

TURNING THE KEY

OPENING THE DOOR TO
NEW WAYS OF WORKING

Brendan McKeever



Family Information Group

© 2003 Brendan McKeever / Family Information Group
10-12 Bishop Street, Derry
Tel/Fax: 028 7128 5675

Typeset and designed by **GUILDHALL PRESS**
Unit 4, Ráth Mór Centre, Bligh's Lane, Derry BT48 0LZ
T: (028) 7136 4413 F: (028) 7137 2949
info@ghpress.com www.ghpress.com

CONTENTS

- 4 Acknowledgements
- 6 Introduction
- 8 The Key
- 9 The Receiving End
- 11 What's It All About?
- 14 The Key Person
- 16 Making It Work
- 19 The Family View
- 24 When A Key Worker Is Needed
- 27 Conclusion
- 29 Checklist (A):
Qualities Of A Key Worker
- 30 Checklist (B):
What A Key Worker Needs
- 31 Checklist (C):
Barriers To Developing Key
Worker Model

ACKNOWLEDGEMENTS

This publication would not have been possible without financial assistance from the Department of Foreign Affairs, Dublin, through the Reconciliation Fund. The Family Information Group is very grateful for this support.

However, there have been many others who, directly and indirectly, have made this publication possible through supporting our work over the past six years: parents, disabled children and young people, their siblings and family members, researchers, disability organisations, voluntary groups, politicians, and many individuals, some of whom work with statutory agencies and others who work in the voluntary sector.

In this current financial year (April 2002-March 2003), we have also received funding from the Department of Social Development, through the North West Development office, and Foyle Health and Social Services Trust to carry on different aspects of our work. We are very grateful for their support.

On a personal level, I would like to thank our publishers Guildhall Press, particularly Paul and Joe, for their patience, sensitivity and

encouragement in seeing this project move into print. A special word of gratitude is due to all our Group's committee members without whose help, support and encouragement, none of this work would have been possible. A special word of thanks also to Breige McLaughlin for typing this book.

Finally, I would like to thank my own family, Teresa, Donovan, Ruth and Jack. Their unseen support is, and has been, vital in all of this work. For us, as for many other families, key working is just one more issue.

Brendan McKeever
Spring 2003

INTRODUCTION

The Family Information Group's main aim is to present the "family view of disability" as experienced by families of disabled children (with an emphasis on children with physical and/or sensory disabilities). Central to this "family view" is raising awareness of the issues that directly affect families.

In late 2002, the Group ran a major conference in Derry – 'Beyond Words' – highlighting several issues that have proved, over time, to be of great concern to families of disabled children. One of these issues was what was termed "key working".

Key working means different things to different people, and to some the term means nothing at all. Other names are also used from time to time to describe the same thing – "link working" and "care co-ordination" are just two of them.

Whatever the terms, this publication looks at the issue from a family viewpoint.

In *Turning The Key*, it is hoped to give a fuller picture of what key working is about. But more than this, it is hoped that a debate will follow which will inform any action on this issue, action that was envisaged at the 'Beyond Words'

conference several months go. Of course, there are barriers that could prevent key working from working effectively, but it is hoped that a deeper understanding of the concept will help break down some of these barriers.

THE KEY

The key to understanding what all this is about is the family of the disabled child, including the child. What confuses many people is the emphasis on how services are **delivered** by those who plan and deliver such services, **not** on how families **receive** these services. To improve understanding, parents, family members and the disabled child must be listened to and what they say must be acted upon. A variety of ways should be explored to help with this listening process.

It does not matter whether key working and the terms associated with it are used by families – they don't have to be, as families have often a very clear understanding of how services should be delivered without all the jargon. The emphasis must move towards those in receipt of services.

If this key shift in focus is grasped, then there is a distinct possibility that some of the barriers that currently exist can be broken down. However, once we have begun to understand this shift, we must question ourselves as to whether we really want key working to happen. If we want it to work, we will put in place whatever is necessary to make it work. Key working cannot operate, however, in a vacuum.

THE RECEIVING END

Families are on the receiving end of services and as a result, have gained experience that can help them identify what is good or bad about such provision. Our Group has listened to families, as have many other organisations, researchers and practitioners on the ground.

The same issues keep appearing and re-appearing ie:

- lack of relevant information
- not knowing who to go to
- disjointed services
- “professionals” not knowing what other “professionals” from the same or other agencies do
- a lack of understanding by the families of the role of some practitioners
- having to fit into other people’s agenda
- inadequate support
- little emphasis on advocacy and rights
- not having one main contact person.

These are only a few of the issues. Key working may not address all of these but it does go a long

way in ensuring that services are delivered to families in a way which they find more acceptable.

Those who deliver services may argue that key working is just not possible because of:

- difficulties over assessing need
- the number of different agencies involved
- not enough resources
- there is not the will to work in this way.

For all of us, these are the challenges that have to be faced if those on the receiving end are to get the services they have a right to, in a manner that suits them.

WHAT'S IT ALL ABOUT?

Many people who work professionally with families concentrate on their own service, their own job, their own agency. At times, they have no understanding of, or indeed interest in, other people involved with the family. This approach can lead to disjointed services and as a result, families can become very frustrated and confused. There are more than enough pressures on them as the impact of having a disabled child permeates their lives, although there is recognition by many families that most of those who offer services on the ground are working under very tight restraints and budgets.

What is even more frustrating is that some of the services provided link into each other naturally, even though they are provided in a disjointed manner. **Key working is primarily about co-ordinating services to families in a way that suits each individual family.**

It has to be emphasised that not all disabled children and their families would benefit from a key working process. For some families it may seem to be yet another intrusion. Others may not receive a sufficient range of services to require key working. And some families just want to get on with their lives.

Key working is not seen as being appropriate throughout all the years of a disabled child.

For some disabled children, this may be so. However, key working may be more effective at critical points in a child's/family's life, particularly at times of change – diagnosis, entry to school, transition etc.

The problem for many families is that there can be so many different people involved with the family. Different people, coming at different times, carrying out their own individual functions, and often not relating to each other at all. Within a relatively short period of time, particularly around the time of diagnosis, a family could see: a nurse, a doctor, a consultant, a paediatrician, a physiotherapist, an occupational therapist, a speech and language therapist, a health visitor, an educational psychologist – the list is endless.

At times, the family can be very confused over the role of each of these people. Usually no-one is co-ordinating these visits, introducing the practitioners to the family, explaining their roles or keeping each of them informed about the family. Many families still say they don't know who is the best person to contact, that they feel unsupported, and that they are not receiving the right kind of information. Many have been advocating that

there should be one key person that they could contact. This is what key working is about, and it is envisaged that a key worker would take on these roles and more.

THE KEY PERSON

Key working can happen without a key worker, but often – because there are not enough resources, not enough co-operation with relevant agencies, and indeed not enough time – it is not as effective as having one key person liaising with the family of a disabled child. The need for a link person has been identified for some time; however, he/she will need the resources, time, co-operation of others etc, to have an effective role with a family. Of course, he/she will also have to gain the confidence and trust of the family and demonstrate all the qualities – sensitivity, empathy, ability to challenge etc – that such a position requires.

We have already looked at the major areas of concern facing many families of disabled children. Some of these areas have created a maze of bureaucracy which is very difficult for families to navigate. A key person, working with the family, could help get through this maze. The key person must have the authority to be able to work across all the agencies, but this does not necessarily mean that the person must be employed by a statutory agency.

There are those who argue that everything needs to be in place before a key worker can be

appointed. In an ideal world, this would be the case, but we do not live in an ideal world. If there is an awareness of what is needed, and a willingness to work towards this goal, then the appointment of a key worker can indeed contribute towards this. Through working in partnership, more and more agencies may begin to show a higher level of co-operation.

MAKING IT WORK

If we have really listened to families of disabled children, through direct contact and by using the findings of researchers, we will begin to understand what the role of this key person could be. Also, if we take the views of those who work most directly with families in the voluntary and statutory sectors, a picture will emerge as to how we can address this issue.

In the UK, there are a number of examples of how key working has developed. A national organisation bringing many of these experiences together is **Care Co-Ordination Network UK**. From Scotland, England, Wales and Northern Ireland, examples of key working and the development of key worker systems are brought under scrutiny. This information is then passed on to the public and to those with an interest.

Certainly, an example in one specific area may not work in another area, but there are many lessons that can be learned before someone tries to reinvent the wheel. Care Co-Ordination Network UK in recent years has become the only umbrella organisation in the UK promoting key working for disabled children and their families. It involves disabled people, parents of

disabled children, carers, representatives from the voluntary and statutory sectors, individuals and organisations.

Much work has already been done to prepare the ground for key working. Although this may not have been the intention of such work, the results of the process may be helping towards this. For example, within each of the Health Boards in Northern Ireland, there has been the development of **Children's Services Planning Groups**, and within these there are **Disability Sub-groups**. For some years, these groups have been exploring how different agencies (voluntary and statutory) can work more closely together on real partnerships.

In the development of **Healthy Living Centres** there has been increased co-ordination between the voluntary/community and statutory sectors in trying to meet health and social needs. The ongoing development of the **Regional Child Register**, in response to the Children's Order, is a real attempt at trying to bring information together. There are other examples of a holistic approach to disabled children – eg the **NI Children's Hospice** and the **Palliative Care Teams** – which could so easily contribute towards the development of a key worker system and help to make it happen.

All this, coupled with what is often called “user involvement” (a central part of government policy which is sometimes more spoken about than acted upon), could make a major contribution towards the key model role. But there needs to be the will to make it happen. There has never been a better time to initiate an effective key worker model.

By drawing on the experiences of disabled children and their families, by learning from the experience of those who work with families (no matter where they come from), by identifying – at local and regional level – examples of what could be termed ‘good practice’, and by studying the work of researchers and models being used throughout the UK, it may not be too long before we can all make it happen.

THE FAMILY VIEW

There is much discussion and debate as to when key working would be beneficial to families of disabled children. In some cases, these discussions and debates delay the implementation of a key worker system. However, there are a number of factors which determine whether key working would be effective or not. **But it must be emphasised that key working should only be introduced to a family with their agreement and never be seen as yet another burden on family life.**

Each family is different. How **disability impacts the family** is one of the main factors which should determine whether key working is appropriate or not. It will take a skilled person, working closely with the family, to try and determine this impact. Research and experience has shown that the time of **diagnosis and disclosure** is often one of the most crucial times when key working would be supportive to families as it is this time when disability impacts most. Another crucial time is when an assessment is made of who is actually involved with the family. If this highlights that a **significant number of practitioners and/or agencies are involved then consideration should be given, at that time, to engage a key worker.**

It is often this situation which causes the greatest amount of frustration to families with different “professionals” coming and going, the families not knowing who they really are or indeed what they are actually doing, and a multitude of appointments at different times and places. Also, it is the frequency of these visits that has to be measured. For example, a family with five “professionals” involved may be considered as benefiting from key working. But what if those involved with the family were:

- a consultant paediatrician (seen once per year)
- an educational psychologist (seen once during the year for a preliminary assessment)
- a social worker (whose only involvement is a one-off assessment)
- their regular health visitor (seen periodically)
- their own GP.

It would be appreciated that this family would not want an additional resource worker **at this stage** as long as they were fully informed of the role of those “professionals” not known to the family (eg the educational psychologist and social worker).

Key working will not work for all families and often would not be of benefit. It is ideally placed to assist families of disabled children with complex

needs and/or where the impact of disability has been profound in the family.

However, families with fewer “professionals” involved could benefit from key working. For example, when a child needs a wheelchair for the first time, the family may need a lot of information and support from a social worker, physiotherapist, occupational therapist and community nurse at a very critical time in their lives. Someone like a key worker – who would have information, be supportive, have counselling skills, be able to co-ordinate services and appointments while advocating with the family – would have a lot to offer.

It is therefore clear that different factors, including the views of family members, have to be taken into consideration when discussing the role of key workers. Also, it has to be emphasised that not all disabled children and their families would benefit from a key worker; in certain circumstances such a system would be seen to be intrusive.

In an era where partnership and “user involvement” are to the fore of government policy and central to the workings of statutory and voluntary agencies, it should be somewhat easier to gauge **with** families as to whether key working

would be of benefit or not. If families are:

- overwhelmed by the impact of disability
- and/or totally confused by inappropriate information
- and/or unsure of the role of those involved with their family
- and/or totally frustrated with the number of appointments for their child and themselves
- and/or faced with a major change in their lives to do with: health, housing, education, social circumstances etc,

then, in such circumstances, perhaps serious consideration should be given to initiating a key worker system for the family. This can always be reviewed.

In most circumstances, key working is only appropriate to a particular time in a family's life. The essential component of key working is that it must be **flexible**.

From a family viewpoint, it is not confusing: a key worker is needed when circumstances dictate that this would be best for the family. To the person/s involved with the family, it is also very clear, that someone who could co-ordinate services, inform the family and advocate with them, would be

beneficial not just to the family but to those who provide services. An informed family will know if a key worker would be appropriate or not.

Perhaps this process would be smoother if the person most involved with – and hopefully trusted by – the family (if there is one), eg health visitor, social worker, voluntary worker etc, should help assess the family in relation to the key worker service rather than send another unknown individual into the family to do this assessment. How this assessment is to be carried out can be worked out in advance in consultation with all those involved to ensure that no matter who does the assessment, the criteria is the same.

Key workers and a key working system, if implemented properly, will prove to be effective tools in meeting the needs of some families. Research and experience have shown this. Getting the criteria for assessment is only one minor step in a process that needs to be initiated to meet the individual needs of those families who would most benefit.

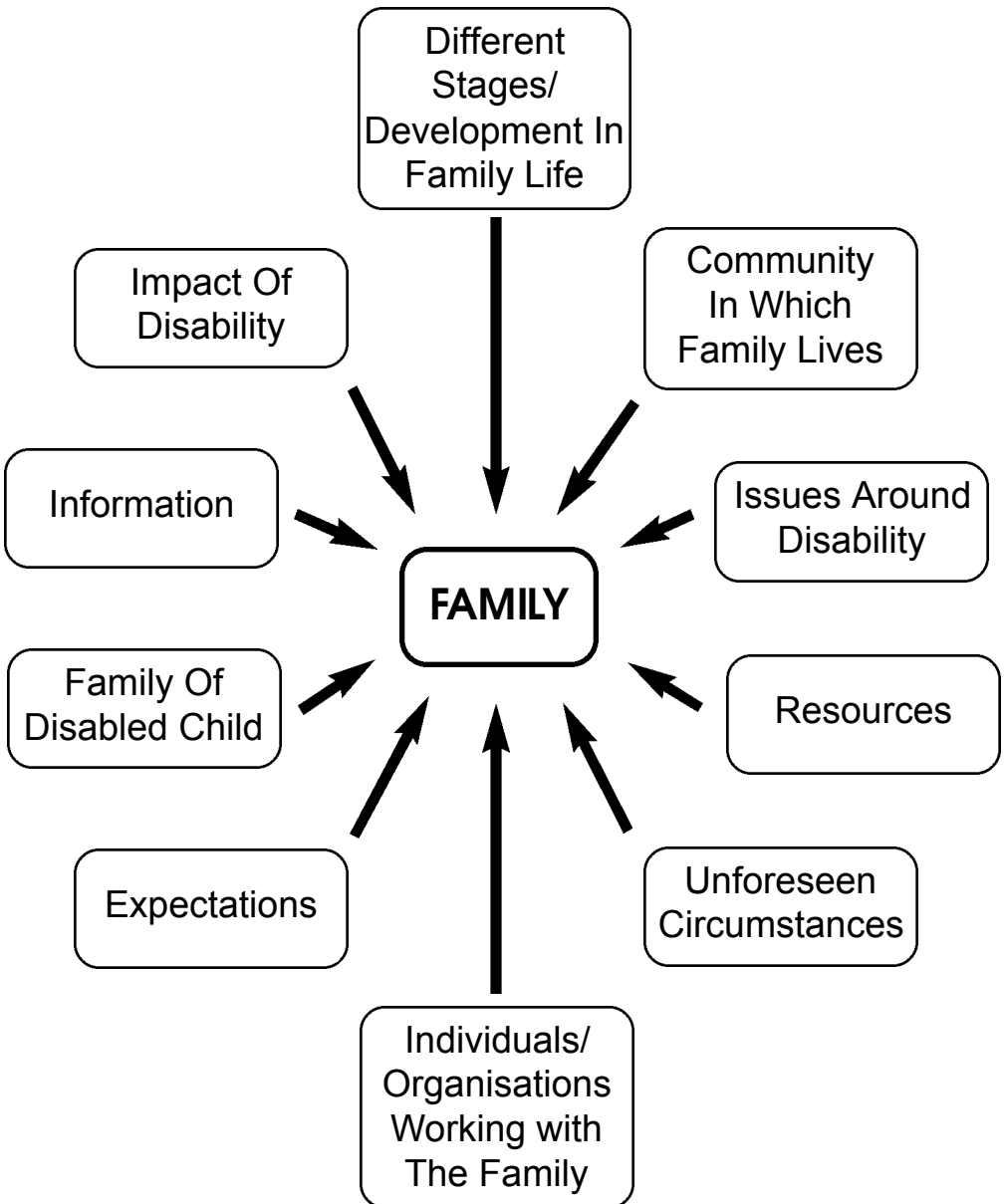
WHEN A KEY WORKER IS NEEDED

A key worker is needed when some or all of the areas impacting on the family of a disabled child create difficulties and frustrations for the family members which prevent the family attaining a reasonable quality of life (see diagram opposite).

In this instance, a key worker could help lessen the impact of disability (through accessible relevant information, support, advocacy etc) by co-ordinating services and individuals going into the family – again with appropriate information on rules, responsibilities and services at different stages in a family life eg diagnosis and disclosure, entry to school, transition period etc, and when unforeseen circumstances happen (eg health crisis). An assessment as to whether a key worker is appropriate should involve the family and depend on how (and to what degree) the above factors affect family members.

It has already been pointed out that there are a number of factors – including the wishes of the family members – which should determine whether a family would benefit from the appointment of a key worker. It has to be stressed that often a combination of factors will determine whether such a service is appropriate

Factors Impacting On Family Of Disabled Child



and that often such a service may only be for a limited time.

Again it must be stressed over and over again that key workers and a key worker system will not be beneficial to all families of disabled children. Indeed, the initiation of such a system should help develop information services in general, help co-ordinate services to families, and encourage inter-agency and cross-sectional working. This should, in turn, benefit all families. In the long term, this is the real benefit of the initiation of a key worker system; with dedicated key workers, all of us will benefit.

CONCLUSION

For many people, all of this is just a repetition of what has come before. There are many families who have never used the words “key worker” but who have been saying for years many of the things that have been said in this booklet. Also, there will be those who provide services to families who will welcome a different approach to delivering services and working with families. And there will be those who have tried to work with families in a supportive role, using many of the elements of key working, or perhaps have been key working, who will acknowledge the benefits of such working.

However, there will be others who, for one reason or another, will focus on the barriers: difficulties over assessment, lack of resources, “professional elitism” etc. This booklet will do nothing to convince them of the merits of key working. But for those who are willing to change, to face the challenges, the prize is a greater quality of life for all and better working relationships between those who use and provide services. It is this that will make it all worthwhile.

CHECKLISTS

CHECKLIST (A)

Qualities Of A Key Worker

A key worker should be:

- Trusted by family members
- The person who links the disabled child and the family with outside agencies
- The central source of information (on who does what and what services are available)
- The person who co-ordinates services and service providers (from all agencies)
- The advocate for, with and on behalf of the family – depending on individual circumstances
- Sensitive, empathetic, non-judgmental and with relevant counselling skills
- Challenging and able to liaise effectively with own and other agencies
- Willing to listen and act on what is being said
- Suitably trained for the job
- Capable of addressing the individual needs of family members
- Intuitive enough to know when to step back
- Supportive
- Good at communicating
- Aware of the issues affecting families of disabled children
- Willing to work unsocial hours

CHECKLIST (B)

What A Key Worker Needs

- **Time** – dedicated time to do the job properly (not additional duties added on to an already overloaded work schedule)
- **Resources** – adequate resources to offer appropriate services to families of disabled children
- **Information** – access to the information that the family needs, links with the relevant people in other agencies, and assistance in interpreting information so that it can be useful to families
- **Training and experience** – relevant training and experience in counselling, advocacy, awareness (of disability issues and rights) and a commitment from employers to facilitate ongoing training and development
- **Support** – individual support and supervision, and support and commitment from senior management of his/her agency and other agencies to the concept of key working
- **Long-term view** – willingness to develop key working as a long- term response to identified need, not as a short-term fix-it tool
- **Help** – in identifying and addressing unmet need
- **Commitment to “user involvement”** and the skills to help involve the family in the planning and provision of services.

CHECKLIST (C)

Barriers To Developing Key Worker Model

- Lack of commitment from agencies to key worker principles
- Current way services are provided, fragmented into different age groups, variety of disabilities and confusion over differences between adult/children services (where there are children services)
- Inconsistencies in the way different agencies assess and deliver services, collect information and use different criteria
- Lack of willingness for agencies to work together and share information
- Absence of co-operation within agencies – each discipline providing their own services without connecting to other services
- Disabled children and their families being treated as a low priority when it comes to planning and delivering services
- Lack of appropriate resources (including time and relevant staff)
- Impact of disability on the family (feelings of isolation, loneliness, marginalisation, lack of trust etc)

- Lack of awareness of issues facing families of disabled children
- Emphasis on short-term intervention rather than long-term support (often not assisting families who “seem” to be “coping”)
- Absence of focus on family of disabled child.