

BEYOND WORDS

Brendan McKeever
(Autumn 2002)



Family Information Group

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 five 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 Derry 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 families, these issues are just a way of life.

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Typeset and designed by GUILDHALL PRESS
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PREFACE

By raising the issues that affect families of disabled children, we could be accused of going over the same old ground once again. Perhaps if families felt they were being listened to, this could be seen as true. But some families continue to believe that very little has changed for them over the years – all they hear are words and promises. After five years working full time on such issues, it is hoped that this publication may mark a turning point for the Family Information Group as well as families themselves

Although many issues remain the same, when families experience them for the first time, they are new to them. Through research findings and the experience of families, this book intends bringing these issues to the fore to be re-examined. It is only by examining the issues, from all sides, that we can perhaps go beyond the words. At times there may be no immediate answers, but if we are to move forward we have to be open and honest and be willing to explore all avenues, before throwing in the towel.

On a number of occasions in the past, the Family Information Group has put forward various ideas and made recommendations on how things could be changed from its perspective. Some of these ideas are included for discussion. ***Beyond Words*** is about engaging people in

the discussion of these issues; people from different backgrounds and with very different interests. But it is about more than discussion, it is about action. Action may sometimes mean finding out why change is currently not possible but also it may mean initiating change. If, at the end of all this, a group is set up from mixed interests to explore the issues and begin to move beyond words, then this publication will be worth while.

Many parents of disabled children feel powerless; they seem to have no voice, nor do their children. This is probably why the issues that affect them are often ignored. If those issues that do affect them are not even on the agenda then some way must be found to bring them to the attention of those responsible for supporting families. It is recognised by many people that disabled children and their families are indeed very low down on the priority list within the Department of Health and Social Services and Public Safety, Health Boards and Trusts.

Somehow, families of disabled children (including disabled children and their siblings) have to find a voice, have to have a significant say in the planning and provision of services. But just as importantly, those who plan and provide services must be willing to listen and to act and work with those who use services. This will take mutual trust and respect. There are many sensitive individuals from both the statutory and voluntary sectors who already

realise this and put such trust and respect into practice. They indeed go beyond words. However, for some people, it will take a massive cultural shift, particularly among those who work in statutory services and more particularly those in senior management. There can be no room for tokenism. Inclusion means change and a different way of doing things. For each issue we must ask ourselves:

- Is this really an issue?
- What is preventing us from resolving the issue?
- If it is a resources issue, where can we access them?
- If it is an attitude change, can we change it?
- What way could we resolve the issue?
- Can the issue be resolved?

For this report to have any impact and to prevent it gathering dust on some shelf or other, these questions need to be asked and also they need to be answered. If those who provide services and those who use services can work through these answers, preferably together, then maybe – just maybe – there can be a positive outcome and we can go beyond words. At the end of each section there are a few points highlighted – ‘Beyond Words’. It is these points that our Group believe should be the basis of further discussion which could lead to action on the ground.

We have to remember that politics, through the Assembly in Northern Ireland, has a very big say in what services families of disabled children receive or do not receive. So the list of those who should ask these questions, and at times answer them, grows:

- Disabled persons
- Siblings
- Parents
- Family members
- Those who provide services
- Those who plan services
- Department of Health & Social Services & Public Safety
- MLAs (Members of Assembly)
- Politicians
- Political parties
- The Assembly

If this report can really get this debate going on the issues that affect families, it will be a start. If people feedback to the Family Information Group their thoughts on such issues, that will be progress. If, as a result, change does happen, positive change, then at long last families may begin to receive the services they are entitled to, and the quality of life that most other people take for granted.

INTRODUCTION

There have been so many reports, consultations, workshops and conferences, and yet for many disabled children and young people, their parents and family members, as already stated, little has changed. Words and more words. After five years of working in the area of raising awareness of “the family view of disability”, (how disability impacts the family when a child is disabled), the Family Information Group wants to explore if we can now go beyond words. The challenge is: Can we all work together towards positive change instead of continually finding reasons why we can't?

Of course there are real burning issues such as: lack of resources, disabled children being a low priority, the inability to plan support for families, crisis intervention, insufficient services on the ground, overworked social and health care workers, listening but no action etc. No one group, no organisation or agency has all the answers. Indeed, at times there may be no answers. However, if there is respect for all involved, if the experience of parents, disabled children and young people and other family members is as valued as the experience of those professionals involved with families, then this is a positive starting point. If this respect is missing, it becomes very difficult to develop real constructive partnerships.

In ***Beyond Words*** we will look back over the five years that the Family Information Group have been working full time in the community. But this is not simply a review. Over the years, many of the issues remain the same, although each family experiences them differently. Parents, researchers and many of those who work with families have identified these issues, yet still there seems to be a reluctance to really address them. Rather than a review, this report is a challenge.

To state clearly and bluntly that many issues remain unaddressed does not deny that there are many people, in the voluntary and statutory fields, that are working very hard to resolve some of these. But there does appear to be confusion over what is often termed “user involvement” (involving those who use services in the planning of services) and the actual delivery of services. In real terms, there have been a number of significant changes in service planning as more parents, users, and representatives of the voluntary and community sectors become engaged with statutory agencies in various committees. Examples are: Children’s Services Plan, Regional Childs’ Register, User Groups etc. However, in some of this “user involvement” there still needs to be an awareness that everyone has to change through this involvement, and that it is not always about training users/parents etc to fit in with existing structures.

If ***Beyond Words*** is to have any impact, then the issues raised have to be the basis of discussion for all those involved. As parents, disabled children and young people, their siblings and family members begin to find their own voice, then there must be people willing to listen to what they say. More than this – beyond words – action must result, and that must be positive action.

To help in this discussion, it is intended to journey through the issues as identified by parents of disabled children. At the end of each issue, if relevant, certain points for discussion will be highlighted. To really make this contribute towards positive change, it will be important for everyone involved to think about these points, discuss them and feed back to the Family Information Group. By bringing this information together and circulating it to the NI Assembly, Assembly Members, Department of Health & Social Services & Public Safety, Health Boards and Trusts, relevant voluntary and community organisations and families of disabled children, perhaps the basis for further action will begin.

Before this discussion can happen we should consider a number of relevant underlying points:

- Resources are scarce but we must try and identify where additional resources could come from. This could include the development of partnerships between voluntary and statutory agencies.

- Real consideration must be given to supporting families, earlier on, in an appropriate manner and not just crisis intervention.
- Mutual respect is essential and an acknowledgement of expertise, particularly the recognition of the expertise and knowledge of families of disabled children and young people.
- The needs of disabled children/young people and their families have to have a higher priority in the community, and ways found of facilitating all of their 'voices'.
- The meaning of 'inclusiveness' should be explored more fully and the realistic understanding of the implications of it.
- For all those involved, there has to be a commitment to go 'beyond words'.
- Ways of realistically funding the community and voluntary sector to deliver direct services to families need to be explored, as does some mechanism of resourcing groups raising issues and advocating with families of disabled children.
- A holistic approach to supporting the family needs to be pursued.

These are the concerns that will inform this discussion.

The journey therefore begins and begins at the time prior to diagnosis – 'Before'.

BEFORE

For many parents, what went on before the diagnosis of their child is often forgotten or transferred to the back of the mind, so that it seems to have been forgotten. The day-to-day care duties have taken over their lives so much that many cannot remember the time when such duties did not exist. With no training, no experience and with little or no choice, they are forced into a caring role that can last for many years, believing that this is what they have to do and are expected to do it by those who provide services. The different world that they now live in has no real connection with the everyday lives of the wider community, it is so different.

Yet it is in this time before that most other people live in, with no experience, no interest and no connection whatsoever with disability issues. It is into this world, as well as all the other areas where disability issues do exist, that awareness, training, education (or whatever people call such approaches) have to take place. Disability affects people in an individual way but it also impacts on the community. The community can be very supportive or remain totally disinterested, depending on what attitudes prevail and how much awareness there is.

Any positive awareness training, information on the Disability Discrimination Act, information on the issues affecting disabled people and their families, can all help to develop a healthy community response to disability.

If, as a community, we are trying to develop a positive attitude towards disability then we have to move away from what is called the 'medical model of disability' to the 'social model of disability'. Much awareness training concentrates on this social model, which is a more holistic approach, rather than looking at the medical condition of an individual. Many of the barriers that are created are to do with the environment rather than the individual, according to the social model. For example, someone in a wheelchair could be disabled when they confront steps going into a building; if there were a ramp – in this situation – they would not be disabled in the same way.

This is not meant to be a wheelchair debate about disability; rather it is an attempt to bring disability into the mainstream, away from the margins. Attitudes need to change, but they can only change through awareness.

Beyond Words

- Awareness training for the community (in the widest sense)
- Emphasis on the social model of disability.
- Planned awareness training in schools
- More involvement of disabled people and their families in the provision of training
- Provision of accessible information to build up knowledge of impact of disability

DIAGNOSIS AND DISCLOSURE

There is no easy way of telling news that is going to devastate a family but there are ways of making it less hurtful. In her presentation on this subject, Dr. Mary Magee (Psychologist) does not say these exact words but the meaning is very similar. At this point, families are naturally very vulnerable. Explanations are given to them, information is presented, words are used and hopes/fears for the future are discussed – all of these and more will have a major impact on their lives. Just as crucial will be their understanding of what is being said as very few people can take in a lot of information when they are in a state of shock, as many families will be at such a time.

Even yet there are still many examples where the way the news has been broken is as devastating, if not more so, than the news itself. Often this is not intentional, but it is still hurtful. There are a number of issues around sensitivity and training that need to be explored more fully. Research has been carried out on this subject by the Family Information Group and others and a number of important issues have been raised if we want to positively address this very key area in people's lives.

Beyond Words – Diagnosis and Disclosure

- Training and education of those who work professionally in communication skills, with emphasis on empathy, sensitivity and listening.
- Involvement of an independent advocate for the family, from the time of the very first diagnosis and disclosure.
- Appointment of a key worker to the family.
- Accessible information, in appropriate language, to be available in different formats, at times and places that suit parents and their family. Written information summarising details of each appointment to be given to parents and family members, a contact number for any support group and a contact number for the family key worker who should be available out of hours.
- Support for parents at time of diagnosis and follow up, including counselling support services.
- Diagnosis and disclosure should be gradual, at a pace that meets parents' needs.
- Home visits to be considered where appropriate, possibly for first diagnosis and disclosure and afterwards.
- Preplanning of diagnosis and disclosure: who should be there? (including significant others), where should it take place? at what time? Are services such as telephone, refreshments, and arrangements to travel home put in place? Written guidelines drawn up.
- Parents and children should be valued, respected and treated as individuals.





- Positive but realistic approach to the future; remember, children are more than standard conditions or syndromes.
- Social model of disability should be used.
- Further research.

Related to this are the very deep concerns and worries that parents have around rare conditions and syndromes, as well as conditions for which there is no diagnosis. Contact a Family have been working in this field for years, supporting individual families and groups, providing information and contacts for parents. Often there is little or no information on such conditions for parents, and families are often left to their own devices to find things out for themselves. Sometimes there is no news, never mind “bad news”.

FAMILY VIEW OF DISABILITY

Although this is at the core of the Family Information Group's work, it is often ignored, particularly in the medical field. Issues around disability do not just affect the disabled child; they affect his/her siblings, parents, family members and friends. Just as important as this is that the disabled child is more than just his/her condition, the child is an individual, and often is quite different from other people who have similar conditions. He/she is a family member first, who has whatever condition. In conversations at times you do hear the child/young person referred to as the "_____ child", as if all children of the same condition are similar. The only way to address this is through awareness training/education as already highlighted.

If the disabled child, as a person, is ignored then so too are his/her siblings. Only a little work has been done with siblings but it is obvious that many of them miss out, even though there are positive aspects of having a disabled brother or sister. Many siblings become carers, by no choice of their own, from an early age as they help out at home with the extra duties. It is so easy to see how resentment and frustration can grow if they perceive that their disabled brother/sister seems to be getting everything (even if this is care and attention because of his/her condition) and they seem to be getting nothing. Even in areas where there is some level of provision for disabled children/young people, there is little or nothing for

siblings. Locally, in recent years, some summer schemes have tried to address this, but there is certainly not enough provision.

Caught in the middle of all this are parents. There seems to be some kind of expectation that somehow or other parents will find a way to cope. In the wider community there is a perception that they will be given all the support they need to do so. Very few, outside the home, know the reality. What is the reality? For many parents the diagnosis and disclosure have torn their world apart, they are robbed of their dreams, their happy memories and for quite a few the time ahead may seem like an unreal nightmare.

In the months and years after diagnosis, many parents will clearly say that they feel they have to fight for everything when it comes to the needs of their disabled child. The bureaucracy, form-filling, endless phone calls, waiting etc are known to too many parents. Also, they have to learn to balance; to balance the needs of all family members (including themselves as parents, which they often ignore), balance work and caring duties – there are many parents of disabled children who do not work, or work part time, not by choice but out of necessity. Very few have to balance recreational needs as these are few and far between, if any.

Despite all this, many parents do cope. Many are in a journey but at different stages and it is important that those who provide services realise this. It is not automatic

that you move from one stage of coping to another eg from the shock of diagnosis to the positive approach to disability; many families are locked into one stage or another. But if parents are trying to cope, they should be supported in this just as they should be if they have difficulty in coping.

Family support is often only given at critical intervention times when there is a crisis or emergency. Supporting families who are trying to cope should be where family support is also available. Many parents believe that there is little outside support when it is perceived that they are doing all right anyway. Appropriate, early and ongoing support can prevent a crisis happening.

There are other family members (aunts, uncles, grandparents, cousins etc) who may also be affected by disability. They have needs too that must be addressed. If a holistic approach to family support is to be taken then it has to be highlighted that many of these family members are the source of support to the family of the disabled child so any help that can be given to them can also directly support the family of the disabled child. The wider family of friends and the community, the issues that affect them and how they can be made more aware are touched upon in the 'Before' paragraph.

Beyond Words

- Disability is not a condition, it impacts people (and people are different)
- The needs of all family members should be highlighted particularly:
 - (a) disabled child/young person
 - (b) sibling/s
 - (c) parent/s
- Appropriate early family support with no red tape
- Awareness/information/training for all family members and those who work with them

JUST US

In the midst of all this – diagnosis, disclosure, and the family view of disability – there is often a sense of aloneness and isolation, of being on the outside looking in, on the margins. Families feel this, and often it is with great reluctance that they will share these feelings outside their immediate families. It often seems that the issues around disability just affect them and that no-one else has experienced these feelings before.

As an issue-based organisation, the Family Information Group has tried to show families, and those who work with them, that many of the issues affecting family life go beyond the immediate family. Also, like other groups, we have tried to point families in the direction of others in a similar situation so that they do not feel totally alone and isolated. Although some families are reluctant to join support groups, there are many organisations which can provide information that is supportive.

At times, such situations are not helped when some people who work with families do not see the connection with other families and with the wider issues. Tensions can arise when, mistakenly, those who are in a position to provide services are often seen as the ones who plan and resource services and indeed have choices over the funding of services. There is a clear need, in certain

circumstances, that those who provide services on the ground also work in partnership with families, in an advocacy role with them, to try and gain access to the services that are needed.

Families should not be left alone unless this is what they genuinely want. Each service provider (health visitor, social worker, occupational therapist, physiotherapist, nurse, doctor etc) should not see themselves as working alone with the family and only interested in their own particular profession. They must work together and in a co-ordinated way (see “key working section”), giving out appropriate relevant information (see “information section”) and with a sensitivity and empathy which such situations merit, using the full resources of both the voluntary and statutory sectors.

Of course, the trauma of having a child diagnosed with a disabling condition can never disappear. However, with appropriate relevant support, an awareness that you are not alone and an understanding that there are others willing to help, the trauma can be lessened, but never taken away.

Beyond Words

- Issues around disability may make families feel isolated but these issues do affect others
- Advocacy role for those who work with families
- Relevant accessible information
- Co-ordinated, integrated services – key worker
- Full use of resources in both voluntary and statutory section
- Awareness training for families and those who work with parents and families.

INFORMATION

This is yet another key area for our group. Indeed, our group evolved because there has been what we saw as a lack of accurate, up-to-date, relevant information in a suitable format. This includes information on the role of professionals, on services available, on housing, education, transport, equipment, access and related issues.

Also, many professionals are not aware of the family aspect and view of disability. To be sensitive and to have empathy it is important to be aware in this way. Sometimes we have to leave behind the models of disability that we have learned and simply be with the families.

Too many times we have said it to ourselves or heard other people say it: "If only I'd known." It is true if we had known something in advance, perhaps we would have made a better decision or a different choice. Perhaps it could be just a small, insignificant matter, but also there is a possibility that major decisions are made without the relevant information.

Making decisions and/or choices can sometimes be very difficult, particularly when you have a number to make at the one time. To make an informed decision or choice, as most of us would want to do, it is obvious that you need relevant information. That information can come from a

variety of sources, both formal and informal. The informal support information that passes between individuals and groups in the community should not be overlooked; it is valued by those who use it.

It is true that we have a lot of information at hand. An abundance of information, however, is not the same as relevant information. Indeed, often too much information can be just as confusing. We have advice centres, telephone help-lines, advisors, information leaflets, books, videos, presentations, awareness sessions etc and on and on it goes. Yet we still have people who say they do not know what they need to know. To produce effective information we must stand back and be clear about what we are saying and to whom we are saying it. Difficult as it may be, we have to try and get inside the heads of those to whom we are delivering the message.

However, this is still not enough; we also have to scrutinise how we present information.

For information to be useful, it has to be **relevant** to the person who wants to use it. This may seem very obvious, but many people receive information that is not relevant to them at all. Perhaps the information provider may think it's useful but that is not the same thing. Some organisations build in a check system to find out from the person if the information has been useful.

To ensure that the information can be used effectively, it must be **accurate** and **up to date**. There is nothing more frustrating to have information at hand that no longer applies, or which has some errors in it that lead to even more frustration.

Accessible, when it comes to information, can mean a lot of different things to different people, but basically people must be able to get the information.

The **format** that the information is presented in is very important. If it is not in the relevant format for the person who needs it, then really it is useless. There are a number of different formats or ways of presenting information, depending on who wants to use it. Often it is worthwhile thinking of a general format that would suit most audiences. For example, it is just as convenient to have published material in Large Print for the general audience as it is for those who have visual impairments. Braille, use of symbols, jargon-free language, audio, video, through computer technology, websites, internet, database, drama and subtitles are just some other formats or ways of presenting information.

Many of us are so caught up in the **language** we use that we seldom realise that most other people just do not know what we are talking about. The specialist language used in some work situations is referred to as jargon.

We often take this language and use of words and phrases for granted, and this can lead to a breakdown in communication when we talk to people outside our working environment. If we have to use language that may be unfamiliar, it is good practice to explain what we mean and define any unusual terms.

As a result of our own work, which falls well short of some of the points raised here, I feel that the time is right to explore a more co-ordinated approach to information provision. The **one-stop-shop** concept is only a starting point for discussion, a framework to build on.

This concept has grown out of the frustration of trying to access information over the years. It attempts to dispel any procedure or process that leads to frustration and confusion. At the same time it advocates the independence of organisations in this field and respects the confidentiality of their work.

By initiating a one-stop-shop it is argued that those who are seeking information will have just the one point of contact initially. The onus will be on the information provider to seek out the relevant information, rather than the information seeker. At different stages, additional contacts will be made for someone seeking information.

The person at the initial point of contact should be sensitive, approachable and knowledgeable – whether this

contact comes through a telephone call or in person. If it is a telephone query it should be answered by a person if possible, not an answering machine, and definitely not a computer-generated voice listing several options.

If time is needed to gather information, then an offer to call back – in response to a telephone query – should be made, thus saving the caller money and giving time to explore the request more fully. This point of contact ideally would be created as independent of interested groups and organisations but linked to them. If this was not possible then a key person in each of the interested groups should be appointed.

Groups would have to commit themselves to the concept, share non-confidential information and work in real partnership for the benefit of those willing to use the service. The resulting network would then be the backbone, linking support to the person at the point of contact. All of this would be backed up with an up-to-date, relevant and accessible database of information.

To make this idea work, much soul searching will be needed. Now is a good time to begin. Information is too important a commodity to be handled in ways that only lead to confusion and frustration. We can learn from the good practice of each other.

Beyond Words

Information must be:

- Accessible
- Jargon free
- Appropriate and relevant
- Given at the right time
- Given as early as possible
- In a suitable format
- Accurate
- Up to date

Initiation of a one-stop-shop for information provision that cuts across all agencies.

KEY WORKING

For some families, the various professional workers, each offering their own service, can lead to confusion and frustration rather than a feeling of being supported. This can be particularly true just after diagnosis and disclosure, when everything is new to families. Services need to be planned and co-ordinated. This is where a key worker is needed. Unfortunately, not all families have such support, particularly when it comes to physical and sensory disability.

The key worker, if he/she is trusted by the family, could act as a go-between, a go-between for the services and service providers which are being offered to the family. By being supportive this means that the key worker will explain fully to the family the role and duties of each of the professionals who become involved with the family before they do (if possible). But more than this, the professionals will be introduced to the family through the key worker as the focal point of contact.

Often, it is this introduction to professionals that can be very emotionally draining for families as they are asked to recount the diagnosis or other details to each visiting professional. By having to do this, many parents are not only recalling the diagnosis but actually reliving it and in a very traumatic way.

If the role of the key worker is really to co-ordinate services then he/she should have been able to compile a complete picture for the visiting professional of the family – the diagnosis and the condition – so that this hurtful process of repeating everything does not have to happen, unless the family wants it to.

This does not mean that professionals pop in and out of families with no real communication or genuine contact. Instead, the family will have a clear idea of the professional's function in advance, will be able to talk to him/her in a more relaxed atmosphere and not feel forced to relive a traumatic memory which is always to the forefront of their minds.

The key worker, after the initial introduction, may no longer be required during that visit. As time goes on and more and more services are introduced to the family, perhaps the key worker may not be needed as much as initially as the more specialist services come to the fore. As long as the family know that they can get in touch with the key worker, this may be enough for most families as they begin to learn to live with their new situation.

Through time, one of the more specialist professionals could take on the role of the key worker in certain areas if the family were happy with this, thus releasing the original key worker from his/her role. For example, a health visitor

could originally be the key worker but through time a social worker could become more involved with the family, offering practical information etc, then perhaps the social worker has more regular contact and becomes the key worker.

Families of children with disabilities need help and support. Ways have to be found to maximise this help and support. But also, ways have to be discovered to ensure that those who provide help and support are not thwarting these by confusing, unsystematic approaches, or by over bombarding families with information and services which only accentuate the trauma the families already feel.

A key worker can help identify the services with the family and explain the role of the service provider as well as the service itself. They can also introduce the service to the family in a sensitive and planned manner. However, the vital key component to ensure all this works is proper information.

No-one will have all the information needed. However, a key worker has to at least have access to information and know who and where to go to for different enquires. The key worker will need to know about the range of services available, not only from health and social services, but also from other statutory and voluntary agencies. Also, he/she will have to have a reasonable working knowledge of the functions of other professionals.

The key worker would not have to know all the medical implications of different disabilities, but a working knowledge of those he/she comes in contact with is vital. Already, certain databases of information on conditions are available and being used by various health boards. Contact a Family have a comprehensive information resource on various conditions, including support groups, known as the Contact A Family (CAF) Directory.

To ensure that information is useful, it has to be shared. Often this does not happen. Parents often have to ask, rather than information being offered, and there was awareness that this is an issue for many other parents. On the one hand we have the various services and providers of services. On the other we have the families. In between all this is the vast amount of information – some useful, some not so useful. If the concept of key worker is to be developed then the area of information and its provision is important.

Certainly it will not develop at all if a central resource of accessible information is not available to the key worker. However, to evaluate if it can work at least initially, the concept should be tried, and tried realistically. Giving someone who already has other responsibilities the title of key worker does not necessarily make that person one. Also, bombarding someone who already has a full caseload with the further duties associated with a key worker will not work.

Time is needed, quality time, for the key worker and for the family, if there are to be any benefits. Resources must be made available so that the key worker has the support that he/she needs while working with families. This is a long-term investment that could prove more than cost efficient. However, the initial costs will be quite high, particularly around the time of diagnosis. If trust can be established or even restored between the family and the statutory agencies involved then this could prove to be a very positive relationship in the time ahead. Building trust takes a lot of time and resources.

Beyond Words

- We suggest an immediate pilot project ie funds sought to employ a full-time dedicated key worker (with qualities outlined below), supported by adequate resources and relevant information sources. This project to be monitored and evaluated.
- Excellent communication skills
- Ability to demonstrate empathy
- Knowledge and experience of disability issues
- Appropriate education/training in family work
- Specialist training in dissemination of information
- Non-judgmental attitude





- Ability to liaise with other statutory and voluntary agencies
- Knowledge of local resources
- Good counselling skills
- Willingness to follow through enquiries
- Ability to work unsocial hours (possibly be on standby)
- An understanding of loss and dis-empowerment

INCLUSION

This means different things to different people, depending where you are at. Yet it is central to a number of issues affecting families and those providing services – housing, education, recreation and social life etc. Not that long ago, disability was often treated as a separate isolated subject and those with disabilities were often found outside the usual systems with very specialist facilities. Then there were moves towards fitting people in, integrating with others; often this was without support or preparation. More recently, inclusion has become the buzzword. It is seen as more than integration, rather treating everyone the same with appropriate planning and support, where necessary. Everyone is included.

Another tool in trying to make this happen is consultation with those who use services, and legislation meant to give some sort of protection of rights. However, with all this, at times there is a feeling that if something is seen to be done then it is really happening. This may not necessarily be true. Consultation exercises are often carried out with key organisations but this does not mean that those most affected are having their say. Many perceive that they do not want a say anyway, perhaps because they feel they would not be listened to, or have not been listened to in the past.

Of course there are still people in the margins, people in specialist facilities, some people in what are seen as integrated settings which make them even more isolated. For some disabled children and their families, inclusion means very little as they do not feel part of the community they live in. Inclusion covers all areas and serious changes must be made on the ground and at planning level to ensure it happens. There are those who believe that inclusion is about access; access is important but it is not inclusion. Others believe that by simply involving people in already established groups, organisation, committee etc that this is inclusion. In reality, this may not be even integration.

Inclusion has more to do with respect, change, support, awareness and the removal of physical, mental, attitude barriers that all can prevent inclusion happening. Inclusion should not be seen as an ideal, rather an achievable goal that is within all our reach if we really want to make it happen.

Beyond Words

- Inclusion means everyone involved changing
- Inclusion needs preparation and new ways of working
- Mutual respect
- Sense of ownership

ATTITUDES

Attitudes could be called access of the mind. If attitudes are positive then it is much easier to address physical access or any other issues that arise around disability issues. Children and people with disabilities have to be seen as people first and treated as such; unfortunately this does not always happen.

Many people see the disability and act on their own prejudices first. Others treat children with disabilities as if they do not exist, talking to the parents or carers of the child about the child as if he /she were not there. Many people just do not know how to treat people with disabilities; this is where awareness training could help. Also, common sense can prevail. If you want to know how to treat someone with a disability, ask them. If you want to know what the right language is to use, discuss this with them. Sometimes it is as simple as that.

Beyond Words

Only with a greater degree of awareness, through awareness sessions, training and education as well as directly working with disabled people, will there be any opportunity of changing negative attitudes, perceptions and prejudices.

TIME OUT / RESPITE

Time out in the context of families who experience disability is simply that – time out. It is a short period of time out from the usual routine, often referred to as respite or respite care and it can take different forms.

There is little or no realistic respite provision for families who have children with physical and sensory disabilities and many families with children and young people with learning disabilities often face very similar difficulties. This is despite the positive impact that respite/time out can have.

In relation to the time out concept, flexible short-term care could mean a few hours, perhaps a day or overnight. These chunks of time could be over a number of days. However, the main difference between time out and traditional respite is that the time out facility is not respite over a prolonged period of time. Also, the child may not have to leave the family home although in some cases he/she might.

There is no doubt that time out is needed and needed urgently. However, it will take a multi-agency approach that is sensitive to the needs of children with disabilities and their families, if it has a chance to work. It will take people with vision and energy within the statutory

agencies if all the bureaucracy is to be overcome to make this concept work.

There are a number of types of provision that already exist that could be used more fully to facilitate time out:

- Hospice
- Playgroup/Special Playgroup
- Nursery/Special Nursery
- After Schools Club
- Homework Club
- Day Centre
- Youth Club
- Specialist Activity Club
- Childminding in family home
- Childminding outside the family home
- Host families

These are some of the main areas of provision. In all these it is essential that the child is safe, comfortable, stimulated and that often the provider of time out is known to the family, or gets to know the family and the child. Also, all staff involved must be trained or have relevant experience of working with children who have disabilities.

One of the other main requisites is that provision outside the home must be in an accessible property, particularly for children in wheelchairs and that there should be appropriate provision with regard to equipment and facilities. An awareness and sensitivity to disability issues is essential.

It could be envisaged that existing provision could, with a little modification, be adapted to meet the needs of children with disabilities. Indeed there are already a number of children with disabilities in such provision. However, sometimes a separate specialist facility is needed, at least at first.

Time out is cost effective for everyone. It could give time for leisure, to study, to take up a career, to work or simply just to help someone to have a good rest. The pressures of living with disability are too much. It is time to look at the situation realistically and to radically address the needs of families.

The potential to try and address time out lies in the collective experience of all those involved, including the parents and the children. It will take all that experience if it has a chance of working. Transport, premises, staff, facilities, equipment, stimulation – these all cost but so does the undervalued caring provided by family members, particularly parents. It is time to give a little back.

Beyond Words

A comprehensive review of respite provision and research into innovative ways of providing respite in various settings (including the home), building on existing models of good practice.

LIFE LIMITING CONDITIONS / PALLIATIVE CARE

Families of children with life-limiting conditions have been raising issues around this for years eg the need for support from the time of diagnosis, a key worker to co-ordinate services, creative innovative respite/time out, respect for the parents' and children's views etc. These issues have also been raised in other areas of disability but they take on a greater sense of urgency when disabled children and young people with life-limiting conditions are involved.

But there is also expertise within the community that can be resourced, developed and called on to support families; none more so than the families themselves as well as those who have experience of this in the past.

Families, including the children with life-limiting conditions and their siblings, staff from the Children's Hospice, Macmillan Nurses, Sargent, sensitive and caring staff from hospitals, health and social care settings, child development projects etc are just a few examples of human resources that could be the basis of a mechanism to move this forward.

The real challenge is can we put the needs of those who would potentially benefit from palliative care above the needs of installing a perfect mechanism of delivery first?

Families want a high quality of life; they are the potential monitors and evaluators of any schemes. Listen to them first, along with those who work in this field and let all of them form and shape how this programme is to be delivered.

Palliative care will not take the pain of death and dying away. But maybe, just maybe, if it is delivered sensitively, it will give some families back a little life, a quality of life they deserve, as a right. A right many of us take for granted.

Beyond Words

- Holistic, integrated approach to services, informed by parents, disabled children/young people and siblings.
- Initiation of key worker system and twenty-four hour support for families.
- Flexible, imaginative and innovative approach to respite, meeting all the family needs.
- Training and awareness sessions, from a family viewpoint, for those involved with families, including issues arising from diagnosis and disclosure.

HOMES FIT FOR CHILDREN

Disabled children often need adaptations to their homes to make them safe and accessible to live in. The Disabled Facilities Grant (DFG) is supposed to help in this.

However, because there is a Test of Resources (means test) as part of this process, some disabled children are missing out.

Many families who have disabled children cannot, in reality, afford the adaptations that have been recommended by an occupational therapist as necessary for their child.

An unjust and unfair means test excludes them from a quality of life which by right they are entitled to because:

- Parents of disabled children are means tested, not the disabled person (as is the case with disabled adults).
- Means test (Test of Resources) does not include actual expenditure.
- Additional costs of caring for a disabled child are not fully included in the means test.
- The rights of all family members, including those of the disabled child, are being denied. Rights to a safe accessible home, dignity, quality of life and the right for children to be children.

- Families often do not continue with the grants process because they are assessed to pay a contribution that they just cannot afford.
- Time delays, bureaucracy and insufficient number of occupational therapists are all added concerns, which can create even more difficulties.

Beyond Words

Abolish the means test in relation to disabled children and their families.

CONSULTATION

Consultation, in many circles, is dreaded. Often opportunities to consult are seen as a waste of time because nothing happens as a result. Below are some points to consider with regard to this.

Beyond Words

- Summarise main points of the consultation in bullet form for consideration
- Ensure that summary is short, accurate and to the point
- Allow space for contributors to make their own suggestions as well as commenting on specific items that the agency/department believe to be of interest. Often there can be resentment when issues highlighted on a specific subject are not the same issues as experienced to be of concern by others
- All language is jargon free and in plain English with size 14 font (with alternatives of course in other languages that are required, but again in plain versions).
- Provide summary and full copies of the consultation document to those who want them but do not overload people with materials they do not need.





- Fully acknowledge those who do reply by at least commenting on their contribution.
- Follow up with updates and progress reports. If people do respond, they should be respected enough to be given regular information on whatever policy they commented on.
- Involve parents and those who use services in the planning and delivery of the consultation process and adequately resource those who do as their expertise is a valuable commodity which is often given value through lip service but seldom given any monetary value.

POLICY IS NOT PRACTICE

In working with voluntary groups, families and parents the statutory authorities should appreciate the frustration that is felt by service “users”. This frustration is often as a result of the lack of response from statutory organisations to the issues raised in the community. There has to be recognition that families of disabled children can have a professional input in the planning and provision of services for their children.

The people who use Health and Social Services, and the professionals working on the ground, know the needs. Recent reports only serve to confirm what is already known. Yet still there seems to be little co-ordinated action on the ground to impact the lives of the “users”. Although at policy level, and the endless directives from government towards the inclusion of “users of services”, whatever involvement there is does not seem to have any significant effect on disabled children and their families.

Let us be blunt. There is significant unmet need. It has to be stressed that addressing unmet need does require a financial commitment but also there are areas of concern that can be addressed with a change in attitude, a change in procedure or simply a shift in emphasis and priorities. For too long, and it has to be repeated over and over

again, disabled children and their families have seldom been a priority when it comes to family support services.

Service “users” have had to listen for years about the limitations and restrictions that pruned budgets have led to. Now is the time for the Department, Boards, Trusts and other agencies, to listen to the people who use the services that are purchased and provided on their behalf. However, it is essential that a long-term view of how disability impacts on a family be taken to appreciate that annual budgets only thwart an effective response to this.

Unless there is good practice, then all policy directives are meaningless and only add to further frustration, as the perception builds up to a myth that something is really happening.

Beyond Words

Real inclusion of those who use services in the planning and provision of such services, with appropriate relevant support for **all**.

TRANSITION

The depth of feeling over this issue for parents and disabled young people is very strong. For many teenagers the move from childhood to adulthood is difficult enough, for disabled young people both in mainstream and special schools, it is often horrendous.

For many parents, a mistrust of statutory agencies, particularly those in the health and social services field, is very apparent as for some it seems that very little planning has taken place to try and ease children into adult services. There is also a sense of frustration at their voices not being listened to in the past.

There is particularly a sense of sadness over how each individual has had to fight for their own disabled child. Parents of younger children we have listened to in the past seemed genuinely disturbed by this when they heard the stories of older parents. Nothing seems to have changed.

The lack of services available for disabled children, particularly speech therapy, occupational therapy and physiotherapy, contribute to the perception that there is not enough support for teenagers. This situation is exasperated when children are facing adult life and leaving school, and services are even thinner on the

ground, if there at all. Indeed, there are very few **opportunities** for disabled students in the North West compared to those young people who are not disabled.

Beyond Words

- More planning is needed towards integration and independent living, perhaps with intermediate steps (14-15 years); more timely input and children have to be listened to. From an early age, children should be given an insight as to what is out there, with assistance from parents, carers and schools.
- Befriending, developing relationships and the skills necessary to do this for children and young adults, and how parents can be supported in facilitating this.
- It is futile to start support at 14 or 15 if there is no support earlier. There should be support from a very early age, perhaps at the diagnosis and disclosure stage, facilitated by the appointment of **a key worker** to the family.
- The concept of key worker has yet to be developed fully but many parents indicate the need for some kind of co-ordinator. Support, information, and good communication, including support from other parents, are important, as is the availability of more choices.
- There also needs to be a realisation that our young people have rights, rights that seem to be denied.

CONCLUSION

As already pointed out previously, the issues affecting families of disabled children are known, and have been known, for some time. Despite this, for many families little has changed. This has to be repeated until such times as we can go beyond the words and act.

If this publication can focus or refocus attention on these key issues by all of us, then it will be worthwhile. But to have a real impact on the ground, as stated earlier, families affected need to see changes, real changes.

Below is a brief summary of what changes could happen that would significantly enhance quality of life. As a community, we have to ask what response can we make to go beyond the words; perhaps these responses are worth considering as we consider where we are going next:

- The building of an inclusive community where the rights of all are promoted.
- Real involvement of those who use services in the planning and provision of such services.
- Priority given to the needs and issues affecting disabled children/young people and their families.

- Investment of resources in services to families of disabled children.

There can be no real conclusion until all of the issues are addressed in one way or another. Then, and only then, can we go beyond words.

