a series of hospital admissions - planned and unplanned. The planned stay was for a gastrostomy operation as Simon had not been able to accept a sufficient level of oral feeding to enable him to manage without his naso-gastric tube. Other stays were the result of serious chest infections or bouts of what appeared to be uncontrolled fitting. Apart from the obvious anxiety the family experienced with each of these admissions, it also resulted in some disruptions to the continuity of his care. The community physiotherapist and occupational therapist could only do home visits, and therapy during hospital stays was provided by the hospital-based therapists.

During each of these hospital stays I continued to offer support and contact with the family. My role at this time ranged from discussions with any of the family members (grandmothers included) about their feelings about Simon's prognosis and inevitable early death to being someone who could sit with them during the long anxious days sat by Simon's hospital bedside. Another issue the family had to face at this time was the question of whether they would want the hospital staff to attempt resuscitation procedures should the need arise. Over the ensuing months we were able to discuss this issue at length and this enabled Simon's parents to explore their feelings about this and the decision that they gave to the hospital. It also gave them the opportunity to reconsider the issue at later stages when they felt they wished to change their decision.

By the time Simon achieved his first birthday he had established a more settled routine. He was attending a local playgroup for children with special needs. The family felt that his care from the Child Development Team had become more co-ordinated following a request from the family (with support from myself) for more information about their plans for Simon's care and information about his condition. The pattern of my visits had reduced from weekly to every two or three weeks. The length of each visit was dictated largely by the family but remained at around two hours per session which gave Alison the opportunity to relax into each session and enabled her to raise any issues she wanted to discuss after I had been there for a while rather than having to launch straight into anything that was worrying her as soon as I entered the house. Having enough time to spend on each visit seemed a crucial element at this stage. Longer, less frequent visits were more effective than shorter more frequent visits.

By the time Simon was eighteen months old his periods of good health had become shorter and he was suffering from more frequent chest infections. At that time the family decided that they wanted to find out more about the services that the local children's hospice could



offer them. I had told them of this service twelve months previously but they did not feel the need to use it at that time. By now however, they were feeling that they needed more support than their friends and family could provide and asked if I could carry out the necessary referral.

In the following months, Simon varied between periods of relative good health and periods of crisis - all to do with his recurring and increasingly serious chest infections. During this time I attended clinic appointments with Alison to act as the support she needed to enable her to raise painful issues, such as the question of ventilation and plans for Simon's future care, in the context of a clinic appointment rather than for it to happen when Simon was in crisis in Intensive Care again. My role was also to listen whilst Alison and Russell explored their thoughts on the immediate future. They constantly reconsidered the question of ventilating and resuscitation and wanted to discuss where they would want Simon to die - at home or in hospital - should they have the choice. They were also able to discuss practical issues about the funeral.

In the last two weeks of Simon's life he had two further admissions to hospital and was finally transferred to the hospice three days before he died. This was the family's first time at the hospice as there had not been time to arrange an introductory visit due to Simon's health crises and recurrent hospital admissions. I visited Simon once at the hospice and could see that the family were visibly more relaxed being in the supportive atmosphere of the hospice. However Alison still had a lot of questions about the practicalities of what happens when a child dies whilst at the hospice. I was able to direct her to the staff there to discuss her questions with them as they would be more knowledgeable about these things than I could be.

## **The winding down phase**

My role immediately after Simon died was to offer as much support as possible. Due to the fact that they had had such short contact with the hospice, it was felt by both the family and the staff at the hospice, that I would be in the best position to offer the post-bereavement support. This I continued to do initially through regular visits, which became less frequent as the needs of the family dictated. Of all the professionals involved with Simon's care over the 20 months of his life I was in the unique position of being able to continue to offer support to the family after Simon's death. As someone from outside the family this role was a crucial one in allowing family members to speak about Simon. I was someone who knew him and had shared in so much of his life, but was someone with whom they did not have to be afraid of discussing painful issues.

This role diminished over the months following his death until my contact with them became occasional telephone calls to me should they need to talk. The final contact was a visit to the newest addition to the family, with the birth of Simon's younger brother one year later.

## **An evaluation of the keyworker model**

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One Hundred Hours conducted regular user surveys during its time of work to assess whether the keyworker model was meeting the needs of parents in the manner they wanted.

The results of the final evaluation, conducted in 1999, are given in the following pages as a guide to those setting up similar keyworker services. This was first published by One Hundred Hours as *Listening to parents* in 1999.

One Hundred Hours was fortunate in the openness and honesty of the respondents throughout these surveys and their candid responses have enabled us to learn a great deal about the experience of using a keyworker service.

### **The methodology**

The evaluation was conducted by anonymous postal questionnaire by Gudrun Limbrick-Spencer. Twenty families took part in the survey, each of whom had not taken part in previous formal user-surveys conducted by One Hundred Hours.

Parents were asked a range of questions about issues from their first point of contact with One Hundred Hours, through to their feelings about no longer using the service. To give background information, respondents were also asked about their child, his or her disabilities and the family structure.

### **The quotations**

The bulk of the text on the following pages is in the parents' own words - taken verbatim from the returned questionnaires - and the author's commentary has only been added where strictly necessary. Although this makes for a lengthy report, the aim was to represent parents' views fairly and the only way to do this is to use their own words as completely as possible.

Each family is represented by a letter of the alphabet to enable the linking together of series of quotations. Otherwise, we have removed names and other identifying details. All the children are referred to as being female, all the keyworkers as male.

# Summary of key results

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## About the families involved in this survey

- 1.1 The children were aged between 2 months and 30 months when their families became involved with One Hundred Hours.
- 1.2 The children had a range of complex needs, the most common combination being general developmental delay and learning disability together with feeding and sleeping problems.

## Parents' experiences prior to meeting with One Hundred Hours

- 2.1 Parents talked of this time as being a succession of hospital visits, a time of uncertainty about either diagnosis or prognosis with some frustration experienced in their efforts to reduce this uncertainty.
- 2.2 74% of parents cited grief as one of the most significant emotions they were feeling. Other emotions cited included sadness, anger, frustration and guilt. One family also cited happiness.
- 2.3 Of this time parents said they felt:
  - isolated with no-one listening to them
  - lost as to which way to turn
  - as if their whole world had caved in
  - fearful
  - depressed and desperate
  - it was a very traumatic time
  - they were heading for a breakdown
  - they were facing an uphill struggle
  - unsure about how they would cope

## The care of the family

- 3.1 25% gave their immediate families as being significantly involved in care. The most frequently cited professional involved was the hospital doctor - listed by 95% of families. This reflects the fact that most families were in and out of hospital with their child at the time of meeting One Hundred Hours.
- 3.2 Families felt they were not being supported by the professionals involved in the care and treatment of their child because the professionals did not have appropriate expertise (in particular syndromes and conditions) or they did not have time to offer support. Others felt that nothing really 'kicked in' until after diagnosis had been confirmed.
- 3.3 Other comments were that:
  - parents felt the atmosphere in which professionals worked was alien to them
  - parents lacked confidence to talk with professionals

there were meetings which parents weren't allowed to attend  
parents had to keep repeating things to different professionals  
professionals worked separately, each from their own point of view  
parents were treated as nurses rather than parents  
parents became tied up in bureaucracy with everything moving too slowly  
no formal intervention was available between appointments

### **Using the One Hundred Hours model of service**

- 4.1 In those initial days, parents wanted from One Hundred Hours:
  - emotional support for themselves
  - advice about care
  - someone 'on their side'
  - someone to explain things in a clear and appropriate way
  - someone with whom they could be honest and open about their feelings
  - information about other services
  - support in communicating effectively with professionals
  - time to talk with someone who would listen.
- 4.2 All the families in the survey, except one who felt that they were already receiving enough support elsewhere and another who used the service for only a short time as they felt their lives were already too busy, used the One Hundred Hours service.
- 4.3 78% of the families who used the service felt that they used mostly the elements of emotional support and accessing or linking other services. Parents wanted both support for themselves and effective services for their children.
- 4.4 Parents gave their experiences of what the One Hundred Hours model of service actually meant to them in practical terms:
  - someone to listen
  - information about services, care
  - information about their child's disability
  - more effective links between professionals
  - a positive view of their child
  - practical help (such as visits to appointments)
  - developing confidence of the parents
  - home visits
  - looking to the future
- 4.5 In general terms, parents saw this as making a difference to them in the following ways:
  - getting the most out of existing services
  - accessing other services, statutory or voluntary
  - greater understanding of their child's disabilities

a greater ability to cope  
feeling stronger and more confident

Two families felt that they would have been able to come to this point on their own, albeit at perhaps a slower pace.

### **A time-limited and flexible service**

- 5.1 44% of the families, at the time of the survey, were still using the One Hundred Hours service having used it for between five and 42 months - an average of 20 months. Of the remaining families with whom One Hundred Hours no longer worked, the service had lasted an average of 12 months - ranging between 3 months and 2 years.
- 5.2 Families talked of experiencing the service change over time as their needs changed.
- 5.3 Families who stopped using the service, because they were now coping fine alone and/or had now moved onto different service, such as Portage or school, spoke of appreciating the knowledge that they could contact the service at any time in the future if they felt the need.

### **Accessing the service**

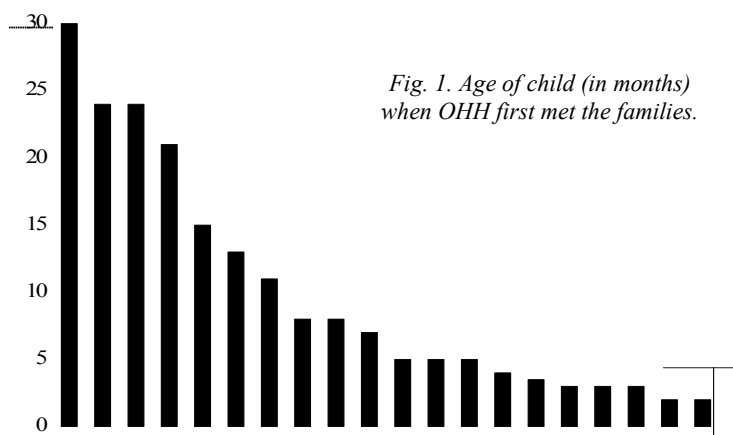
- 6.1 A major theme running through parents' responses is that they wanted to find out about the service earlier and wanted this link to come from the hospital where their child was undergoing tests or receiving treatment. 35% had heard about the service in ways unconnected with the hospital, and in ways which could be considered a matter of chance - from friends, family, other charities and leaflets distributed by One Hundred Hours.
- 6.2 56% of the parents associated their ideal time for hearing about the service with the time at which the diagnosis was confirmed. On average families heard about the service 7 months after this time and 44% were aware of their child's problems at least a month (and as much as a year) before confirmation of diagnosis.
- 6.3 All families found their initial contact with One Hundred Hours, whether they were talking about the first phone call or the first visit, very useful telling them all they needed to know about the service at that time.

### **The last word**

- 7.1 Aspects of the service particularly appreciated by families:
  - bridging the gap left by other services
  - a positive approach
  - a non-medical approach
  - independence
  - home visits
  - understanding and listening
  - involving the whole family
  - linking other services

## About the families

### How old were the children?



The children were an average of 10 months old at the time of becoming involved with One Hundred Hours.

### The nature of the disabilities

The children each had an average of four of the following:

cerebral palsy	deafness or hearing impairment
autism	sleeping problems
feeding problems	breathing problems
blindness or visual impairment	genetic syndrome (including Larsens, DiGeorges, Pallister Killion, Krabbe, Retts and Edwards).
general developmental delay	
microcephaly	
hydrocephalus	
learning disability	

In addition to the above, eight of the children also had one or more of the following: Agenesis of the Corpus Callosum, hyperactivity, epilepsy, inability to speak, Downs Syndrome, under-developed nervous system, digestive, urinary and bowel problems, astrocytoma, quadriparesis, recurrent apnoeas, oxygen dependency.

Three of the children did not have a diagnosis.

### Who is in the family home?

In all but two of the families, both parents are at home. In six families there are no other children. The remaining 14 families have between one and four other children.

## What was it like in those early days?

*She had a diagnosis but didn't know how she'd be because there's different degrees and problems (C)*

*Completely isolated. No diagnosis. In and out of hospital. Felt no-one was listening. Needed someone to help us sort through it (S)*

*My child was diagnosed at 9 months. But I felt the hospital could have been more truthful much earlier on (E)*

*Brain damage was always mentioned and being observed. [Our child] was in hospital for 5 weeks. She had feeding difficulties (F)*

*[Our child] was diagnosed with DiGeorges at about 6 weeks old. She was seriously ill and waiting for major heart surgery. We were told she might not survive and if she did, she may not walk, talk or be able to do anything for herself. Nobody seemed to know anything about the syndrome (G)*

*Baby diagnosed after routine scan. Confirmed at 19 weeks pregnancy. At 25 weeks spoke to surgeon about shunt and epilepsy. [Our child] was diagnosed hydrocephalus but mother's intuition was that she had other problems. I gave details of these to obstetrician and neonatal doctors. No-one believes you but I was proved right after much testing (N)*

*[Our child] was first diagnosed a failure to thrive until we sought a second opinion (P)*

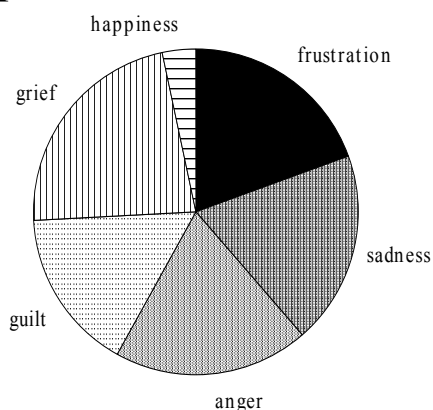
*We have had an uphill struggle with a lot of issues and we feel as a family you are discriminated against for having a disabled child who is young and times are stressful enough - it just makes you very angry and frustrated especially when other families seem to have no problems in this area (B)*

*We did not receive a diagnosis until about one year old. Our child spent a lot of time in and out of hospital the first year and a half and a lot of outpatient visits. We were lost as to which way to turn (B)*

## Existing support

### How did parents feel?

Fig. 2. Emotions cited by parents



Parents were asked to indicate the emotions they were feeling prior to meeting One Hundred Hours. Grief was the most frequently recurring emotion.

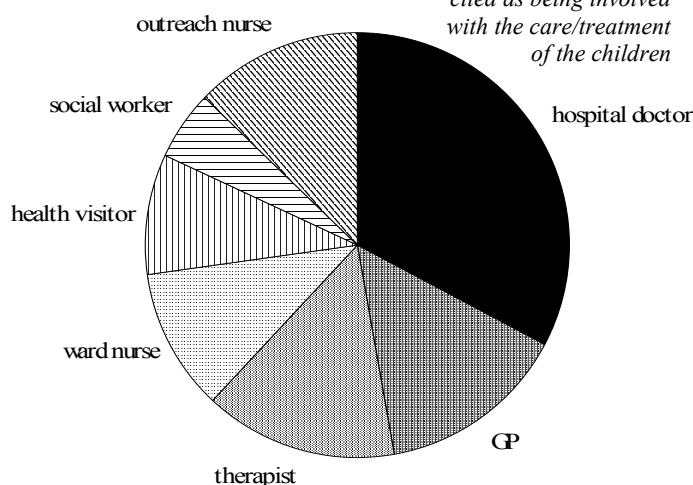
Other emotions cited were 'fear', 'isolation', 'depressed, confused, mixed up'. One family said, 'We just took things as they were and dealt with problems'.

### Workers involved with the families

Five families (25%) gave members of their immediate family as being significantly involved, two families gave another parent as significant.

Families found an average of just under three professionals were involved with the care/treatment of their child, a hospital doctor was most frequently mentioned, the health visitor most infrequently. One family had a very supportive home help. None of the families were involved with any charitable or voluntary organisations.

Fig. 3 Professionals cited as being involved with the care/treatment of the children



When asked which of these were offering the parents support for themselves, 58% said they were offered none from the professionals listed above. A further 26% said they were offered a little support for themselves but it was not enough. Some families chose to specify which people had offered them support: 'GP', 'Outreach nurse', 'We had tremendous help from GP', 'Outreach nurse and therapist', 'Doctors and nurses of neonatal ward, midwives'.

### Why did parents feel they were not being supported by those already involved?

*The outreach nurse was excellent but we were not her first concern (R)*

*All of them offered us support although we felt they didn't have the expertise to meet our specific needs (M)*

*Doctors and nursing staff want to help but do not have enough time (N)*

*I think your run-of-the-mill health visitor would not be able to deal adequately with the situation, never mind give you support (N)*

*Everybody was very supportive but they did*

*not have enough time to go through with us all the things that we've gone through (A)*

*Outreach offered me no support at first - they were frightened of [our child] and did not want to know about me at all. I complained and got a different outreach nurse. She is excellent. She told me about One Hundred Hours (G)*

*From referral to diagnosis took many months and we were left in limbo. Nothing really kicked in until after diagnosis (L)*

## Unmet need

### What did parents want from One Hundred Hours?

Parents were not asking for the earth.

- Someone who was there for us (A)*
- Support and any advice towards the best care for our child (B)*
- Just somebody to help me and understand I wasn't sure how to cope or how hard it was going to be (C)*
- Some advice (D)*
- Somebody to explain things so that I understood (E)*
- To help [our daughter] learn to do things like normal children could do ie grab toys, play, sit (F)*
- To know what was on offer for [our daughter] but mainly to talk to somebody about how I felt and to let off steam - I needed somebody to encourage me to go on as I felt my whole world had caved in (G)*
- Someone to talk to and to be there and to help us with various obstacles with the medical profession (H)*
- Information and support (I)*
- I wanted to begin to give my child some positive help aided by people who understood how I could do that (L)*
- Support, understanding, advice with experience with disabled babies and their families and someone who was not too close (M)*
- To have talks about fear. A friend who understood what I was going through, who would be there for me to moan at or cry or laugh with, but would not be giving me new drug times or asking about weight gain (N)*
- Somebody to listen to ourselves and not dismiss our worries and somebody to help us get the doctors to listen to ourselves (O)*
- Specialist support for a baby with special needs. Help was available but not particularly for babies (P)*
- Support and having someone to talk to. There didn't seem to be anyone else that would visit, help with my daughter and talk things through (Q)*
- Just a listener (R)*
- Someone to talk to and help us with all the hospital assessments. Someone for our family and who weren't attached to the hospital. Someone on our side (S)*
- Help and advice (T)*

### Did One Hundred Hours offer what parents wanted?

All the families but one chose to use the One Hundred Hours service at the time it was offered. One family felt that they were already receiving enough support elsewhere but felt they could contact One Hundred Hours again in the future if need be.

One family chose to use the service only briefly, disappointingly for the very reason that we would have wanted to offer support:

*When the keyworker came I had that many therapists coming to see [my child] - too much going off for One Hundred Hours to get involved at the time...My contact was only one, maybe two visits from One Hundred Hours because there was too much going off...Seemed very supportive and was genuinely concerned and put no pressure on me to keep contact (C)*



# Services offered

## The take-up of elements of the service

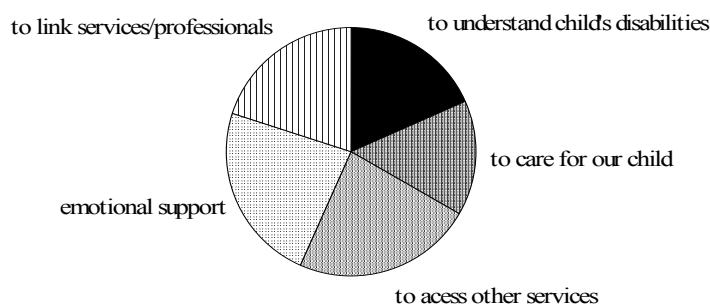


Fig. 4. The take-up of different elements of what One Hundred Hours could offer:

One Hundred Hours offered a very flexible service, recognising that each family's situation and needs would be different. The most frequently used elements of the service were emotional support and accessing other services (taken up by 78%). Of course, all elements of the service are linked and take-up varied over time with each family.

## In what specific ways did families experience the service?

*Home visits, listening ear, lots of information, practical ideas, books to read, mediating to help communicate with the professionals, emotional and practical support (A)*

*A better understanding of disability (E)*

*Teaching us to teach [our child] (F)*

*[Our keyworker] made me look at the good things [our daughter] was doing and not at what she had not yet achieved. Mainly support for myself as my husband works 16 hours day, 5 days a week. So I was on my own a lot with another 9 year old that also needed my attention and affection (G)*

*Support and practical help in finding out about our daughter's condition (H)*

*It gave me the confidence to deal with the professionals (eg paediatrician) and tell them what we as a family wanted (I)*

*Advice, practical support - it enabled us to begin taking some action to prepare for the future (L)*

*A listening ear, experience, advice (M)*

*Helped me to get bulk shopping, also trailed me to appointments - I do not have a car. A friend. An unbiased opinion. Getting all the professionals together to talk rather than everyone working separately from their own points of view (N)*

*Somebody that was there to listen to us, discuss our fears and worries, to co-ordinate hospital visits and represent us in meetings we weren't allowed to attend (O)*

*I had someone to sit and talk to me about things that were worrying me about my daughter (Q)*

*Support, advice on play and care. Someone to talk to about your feelings (P)*

*A listening service and practical help (R)*

*Accompanied me to assessments and hospital appointments. Support, information, gave us confidence, shoulder to cry on, friendship, trust in somebody. He was just there when we needed him and we didn't have to repeat things (S)*

*Help and advice (T)*

## **What difference did the service make?**

*We have survived and become confident partners of the professionals. We could start a new life - new home, new baby (A)*

*It would have taken a lot longer to understand problems (E)*

*We were more informed of brain damage and better able to understand [our child's] problems (F)*

*I can honestly say I would have had a breakdown without One Hundred Hours - they have given me so much to believe in with [our daughter]. They have told and shown me how to enjoy [our child] as her mother and not a nurse. [Our child] has come on so well, being introduced to OT, physio and speech therapy all through One Hundred Hours. Now they are helping me with assessments at [the CDU] and schooling needs (G)*

*We felt we could turn to One Hundred Hours at any time. We felt able to cope and to move on. Without One Hundred Hours I don't know where this kind of support would have come from. There isn't a local Downs syndrome support group - we have since set up our own because we now feel stronger (H)*

*I think I would have continued to find myself tied up in bureaucracy where everything moved far too slowly. Part of accepting your child's problems is being able to move on and build the right future for them (L)*

*I would have gone nuts. Everyone comes by appointment. [My keyworker] came when he was needed (within reason). To know there was someone on the end of the phone (N)*

*It changed [our child's] and our lives. Doctors stood up and took notice of us. [Our child] had an assessment. Other agencies working with our family were co-ordinated so we were all aiming for the same goals. We wouldn't be at this stage with [our daughter], as far down the road as we are, and as parents we would have been a lot more stressed out (O)*

*An enormous help. It helped me to gain my confidence back which had been lost when our daughter was on the ward and diagnosed as a failure to thrive. I was able to talk through my feelings and feel normal for having them. Both sets of parents live away so I had no-one to talk to. We also had no experience of disability before (P)*

*One Hundred Hours helped me through a grieving period and allowed me to cry and be selfish. I did not feel I had to pull myself together or pretend I was coping (R)*

*It made every difference to my family. I wouldn't have been able to continue without One Hundred Hours' support. We can sound our concerns with our keyworker, ask if I'm wrong about my approach to doctors. He helps me to get the best out of the hospital for my child and the way we would like it. The hospital doesn't always like it! Without One Hundred Hours we would have lost our way and I would have had real emotional problems with how the hospital was treating us. A LIFESAVER (S)*

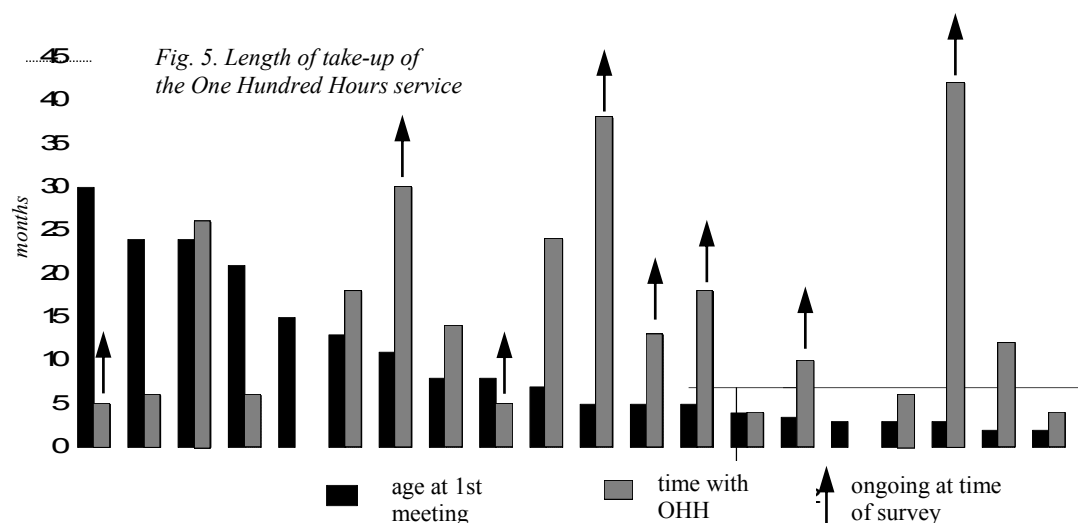
*One Hundred Hours helped us to see the wood from the trees (T)*

Two families gave responses which fully acknowledged their own resourcefulness:

*I don't think things would have been any different. We would still have got the information eventually but it would have taken us longer and it would have been more frustrating (I)*

*It's hard to know what difference it has made. We are quite resourceful people and would have and do sort out help as we need it (M)*

## A time-limited service



### Why stop using the service?

No service can support families for ever, nor would families want that. The aim of One Hundred Hours was to support families for as long as they wanted it and, in doing so, to help parents develop the infrastructure they needed for the future - by co-ordinating existing services, and helping access new services. As one parent said *'I feel I am steadily coping with our situation and can see I shall soon feel I no longer need One Hundred Hours'* (R)

Six parents said they no longer needed the service as they were managing fine alone. One family adding *'we will only manage knowing [our keyworker] is there on the other end of the phone if we need him, as he says he is'* (O)

Another family felt that there was now *'nothing to ask'* (D), another *'our child moved onto portage and then school'* (F), and *'not through any unhappiness with One Hundred Hours, we got our child into a school with the necessary support'* (O).

One family said they no longer needed the service because their child died. Others felt they still wanted support after their bereavement. The family in this survey who have been involved with One Hundred Hours the longest, lost their child some time ago but their keyworker continued to visit and did so as long as they wanted support.

### A flexible service

During the time of working with One Hundred Hours, families and their circumstances will inevitably change. The service taken up will also change accordingly. Families in this survey were asked if the service had changed and, if so, how. Five families said they had noticed a change:

*Just because our needs changed* (A)

*We know each other. My child looks forward to his visit and will happily go to him. I know his advice is genuine. He is bringing together the hospital services. Before, on our initial visits we had to get to know and trust each other.*

*Now I ring him if I have had a particularly bad day* (S)

*It has changed for me - I do not need so much emotional support - more as a go-between for [the child development unit] and what is available as our daughter gets older* (G)

*I no longer need as much support as I did. I've done a bit of personal development. I've made a friend in [my keyworker] and enjoy his company and humour* (N)

*Yes, our keyworker does not come every week now* (P)

## Accessing the service

### Views on finding out about One Hundred Hours

Parents were asked for ways in which the service they received from One Hundred Hours could be improved. 47% of the families who had used the service chose to bring up the issue of finding out about One Hundred Hours, several of them repeating comments they had made about this earlier in the questionnaire (see the last column of the table on the following page).

*I would like One Hundred Hours service to be offered to all parents of ill children, straight from birth. One Hundred Hours should be publicised more - in clinics, at doctors', on children's wards and in ICUs. I went through all these and nobody offered me the service - but a lot of these were aware of One Hundred Hours (G)*

*Perhaps leaflets could be made available at hospitals (maybe they are but the staff were untrained to deal with our situation) (H)*

*It should be offered to all families at the very beginning of their concern over their child. This would help avoid the terrible and often prolonged feeling of helplessness. You do not need a diagnosis to begin helping a child who has problems (L)*

*We would have liked to have heard about the service earlier (M)*

*Information packs about the service in hospitals (M)*

*The only thing I would want to change is the time it took us to hear about the service (O)*

*Just try and get the professionals to tell us about you and your services much sooner (O)*

*I would have liked to have heard about and been offered the services of One Hundred Hours on the ward (P)*

*Would have liked to have heard about One Hundred Hours earlier. Include all paediatricians in giving out literature. Not just neonatal staff and child development teams. I have only had a developmentalist attached to us for 6 months. My neurologist had never heard of One Hundred Hours when I mentioned my keyworker (S)*

As can be seen in the following table, there was considerable concern from families that One Hundred Hours should have been made available to them much earlier - most selecting the time of confirmation of diagnosis as the ideal time. Parents also stressed strongly that they want families to have the reassurance of hearing about it from the hospital rather than the more unreliable methods of hearing about it such as through friends, family and other organisations with whom they may or may not have contact.

Fig. 6. Finding out about One Hundred Hours

	<b>AGE AT DIAGNOSIS</b>	<b>AGE AT PARENTS' SUSPICIONS (if before diagnosis)</b>	<b>WHEN (child's age) &amp; HOW DID YOU HEAR ABOUT OHH?</b>	<b>WHEN (child's age) &amp; HOW WOULD YOU HAVE LIKED TO HAVE BEEN TOLD ABOUT OHH?</b>
A	<i>soon after birth</i>		<i>5 months from a nurse and doctors at the hospital</i>	<i>it was ideal for us because the help was available when we most needed it. But I also wish that we had had [our keyworker] when we were first told about our child's severe condition It should be available soon after the first diagnosis - to be able to talk (to cry) to somebody who is not from the medical staff</i>
B	<i>as soon as born</i>		<i>few months through the paediatric consultant in the hospital</i>	<i>heard about One Hundred Hours at the right time</i>
C	<i>at birth</i>	<i>at the same time</i>	<i>few months - 'Contact a Family'</i>	<i>via the hospital from neonatal - hospital should inform parents what help is out there</i>
D	<i>8 months</i>	<i>6 weeks before</i>	<i>2 years - from therapist who came out to see my child</i>	<i>1 year old</i>
E	<i>6 months</i>	<i>4 months before</i>	<i>2 years old - from Mencap Nursery</i>	<i>2 months old - on diagnosis</i>
F	<i>at birth</i>		<i>2 months old - from the outreach nurse</i>	<i>this was fine</i>
G	<i>6 weeks</i>	<i>from birth</i>	<i>5 months old - from the outreach nurse</i>	<i>6 weeks old - when she was first diagnosed. In the ICU when [our child] was born</i>
H	<i>1 day</i>		<i>2 months old - from the health visitor</i>	<i>a few days old - in the hospital shortly after being informed that our daughter had downs syndrome</i>
I	<i>at birth</i>		<i>13 months old - through another family</i>	<i>6 months old - from the paediatrician</i>
J	<i>5 months</i>		<i>7 months old - from the hospital</i>	
K	<i>13 months</i>		<i>15 months - from a friend of a friend</i>	<i>this was fine</i>
L	<i>8 months</i>	<i>2 months before</i>	<i>21 months from the hospital speech &amp; language service</i>	<i>8 months from [hospital] at first point of concern for our daughter - some 11 months earlier</i>
M	<i>during pregnancy</i>		<i>3 months - a child whose child has similar disabilities to ours</i>	<i>from hospital staff when diagnosis was confirmed</i>
N	<i>19th week of pregnancy</i>	<i>9 weeks before</i>	<i>3 months old - I saw a leaflet on the neonatal ward</i>	<i>at 19 weeks of pregnancy - from consultants, nursing staff, health visitor, professionals dealing with children. It would have been better to have been offered this support immediately from diagnosis as you are either given a choice of abortion or cope single handed. No-one in obstetrics/doctor or midwives told me that you got any help at all - OHH or OT or physio</i>
O	<i>2 years and 3 months</i>	<i>a year before</i>	<i>2 years old - from a leaflet given me by the outreach nurse</i>	<i>9 months - same way or via someone in the hospital but I would have liked it a year and a half earlier.</i>
P	<i>9 weeks</i>	<i>7 weeks earlier</i>	<i>8 months - from the CDC</i>	<i>on the ward when our daughter's condition was diagnosed</i>
Q	<i>1 month</i>		<i>8 months - from the health visitor</i>	
R	<i>2 hours old</i>		<i>3 months old - through our outreach care nurse</i>	<i>just right</i>
S	<i>2 months old</i>	<i>when she was 4 days old</i>	<i>5 months - through outreach nurse</i>	<i>4 days - when we were first told of her problems. Ideally on the ward when you really need somebody</i>
T	<i>from birth</i>		<i>two and a half years old - from a leaflet</i>	<i>when born</i>

## **Aspects of the service particularly appreciated**

(arranged under headings for convenience)

### **Bridging the gap**

*Does much to fill the void of support that most parents meet when they and their child leave hospital. This support is essential if parents are to fulfil their own and their child's potential under inevitably difficult circumstances (A)*

### **A positive approach**

*I could ask One Hundred Hours anything and they would always look into things for me. [Our keyworker] was very good and made me feel comfortable to be able to say exactly how I felt. I could say things to him that I could not say to anybody else and he did not judge me for all the bad things I felt and said, but instead supported me and explained why I felt like I did and said my feelings were normal (G)*

*Keeping track of [our child's] progress - written/video (F)*

*The very calm way in which our keyworker helped us - making us feel that our situation wasn't as grim as the medical profession first led us to believe - by being positive, offering to write letters on our behalf, attend meetings with us, providing literature and telephone numbers (H)*

### **A non-medical service**

*Somebody is there just to talk to not necessarily about medical matters. Somebody to talk to about the little problems that are at the back of your mind (I)*

*Someone else rather than a hospital worker who talks to you as a person/parent rather than a medical book (E)*

*One Hundred Hours is not specifically a medical service so is available solely to listen and help you as a parent. It is the only service I know of that functions specifically for the parent (R)*

### **An independent service**

*Not attached to hospital/social services. There for you and not just your child. Does not judge you in any way. Listens and talks to you without being patronising. Does not make you uncomfortable or doubt that you know what your child's needs are. Supports you all the time but will discuss your concerns logically (S)*

*They do not work for any particular department, they are not therefore confined to red tape. They work with you, for you. They argue for you when you are too mentally exhausted to do it yourself. If One Hundred Hours worked for NHS or other organisation, the service would be limited to what the organisation felt that you needed and could afford. One Hundred Hours works on the basis that you decide what you need and they will do their best to meet those needs no matter how bizarre or diverse the needs are (N)*

## **Home visits**

*Almost uniquely this support is carried out in the family's home and not in the alien atmosphere of the professionals (A)*

*Every meeting was at our convenience (H)*

## **Understanding and listening**

*The support, being there for us at any time in person or by phone (O)*

*I used to be quiet and shy when my keyworker first visited but then I started talking about my daughter. My keyworker helped by talking back, being understanding, helping with feeding and position (Q)*

*Someone to ask who knows what you are talking about (D)*

*We liked the calm manner in which our keyworker presented himself. We felt as though we were not alone (M)*

*It was practical and dealt with us in a direct manner. The medical professionals had 'pussy footed' around and weren't entirely honest (L)*

## **Involving the whole family**

*Just being able to sit and chat and talk about your feelings and how to cope in certain situations. Getting encouragement for what you do. Being able to have evening meetings so my husband can join in too (P)*

## **Linking other services**

*I found that it is a key link between Health Authority, services and the parents, eg when I was focusing on getting [our child] well, my keyworker was letter writing, arranging appointments, easing the pressure off me and supporting me all the way! (T)*

*One Hundred Hours' service was able to bring all the different professionals together and was able to point us in the right direction for any help or advice needed (B)*

## Lessons from this evaluation

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The final evaluation of the One Hundred Hours keyworker model by the parents who used it gives a very clear indication of the expectations and needs of families:

- parents talked of a great need for support at a time when emotions were high, even the immediate future was uncertain and when they were faced with a succession of hospital visits. For some parents, this had been the case for many months prior to getting their keyworker
- despite the intervention of a number of people, parents felt unsupported - largely because those who were involved did not have the necessary time or expertise to help
- parents wanted somebody 'on their side', to aid understanding and with whom they could talk with openly and honestly
- they wanted this person to:
  - aid understanding
  - be a listening ear
  - be an advocate with existing services and represent or support the families in meetings
  - link services together
  - co-ordinate services
- parents stressed the following as being important:
  - involving the whole family (including having evening meetings so that a working parent can attend)
  - accessibility - being able to phone at times of need
  - a service that changes and evolves in line with the family's changing needs
  - a service that ends when the family is ready for it to end
  - a positive and honest approach
  - a non-medical focus
  - independence - the keyworker is detached from other services and can thus advocate effectively
  - visits in the family home
- a key factor in the parents' eyes was that the keyworker service should be offered to parents at the time of their initial concerns or at the time of formal diagnosis, whichever is earlier. This warrants a service that is accessible through the hospital as well as through the community



## **Implications for service development**

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The One Hundred Hours experience of providing a keyworker service to families of children with disabilities throughout the 1990s has led to the development of clear recommendations for the development of other keyworker services. This practical development of knowledge has been supplemented through the Handsel Trust's work, such as the UK research project published as *Parents' Support Needs* and through talking to parents through the *Speaking Up* workshops on keyworking.

### **Who can be a keyworker?**

#### **Relevant professional qualification**

The One Hundred Hours keyworkers came from a range of professional backgrounds - including special needs education, nursing and social work. The precise nature of the professional qualifications seemed less important than the general skills this gave them and the credibility it commanded with other service providers.

#### **Experience**

The ideal experience is in disability and family life, both of which are important in generating understanding of a family's situation.

#### **Empathy with parents**

Families do not expect all workers to be immediately knowledgeable about every disability and every situation but the keyworker role does demand an ability to empathise with families, think oneself into their situation and appreciate the implications for the family.

#### **Counselling skills**

While formal counselling is not necessary, the skills will enable effective emotional support are a fundamental part of the role. Emotional support for the family, while perhaps most important at the very beginning of the keyworker relationship, is a constant thread running through the relationship.

#### **Knowledge of service provision**

Supporting families in accessing services and co-ordinating those services warrants a degree of knowledge about the types of services available and their structure. While very local knowledge can be gained during the course of the work, a general knowledge about relevant services is important. An ability to work well with the personnel of other services, and work well with them in what may be sensitive situations, is equally important.

### **Supporting keyworkers**

The role of keyworker is a very demanding one, emotionally and in terms of practical caseload management. While effective training, management and supervision are essential, the initial skills, experience and personal attributes of the individual will also be a key factor

in determining their success as a keyworker.

One Hundred Hours found that proper support for keyworkers was essential, and a necessary component of this support was a regular opportunity to off-load. Support was either in group sessions to cover general issues or in one-to-one sessions with the keyworker manager to discuss issues relating to particular families.

## **When should a keyworker begin working with a family?**

Parents frequently cite a 'gap' in the provision of services. This may be at the time at which the parents recognise there are problems but a diagnosis has not yet taken place, or shortly after diagnosis before required services have started. These are times of emotional upheaval for the family and yet they report the double problem of having no emotional support for themselves and the concern of having a delay in services for their child.

For this reason, referral to the keyworker service needs to happen at one of two key points. The first is through the paediatric wards and child development units of hospitals, the second is through the health visitor. In the experience of One Hundred Hours, this would have caught the majority of the families at the time at which they wanted support. Other families may also be picked up by outreach nursing services, therapists and nursery or teaching staff, depending on the child's age.

However, this requires a degree of communication which is not always easy. A letter introducing key staff to the keyworker service is not always sufficient. There can be misunderstandings about the nature of the service and appropriate families and a feeling that the keyworker service is an attempt to undermine or replicate the role of other service providers and practitioners. To explain fully the links between the keyworker and the other services and to develop an understanding of the importance of early referral, regular face-to-face meetings and other communication is needed with key personnel.

This is not simply because the concept of the keyworker is a new one, early referral from one service to another can be a problem. This may be because of a lack of understanding about the roles of other services and individuals or an absence of agreement about appropriate referrals.

## **Referral to a keyworker service**

In the One Hundred Hours way of working, the most significant manner of referral was self-referral. The family was typically, told about the keyworker service by a worker in the hospital or the community, or by another family using the service and the family could then decide whether and when to make contact. This put the family in control and did not make the keyworker service into yet another service the parents were waiting to hear from.

Once contact had been made and there had been an initial explanatory telephone conversation with the family, the person designated as their potential keyworker made contact as soon as possible and arranged a first visit. This visit, whether carried out by the

keyworker on their own or with the keyworker manager, was a further explanatory exercise in which the service was described and the parents could ask any questions. The parents were then given the opportunity to consider whether they wanted to take up the service and what they wanted from it and could then contact their keyworker to arrange further visits.

## **The independence of the keyworker**

The question of the independence of the keyworker is not an easy one. In One Hundred Hours, the keyworker was an entirely independent worker as his or her post was managed and funded by an independent organisation. However, the impetus for most keyworker services comes from existing bodies - whether they be within health, social services or education and, similarly, that is where the sources of funding exist.

The importance of independence comes primarily from the need for the keyworker to be able to act as an advocate. With the keyworker being from within, or allied to, one of the services to which it is also acting as an advocate on behalf of a family, the loyalties can be divided and roles confused. The keyworker can find themselves in a very difficult position right in the middle of the two.

The perception of independence to the family is equally important as parents may want to let off steam about specific services or individuals and may find their ability to do so compromised if they don't feel that the listener is entirely objective or that what they are saying may be taken as a complaint or may get back to the subject of their frustration and thus effect future service delivery.

Of course, independence, as well as the practical problems of having a base and funding for the keyworker service, has other problems. Without being allied to established services, the job of making the service known to all players and getting its credibility accepted, can be more difficult.

In the interests of providing the best possible service to families, independence is an ideal to which we should aspire. However, some localities may not have this luxury. In this instance, every effort must be taken to enable effective advocacy to take place without compromising the role of the keyworker or the interests of the family and to reassure the family that they can talk freely and that the service is confidential.

## **Dedicated keyworkers**

The One Hundred Hours keyworkers were dedicated in that they did not combine a keyworking role with another professional role for the same agency. There are many keyworking projects now in which the keyworkers belong to a statutory agency and in which the keyworking role is tacked onto a main role as therapist, paediatrician, social worker, etc. In our experience this approach results in too much pressure on the professional and too little time for the keyworking role. All attempts to support families are to be valued but the One Hundred Hours model of independent and dedicated keyworkers is the most effective.

## **Can there be keyworking without a keyworker?**

The idea has been mooted that a keyworker service can be less focused on the individual keyworker than is the case in the One Hundred Hours model. To this end, the keyworker service would be provided by a team of people who could take on the role. The family could then access the team for support and not necessarily be linked to one specific individual. The advantage of this is that the service is less dependent on the family and their specific individual keyworker developing a good relationship and likewise less dependent on that keyworker not leaving their post during the time of keyworking - which could be a period of years.

The disadvantage is that the family and keyworker do not have the opportunity to develop the close relationship which is so necessary if true trust and respect is to develop enabling genuine emotional support to take place. It also means that the family has to explain their situation over and over again to new people each time of meeting. One of the elements of the keyworker service so appreciated by families in the evaluations is that the keyworker is a constant figure in a field where there are many changing players and the keyworker is thus able to develop a whole and long-term picture of the family while others can perhaps only develop 'snapshots'.

## **The keyworker caseload**

We have often been asked how many families one keyworker can support. All families on the keyworker's case load will have different needs and need different levels of support at different times. The keyworker will be offering some families intensive support while just maintaining contact with others. Some families will be in turmoil, others will be more settled. Our best estimate is that a full time keyworker could support around 20 families during a year, offering emotional support, information, advocacy and service co-ordination.

## **A multi-agency infrastructure**

We have also shown how service co-ordination can be one of the family's major needs. The keyworker can help co-ordinate services in localities where there is no formal service co-ordination only as far as the other professionals want to collaborate with the keyworker and with each other. If the professionals prefer to work separately then the keyworker is powerless to bring about service co-ordination.

The corollary of this is that statutory services that are unco-ordinated cannot assume that by appointing keyworkers they will provide families with a co-ordinated service. Keyworkers need a context in which to perform this service co-ordination role. Such a context might include a multi-agency agreement to provide the family with a combined assessment and service plan or an agreement to provide the family with a multi-agency 'team around the child'.

## **Whose needs?**

Keyworkers are asked to work very closely with families. The role demands intimate knowledge of the family and a close trusting relationship. Just as families have their needs, so do professionals. If the keyworker has a need to be needed then the role provides many opportunities to create and prolong dependency. This must be watched for, acknowledged and addressed in support sessions.

Other professionals too, have a close working relationship with some families and this must be acknowledged by the keyworker as a great benefit to those families. It seems to be human nature though, that this close relationship with families can all too easily become over-protection of the family and strong defence of one's exclusive position with them. Professional concern can become the possessiveness and self-interest of 'this is *my* family'. Keyworkers, all helping professionals and all statutory and voluntary agencies must be aware of this.

# Keyworker protocols

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The following pages give the protocols developed by One Hundred Hours for providing the keyworker service. The protocols were developed to give guidance both to the keyworker team and to the families using the service. The development of such protocols is an important part of the provision of such a service. However, as One Hundred Hours was treading what was basically new ground, they were essentially fluid and developing documents which were adapted as we learnt about provision of the model.

## Providing the keyworker service

### 1. **Definitions**

#### 1.1 ***Parents***

The main carers of the child; this also includes foster parents and adoptive parents. We also recognise that parents are not always the main carers for their child, but that the child may be cared for by someone else, including other family members.

#### 1.2 ***Children***

The service is targeted at pre-school children, who have, or are possibly going to have, complex needs, however these are caused.

#### 1.3 ***Support***

The criteria for offering support is that the parents have more needs than are being met by other services.

### 2. **Development of the service**

Keyworker contact with the family proceeds through four phases:

#### 2.1 ***Introductory phase***

The keyworker and family begin to get to know each other. If the family wish to receive the service, they then move onto the next phase. If they decide they do not wish to proceed further at this point, it is made clear that they can request the service at a later date should they wish to do so.

#### 2.2 ***Intensive support phase***

The keyworker visits, usually weekly or fortnightly, to offer support according to the agreed standards. It is made clear that this intensive support system is a time-limited service.

#### 2.3 ***Winding down phase***

The family come to recognise their needs for this type of support are lessening, thus the intensiveness of the support reduces. This is done by negotiation between the keyworker and the family.

## 2.4 ***Keeping in touch***

The keyworker and family maintain contact by telephone with the possibility of occasional visits. The family know they can initiate more contact at any time should they feel the need.

## 3. **Providing the four main elements of the model:**

emotional support

information - including helping parents find answers to their questions

advocacy - helping parents to get the best services for their family

co-ordination of services - liaison between the family and any other professionals involved with the family as requested by the family

### 3.1 ***Emotional support***

#### 3.1.1 The basis of emotional support is to establish a helping relationship with the parents.

The aims of helping are:

to facilitate ways that all family members can adapt to the new or emerging situation of having a child with complex needs

to enable the parents to best meet the needs of the child, while at the same time being able to have their own needs met

to promote the best possible quality of life for the child

#### 3.1.2 The relationship between the parent and the keyworker is based on partnership and will involve the following elements:

confidentiality

respect

trust

communication

humility

honesty

genuineness

empathy

negotiation

#### 3.1.3 Emotional support will be provided when the keyworker listens to parents within a framework of the above elements. Such listening is done in the family's own home, or in the hospital if appropriate. The parents need to feel it is a safe environment so that they are in control and can maximise how comfortable they feel in what could be a very painful situation. The parents set the agenda of what they want to talk about and the keyworker allows enough time to carry this out and can listen to parents re-telling their experiences as often as the parents feel it is helpful to do so.

#### 3.1.4 The amount, type or phase of support being offered to a family at any time will be

kept under review by the keyworker manager. The value of the emotional support will also be regularly reviewed and evaluated by the parents and the keyworker. This may occur naturally during the ongoing relationship, or it may be carried out in a formal review at an agreed point in the relationship, after 25 hours of support.

- 3.1.5 A keyworker can refer a family to another agency if the keyworker and the family agree that this would be appropriate. (Referral to another agency without the family's consent is dealt with under the heading of Confidentiality.)

### 3.2 ***Information***

- 3.2.1 A keyworker will endeavour to give as much information to parents as they request. This will also involve helping parents find answers to questions they have about their child and the disability.
- 3.2.2 The keyworker will share any information relevant to the family that the keyworker has. Inevitably, the keyworker may at times have more information about a disability than the parents and the sharing of this information would be done in a considered, sensitive way.
- 3.2.3 The keyworker will not give advice to parents, but will give information so that parents can determine their own course of action.

### 3.3 ***Advocacy***

- 3.3.1 Advocacy is seen as enabling parents to make informed choices:
- helping parents to get the best services from local and national statutory and voluntary agencies
  - giving parents as much relevant information as possible
  - supporting them at meetings
  - helping/enabling them to get the best services
  - helping/enabling them to get the best from these services
- 3.3.2 The standard for advocacy is that parents are in control at all times and keyworkers have to be aware of the importance of enabling parents rather than taking over and always doing things for them. This would be very disempowering. There are times when parents ask for, and need, tasks to be done for them but the keyworker needs to recognise that there will also be times when this is not helpful to parents and that the keyworker should take on more of an enabling role in this instance.
- 3.3.3 Helping parents who want to complain - we enable parents by giving them information about the process of making a complaint and we support them in this process by negotiation, helping parents identify what they want, and offering information about how to try to achieve it. The keyworker will not make a formal complaint for a family but will act as an advocate for a family and assist them to make a complaint themselves.



### 3.4 ***Co-ordination of services***

- 3.4.1 The role of the keyworker will include liaising between all the other professionals involved with the family. This will be carried out within the framework of openness and honesty and with the consent of the family.
- 3.4.2 The aims of co-ordination and integration:
- appointments are managed so that visits to hospital and at home can be reduced or scheduled appropriately
  - the professionals know what each other is doing
  - a consensus of opinion on issues relating to treatment and management of the condition
  - services provide collectively for the whole child and family
  - separate programmes of work in education and therapy are combined as far as possible into holistic programmes with shared goals
- 3.4.3 Co-ordination and integration of services is conducted with the full knowledge of all those services involved and with respect for the roles that each undertakes and their existing relationship with the family.

## 4. **Standards of the keyworker service**

- 4.1 The service is:
- free to parents
  - available from the time parents ask for it and at the place of their choice
  - flexible - accommodating the needs of each individual family and adapting as needs change
  - accessible - families can self-refer or a third party can refer, with the family's consent
  - parent-led - families are in control of the elements of the service they use (within what the service can offer) and are under no obligation to the agency. They can opt out of any service at any time, without giving a reason
  - consistent - once a family has established a relationship with a keyworker offering long-term support, the agency will not change the keyworker without good reason

## 5. **Service design**

### 5.1. ***The initial visit(s)***

- 5.1.1 Families can contact the agency by letter, phone or through a third party. Keyworkers will get back in touch with a family after their initial contact within two working days, unless there are exceptional circumstances.
- 5.1.2 If, during the initial telephone conversation with the family, it becomes clear that

what the family is asking for is not something the agency is able to offer, this would be made clear to the family but a member of the team could still visit if the family wished.

- 5.1.3 The purpose of the first visit is to explain the nature of the work that the keyworker can offer as well as to explore as far as possible what the family is asking for.
- 5.1.4 The place and the time of the visit is to be negotiated but is primarily to suit the parents.
- 5.1.5 Parents can choose who they want to be at this first and any subsequent meeting. The keyworker can see parents separately if requested.
- 5.1.6 Keyworkers will allow two hours for this visit and can stay longer if necessary. Punctuality for this (and subsequent) visits is crucial, as is communication about the need to alter the time of a visit if unavoidably delayed.
- 5.1.7 The keyworker would need to indicate how long they would expect the visit to last and to explain that the purpose of the visit is to begin to get to know each other.
- 5.1.8 The family need to be told that the keyworker isn't going to assess their child, and he or she does not have to be on their 'best behaviour'. The child doesn't need to be present if it is an evening visit at a time when the child would normally be in bed.

## 5.2 *Subsequent visits*

- 5.2.1 The time and regularity of the visits and who is present is agreed by negotiation between parents and the keyworker.
- 5.2.2 The family always has the option of whether to meet again and can terminate the service at any time, without having to give reasons.
- 5.2.3 Families have direct access to their keyworker. Families have a telephone number for the keyworker.

## 5.3 *Interaction between keyworker and family*

- 5.3.1 Parents are entitled to honesty about their child and about services.
- 5.3.2 The keyworker will be sensitive to the family's needs, strengths and vulnerabilities.
- 5.3.3 The keyworker will build a relationship based on mutual trust and respect.
- 5.3.4 The keyworker will be sensitive in answering questions that the parents may pose about their child's diagnosis, condition, prognosis or future whilst being aware of what may underlie the question. If a keyworker is in the position of having information that the parents do not, the keyworker needs to gauge how much of the information they are ready for - the aim being not to withhold information but to

share it appropriately.

- 5.3.5 Keyworkers will not embark on communication with other professionals based on collusion. Information about a family will only be shared with other professionals in relevant situations and with the family's full knowledge and consent.
- 5.3.6 The keyworker would be expected to visit at times outside normal working hours, such as evenings and weekends, when it is necessary to meet other key members of the family who would otherwise be unavailable.
- 5.3.7 The service is confidential within the requirements of child protection legislation guidelines.

#### 5.4. ***Interaction between the keyworker and the child***

- 5.4.1 The keyworker should not do anything with or to the child without the parent's understanding, permission and approval.
- 5.4.2 The keyworker cannot be left alone in the house with any children of the household.
- 5.4.3 Where possible, we would suggest a hands-off approach for interaction with the child so that any work that physically involves the child should be done through the parent, rather than by the keyworker with the parent being a passive observer.

#### 5.5 ***Reviews of the service***

- 5.5.1 Families are to be given frequent opportunities to comment verbally on the service they are getting. This service can then be adapted by negotiation. A family will be offered the opportunity for a review of the service to be carried out regularly, a minimum of every 25 hours of input. This could take place as an informal discussion between the keyworker and family or could take the form of a formal review which could also include input from the keyworker manager, depending on the family's wishes.

#### 5.6 ***When a child dies***

- 5.6.1 The keyworker will support families in preparation for the death of the child, at the child's death and afterwards. The length of support after the death of the child is a matter for negotiation between the family and the keyworker. There is no necessity for the keyworker to cease contact when a child dies.
- 5.6.2 If the child is dying at the time we are introduced to the family, the keyworker will support them.
- 5.6.3 The keyworker will focus on helping parents to promote good quality of life for a child whose development is minimal or who is dying.

## 5.7 **Paperwork**

5.7.1 The need to share information with parents, be open about the service and about information held about the child and the family has important implications for paperwork in the keyworker service. As a firm principle, no information is kept about the family to which the family does not have free access.

5.7.2 These are the documents that the agency provides for the parents' and keyworkers' use:

Leaflet for parents describing the service in general terms.

Letter of agreement of service to the family setting the key standards outlined in the protocol documentation.

Document detailing the agency's reviews once they have taken place

Letter at the termination of the service to explain that the service has terminated and why (eg. at the request of the family)

Letter at the end of the winding down phase

The family file - a record of information relevant to the family held by the keyworker but accessible by the family

The keyworker's logbook record - a record of visits made by the keyworker to the family

A 'whole-picture book' - a record, created and held by the family, of the child's progress and any other information they want to keep accessible

## 6. **Outcomes**

6.1 In general, the anticipated outcomes include:

parents feel supported

parents have someone they can talk to

parents feel informed about their child's needs

parents feel informed about the relevant services

parents have attempted to access those services

6.2 A more individualised set of anticipated outcomes may be agreed in negotiation between keyworker and family at the start of the keyworker service and revised during the review process.

6.3 The outcomes are monitored for each family through the process of the 25 hours review detailed above.

6.4 The outcomes for the service as a whole may be monitored through periodic user-surveys.

## 7. Universal standards

### 7.1 Confidentiality

The agency aims to protect each family's right to privacy.

7.1.2. Confidentiality between family members - the keyworker will respect the right of each family member to confidentiality between themselves and the keyworker. This means respecting confidentiality when one family member tells a keyworker something that he or she does not want any other family member to know. This has implications for the family file: only matters that all family members can be party to can be recorded in the family file, any other items will not be recorded anywhere else.

7.1.3 Confidentiality between the keyworker and all the family members - this would only be broken in one of two cases:

where there is an issue of child protection

where the keyworker considers that the circumstances are exceptional and a parent is in need of further help and he or she is seen as a risk to themselves or others. This is to be done in conjunction with the British Association of Counselling guidelines as follows: Exceptional circumstances may arise which give the keyworker good grounds for believing that serious harm may occur to the family member or to other people. In such circumstances the person's consent to a change in the agreement about confidentiality should be sought whenever possible unless there are also good grounds for believing the person is no longer willing or able to take responsibility for his or her actions. Normally the decision to break confidentiality should be discussed with the family member and would be made only after consultation with the keyworker manager.

7.1.4 Confidentiality within the organisation - information about the family is only discussed between the keyworker and the keyworker manager. For the purposes of training and staff development, some information about a family may be shared with the wider team but the identity of the family will not be disclosed to the team.

7.1.5 Confidentiality within record-keeping - all family files are to be kept for 21 years for reference by the family, keyworker manager or keyworker involved with the family. Once keyworker involvement with the family has ceased the family file will be kept by the agency in secure storage.

7.1.6 Confidentiality within the relationship with outside agencies - the keyworker may need to have conversations with other professionals outside of the agency to co-ordinate or discuss their involvement with a particular family. The information to be shared, discussed or sought from other professionals is discussed first with the parent and carried out only with the parent's consent and subsequent knowledge of the result of the discussion. External professionals are made aware that this information is shared with the family, and also that all communication about the family, written or otherwise, is stored in an open-access file.

## 7.2 *Honesty*

- 7.2.1 Families receiving the keyworker service will be treated with honesty by keyworkers at all times.
- 7.2.2 Keyworkers always do what they say they are going to do. There may be exceptional circumstances which mean that this cannot be done but the family will be kept fully informed at all times.
- 7.2.3 The agency and each keyworker will not take on any new work unless it has a reasonable certainty that it will have the funds and resources to see it through to its completion.

## 7.3 *Advice*

- 7.3.1 The keyworker does not at any stage offer advice. The keyworker role is to offer information in as complete a form as is possible and support the family through any decision-making process should that be necessary. The keyworker is not a provider of advice but a facilitator in this process.
- 7.3.2 This alleviates the risk of a family being given the wrong advice and empowers the family to make and own their own decisions.
- 7.3.3 The family needs to be aware from the outset that this is the case and the reasons why it is so.

## 7.4 *Safety*

- 7.4.1 There are significant safety issues involved in visiting families in their own homes, particularly a family that is not already known to the agency. The agency needs to make keyworkers aware of safety considerations and policies within the agency.
- 7.4.2 If the keyworker at any time feels uncertain about visiting a family, they are at liberty not to do so and report the matter to the keyworker manager.
- 7.4.3 The family has the right only to expect visits from the keyworker at pre-arranged times and for the keyworker to carry appropriate identification.

## Putting the model into practice

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The One Hundred Hours keyworker model began life as a practice-based model and so it is fitting to end *The Keyworker* back where we began - with keyworkers supporting families in real situations.

The One Hundred Hours model, despite One Hundred Hours itself ceasing work in 1999, has not been left unused. The following excerpt, from the Handsel Trust's *New Opportunity* newsletter, outlines a project which is currently using the model to support families of children with disabilities.

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A Family Keyworker Project has been set up in Seacroft Hospital, Leeds. Based on the One Hundred Hours keyworker model, the service is for families with a child aged between 0 and 5 years who has recently been diagnosed with a disability or complex health need.

The Health Action Zone for Leeds has provided funding for this two year project to provide support and advice for families and enable them to access and co-ordinate appropriate services. The Family Keyworker Team, comprising the project manager and two keyworkers, provides a Family Keyworker who will:

- make regular visits to provide emotional support and listen to the concerns of parents
- work together with the family in completing an assessment to identify their needs
- advocate on behalf of the family and their child
- support parents in promoting the child's quality of life in all-round development, learning and play
- liaise with professionals involved with the family
- support the family in accessing the services they need and co-ordinate the input
- help parents build on their skills and confidence in caring for their child and in dealing with professionals

*New Opportunity Spring 2001*

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The Handsel Trust continues its work to promote the support of families and the adoption of the keyworker model in the anticipation that many other localities will join existing projects, such as that in Leeds, in taking up the model.

## **Sources of further information on keyworking**

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The following list is in no way an indication of all the resources available on keyworking but instead is intended as a guide to starting points in specific areas.

### **On families' experiences**

#### **Telling it how it is**

Carrie Britton

Published in 2001 by the Handsel Trust. Tel. 0121 441 1580

Price £9.00 ISBN 1 903745 03 9

### **On the need for a keyworker service**

#### **Parents' support needs**

Gudrun Limbrick-Spencer

Published in 2000 by the Handsel Trust. Tel. 0121 441 1580

Price £9.00 ISBN 1 903745 01 2

#### **Real change not rhetoric**

Patricia Sloper, Suzanne Mukherjee, Bryony Beresford, Jane Lightfoot and Patricia Norris

Published in 1999 by the Policy Press. Tel. 0117 954 6800

Price £12.95 ISBN 1 861342 07 1

### **On setting up a keyworker service**

#### **Unlocking keyworking**

Suzanne Mukherjee, Bryony Beresford and Patricia Sloper

Published in 1999 by the Policy Press. Tel. 0117 954 6800

Price £13.95 ISBN 1 86134 208 X

#### **A resource pack: developing a key worker service for families with a disabled child**

Suzanne Mukherjee, Patricia Sloper, Bryony Beresford and Peter Lund

published in 2000 by the Social Policy Research Unit. Tel. 01904 433608

Price £15.00

### **On developing partnership with parents**

#### **Support partnerships: collaboration in action**

Penny Lacey

Published in 2001 by David Fulton Publishers. Tel. 020 7405 5606

Price £16.00 ISBN 1 85346 568 2



## **On co-ordinating services**

### **The team around the child**

Peter Limbrick

Published in 2001 by Interconnections. Tel. 0161 740 7757

Price £9.95 ISBN 0 9540976 0 2

### **Service Co-ordination**

Anette Beattie

Published in 2000 by the Handsel Trust. Tel 0121 441 1580

Price £9.00 ISBN 1 903745 02 0

## **On involving fathers**

### **Just a Shadow**

Sheila West

Published in 2000 by the Handsel Trust. Tel. 0121 441 1580

Price £9.00 ISBN 1 903745 00 4

## **On providing effective emotional support**

### **Counselling parents of children with chronic illness or disability**

Hilton Davis

Published in 1993 by BPS Books. Tel. 01752 202301

Price £11.95 ISBN 1 85433 091 8

## **On technology dependent children**

### **Supporting parents caring for a technology-dependent child**

Susan Kirk and Caroline Glendinning

Published in 1999 by the National Primary Care Research & Development Centre.

Tel. 0161 275 7601