

A FAMILY VIEW OF DISABILITY



## FAMILY INFORMATION GROUP

Working with families of children with  
physical and/or sensory disabilities

# IN THE TELLING

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**Winter 2001**



This publication is funded by the Childhood Fund of the EU  
Special Support Programme for Peace and Reconciliation in NI

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## **PREFACE**

In being face to face with the unthinkable, no one word or phrase can adequately represent the feelings experienced by parents when told, usually by a medical doctor, that their child is disabled.

As an academic researcher, reflecting back upon studies which addressed disability in childhood over a fifty-year time span, the overwhelming feeling is that so much, in terms of welfare provision, has changed, and yet so little has changed. The perspective of the carer is often characterised by feelings of isolation, pain and anger. In 1991, our study looked at the life experiences of twenty-four families who had a child with Cerebral Palsy. We focused upon the social and emotional implications of carers. The message was clear, as evidenced in the title of the book which summed up the feelings of one mother: **'I felt like running away.'**

Literature from the 1950s demonstrated an evocative and difficult journey through the unknown. Our 1997 studies demonstrated that parents had often to fight for what we now understand as equality. The danger is that families and children became objects of a system: they had to fit specific criteria; they had to be placed on waiting lists and understand the differing roles of professionals involved in the care of their child. The fact that duplication occurs, that access to services is impossible, that budgets seem to dictate when and where a need can be met, emphasises a theme of powerlessness.

Brendan's research "tells it as it is", in sharing with the reader the pathos of parenthood in the context of a permanent and progressive disability. He illustrates clearly that handicap is associated with attitude and that disability can be managed. However, the focus is upon the flaws of the so-called medical model, with the attendant emphasis on what the child cannot do. True empowerment advocates for the child as a child, not a disabled child. Similarly, the emphasis of parent as parent, as an expert on their own child, is a message that professionals from all disciplines need to hear. The research shares these evocative experiences, with the underlying message that professionals can create barriers to understanding which detract from the quality of the service offered.

*Huw Griffiths  
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Winter 2001*

## **COMMENT**

The subject matter of this research is: how parents have been told about their child's disabling condition, often referred to as disclosure. It is how the news is broken to them – **In The Telling** – rather than the news itself (diagnosis). Most direct contact will be made with families locally, but other materials will be secured in relation to families elsewhere.

Focus groups, individual in-depth interviews, semi-structured questionnaires, participant observation and the use of tape-recorded interviews are the main tools used to gain information relevant to the research.

Parents of children with disabilities, some of those who are involved in the process of diagnosis and disclosure, as well as reference to relevant literature, were all part of the process of gaining information relevant to this subject.

Through a wide network of groups and individuals – built up by the Family Information Group – contact was made to engage the participants, some known to the researcher and some not known.

In looking at the experiences of people around diagnosis and disclosure, I hoped to gain a picture of what happened for those people at that particular time. Also, if certain themes emerged, these were also to be explored, debated, analysed and, if possible, lessons learned.

On a personal level, this is an opportunity to test the relevance of what once seemed to be a very individual experience in relation to the wider world of theory and research and to gauge whether such experiences, channelled in the right direction and using the appropriate research tools, can lead to real positive change. I want to thank my wife Teresa, without whose help and support none of this would have been possible. Also, Donovan, Ruth and Jack, who keep our feet firmly on the ground, and all the families who shared their pain. I hope that in this telling we will begin to turn the tide towards positive change, and access the right to the quality of life that we all deserve.

*Brendan McKeever  
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## **INTRODUCTION**

The process of diagnosis and disclosure and how it is handled are central themes to this research. It is widely recognised that delivering “bad news” is not easy in any situation, particularly when it relates to a child with a disabling condition. This piece of work concentrates on the experiences of parents of children who have disabilities, how many of them were first told about their child’s condition and their feelings of how this was handled.

Also, I am one of those parents, and I bring to this my own experiences, my knowledge and, of course, my own prejudices and assumptions. Life does not take place in a vacuum, and I see myself as a participatory observer in this work. Our experience of diagnosis and disclosure, diagnosis of our child at four with a progressive muscle-weakening condition – Duchenne Muscular Dystrophy – for which there is no cure or treatment, was not a very positive one. Since then (ten years ago), I have been carrying my own negative baggage around.

This research has given me the opportunity to move beyond our own personal feelings around the hurt and pain of negative diagnosis and disclosure. In this study, I hope not only to hear the views of parents, but also the comments of some people involved in the process of delivering the news, as well as studying some of the relevant literature.

In studying this particular area of concern, certain questions and themes arise which will not be fully addressed in this work. However, often there are no answers, and it is indeed by raising the question that space is made for further research and investigation that could possibly lead to certain answers.

For example, there is not enough information available as to the extent of families having children diagnosed with certain disabilities, never mind whether these are positively or negatively handled. Also, there is little information available from consultants, doctors etc as to their feelings about the process.

What is clear, however, from my own experience and from the experiences of parents who have talked to me as Facilitator for the Family Information Group, is that there are many misgivings about how diagnosis and disclosure have been carried out.

This is confirmed in earlier research carried out by **Bamford, Griffiths and Kemohan (1991)** and in the findings of **Leonard (1996)** in her report *Right From the Start*. It has to be emphasised that these misgivings have little to do with the diagnosis itself, or the hollow feelings of shock that often follow.

From my experience, and the experience of some other parents, I believe that a diagnosis badly handled can lead to a serious breakdown in communication and trust, which often cannot be rectified, between parents and those who work professionally with them.

There are other themes, such as the absence of support, lack of information, isolation, disempowerment, elitism, the role of professionals, respect and the value of parents, which should emerge from the literature, from the parents' statements and also from some of those who work professionally with families.

By carrying out this research, I hope that the concerns of parents will be highlighted. Also, I envisage that, through the sharing of experiences, a good model of practice will emerge, building on positive experiences as well as the work of researchers. Change is often very slow and difficult to achieve, yet change can happen when there is openness and honesty.

## **BACKGROUND**

On a personal level, it is with great apprehension that I approach this subject of diagnosis and disclosure. For some time, I have wanted to look at other people's experiences in this area, but have always stepped back, in fear that my approach would be too subjective to have any meaning.

I have wanted to do this for some time because of my own experiences of diagnosis and disclosure in relation to our own child. However, it is more than this. For the past four years, I have been involved full time in a project – raising awareness of “the family view of disability”.

Central to this view is the social model of disability, as opposed to the medical model – a model that takes a holistic approach to disability, rather than just associating it with a medical condition. In reality, what few services exist are usually directed at the child with the disability and no-one else, yet the whole family is affected. This work is through the Family Information Group, of which I am a founder member. **(See Appendices 4 and 5: Aims and Objectives.)**

This work has brought me into direct contact with many families. For a lot of these families, the whole area of diagnosis and disclosure is either on, or just below, the surface. Just as important for many families is the prognosis. Much effort and time is spent searching for a prognosis, or at least trying to work out one with which the parents can live or come to terms.

Often, however, what emerges is not so much their feelings in relation to a particular diagnosis, but towards the disclosure – how they were told, when they were told, where they were told and who was present. Unfortunately, a number of parents have had very negative experiences of this.

This piece of work is not actively seeking out these negative experiences. Instead, it intends to take a balanced view, aspiring to record both negative and positive experiences. However, a significant number of parents have reported very negative experiences.

Furthermore, by listening to those who work professionally with parents, I hope to bring to the fore any possible recommendations that they have.

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The Family Information Group has, over the years, built up its own network of parents and groups. I hope that by tapping into these, at random, no bias will be shown towards one particular viewpoint.

For me, this will not be an easy process; I am aware of my own hurt being activated when listening to others. But also, I am aware that there are difficulties interviewing people in positions of authority and trying to remain objective when the same people, or colleagues, are involved with your own child.

At times this has proved impossible, and some potential interview opportunities just could not be followed up. Perhaps this takes away somewhat from the analysis of the information obtained. I will have to acknowledge this, but hope that an appreciation of the personal nature of this work will, if not excuse it, at least give an understanding of some of the associated difficulties.

In this research, certain themes will emerge, certain theories, analyses etc, and this is true of any research, not just academic pieces of work. But for many families, faced with the diagnosis of their child for the first time, there are no theories, no philosophies, no explanations. There is just pain, isolation, confusion and shock, which directly relate to the themes of loss, transition and bereavement.

If all these feelings are then accentuated by a mishandling of the disclosure, is it any wonder that at the very point when families need the most support, there is a rupture in communications that sometimes can never be repaired? This is of great concern to those who want to work with families, to support them. It was also a crucial moment in our life history and is now reflected upon in the following chapter.

## **PERSONAL INVOLVEMENT**

When you have sat in a room, lost for words: when your whole world has been torn apart with news so devastating that you cannot believe what you have heard; then, numb and confused, you drive home as if in autopilot because your brain is not functioning; when all this has happened and more, is it still possible to talk about academic research? I just do not know.

Ten years ago, in a Belfast hospital, our son – who was four at the time – was diagnosed as having Duchenne Muscular Dystrophy. This is a muscle-wasting condition for which there is no cure or treatment. Our son is now fifteen and has been permanently in a wheelchair for seven years.

To be told such news is hard enough; but to be told it in a way that, in hindsight, seems so negative, with no sense of hope or positivism, and to be left with little or no support, this is where the research begins. But it begins with hindsight. Few people, unless they have been through something similar, can ever imagine the depth of pain, of loss, of bereavement that is felt when you are actually robbed of your dreams. You are marginalized, to use a current piece of jargon. You are driving towards the brick wall of life, just hoping the impact will smash the pain to pieces. But life goes on.

Coming out of the shock, but not the pain, has led me into a different world where the values of life are so different that disability and the issues around it are now a way of life. Marginalization is only a concept in the reality where many other families are facing the same issues as you. Change is slow and there is a realisation that the wider community, despite all the legislation, has little or no concept or sensitivity towards disability issues.

I helped to found a small organisation, the Family Information Group, to help raise awareness of these issues: to advocate for change, to campaign. This Group is founded on the principles of community development, advocating that those who use services should be involved in the planning and provision of them. I have now worked full time for over four years for the Group. This research is part of that drive towards change.

It is hard to imagine that, from sitting in that room ten years ago, I am now trying to reclaim that power lost so long ago – the power of control

over our own lives. Academic research may not be the way, but the possibility of using academic tools to effect change on social policy is attractive.

My own journey has led me to value the experience of parents, to recognise them as professionals in the knowledge and care of their children. It also has made me question the so-called professionalism of some people who work professionally with us families.

With this insight, right or wrong, I can now look back to the time of diagnosis and disclosure and examine it with a little more objectivity.

In hindsight, we can then look at the diagnosis and disclosure. In this research, we will then look at how the disclosure happened (interviews with parents and those who work professionally with parents), undertake an analysis of this in a wider context (literature review), as well as highlighting good practice from various sources.

But all of this stems from my own personal involvement. In some ways I am lucky: I have found a voice and a way of channelling this – many others have no voice at all. In one sense, I have moved in from the margins, as an individual, only to find that my community (of families with children with disabilities) is itself marginalized.

In looking at these issues, we are touching on crucial areas of concern, not only to families, but also to those involved in the planning and provision of services. If mishandled, diagnosis and disclosure cause such breakdowns between parents and those who work professionally with them. One of the arguments that could be addressed is that it happens because those who use services are not directly involved in their planning and provision – in today's jargon, "user involvement" or "consumer involvement". This is one of the central themes of our Group, born out of our collective experiences. It is time to delve a little deeper.

As a parent, and through my work with the Family Information Group, I have had the experience, first hand and indirectly, of coming across some of the themes outlined already. At times, I may not have been fully aware of this, but often reflection has been a great teacher. I have written on some of these themes, primarily from a subjective and often an emotional standpoint.

Action research is embodied in the personal experience, but also is at the centre of the workings of the Family Information Group, as it

advocates “the family view of disability” – the view that the whole family is affected when a child has a disability. As families, we are not only living the experience, but often form our experiences, using this knowledge to action changes, which is really action research. In my own presentations, I emphasise that it is only one view, one perspective.

There was always in life the possibility that things could get better. That first year saw the end, not just of that belief, but of many others besides. Alone, isolated, and with no idea of how to go forward, we slipped, unknowingly, into shock, and remained like that for several years. The pain had become too much; we could no longer participate in life, in a world from which we were alienated.

Gradually, over a period of four years after the diagnosis, we began to realise that we had a daughter who was only a baby at the time of diagnosis, and we, as parents, had lives too. Although the pain remained, we began to make an effort to pick up the pieces.

We were crushed again when our son, Donovan, was permanently consigned to a wheelchair at the age of eight. But once again we began to get on with our new life, almost forgetting what it was like before.

## **FAMILY INFORMATION GROUP**

In 1997, I helped found the Family Information Group and went on a career break, which has ended up as a career. During 1999, our Group ran a series of discussions with parents and the voluntary/statutory sector. We named this series "Professionals Together". I then wrote a report in 1999 entitled *Listening to Parents – Parents as Professionals*.

The theme of this report is similar to a lot of the relevant legislation in that parents have rights and must be treated with dignity and respect. Often they are not. Other themes already highlighted were: inclusion; the rights of children with disabilities, and the involvement of service users in the planning and provision of those services.

Later the same year (1999), I wrote another report, *Bridging the Gap*, in which I put in context much of the legislative proposals. The theme of this work was that, despite the seemingly progressive attitude towards disability, particularly in relation to legislation, there is still on the ground a lot of distance between theory and reality.

At the core of this report is the argument that the distance between those who provide services and those who use services is widening. Worse still, this is being compounded by the misconception in the community that the needs of those affected by disability are being addressed. The issues around how people are treated, and whether the expertise of those who use services are recognised, are central to this report.

Through my work, I have had published a number of articles on various themes around disability issues. From these publications I hope to draw themes that can relate both directly and indirectly to this research process.

The journey from the totally subjective emotional first piece of writing to the analytical objective observations in *Bridging the Gap* is a story in itself. It is the story of reflective learning, of assimilating knowledge and theories from experience and then testing these theories further in the process of life.

In the end, it has to be said that the subjective journey has led to the altar of the legislative church. For me, now, our work is rights-based; it is not through privilege or by being considered needy or even worthy. It is the right of every family to have a reasonable quality of life for each family member. It is our struggle to eradicate any barriers that prevent this happening.

This is for many of us parents a new concept. For so long, we have been subject to policies that tend to ignore rights and that are based on limited resources. This theme, and the other ones already raised, will now be explored in the wider literature review involving social research and other related documents

My own personal journey continues. The pain remains and there are no answers to some of the questions. We live with the question and try to live with our reality. We have learned so much from life, yet we know the clock is ticking. Quality of life is everything, and this research is part of that process which examines barriers to that quality of life.

## **ETHICAL CONSIDERATIONS**

There are ethical considerations in any piece of research. The importance of confidentiality for everyone involved, and an understanding of what this means, is a very immediate one.

When it comes to research which delves into very painful emotions and which encourages people to relate experiences from a time when they probably felt most vulnerable, it is vital that ethical considerations are taken on board.

A situation developed in one of the focus groups when one of the parents got very upset. I had to point out that I was sorry I was unable to offer emotional support as I was not trained in that area and it had not been my intention to raise very deep emotions. This was one of the reasons that the interviews with parents were semi-structured with a questionnaire.

However, my main dilemma is that as well as being a researcher, I am also the parent of a child with a disability. In other words, I cannot detach myself from the stories that the parents relate. The feelings that come to the surface in the parents who have talked to me have also brought my own emotions and feelings to the surface. At times, this must have clouded my own interpretation of what was being related.

Furthermore, there are ethical considerations to be addressed when attempting to interview the "professionals". At an early stage, I realised that it would be too difficult to interview anyone who was directly involved with our own family. I would have found it too hard to marry what they would say against the reality of our own experience. Indeed, if what was said and what was done did not correspond, this would have created a very serious dilemma for me. How would I be able to transcribe in research, words and deeds that which did not reflect reality as I knew it?

By acknowledging these ethical considerations, I hope that a better understanding of how the research was carried out will emerge.

## HOW THE RESEARCH WAS CARRIED OUT

There are merits in various types of research. For me, when looking at how to do it, I have to ask myself what am I looking for and how best to find it. There are philosophical debates about what is the best approach, but the crux of the matter is what will work best in the given situation.

When I look at the task ahead, the collection of experiences around diagnosis and disclosure, I know that I cannot carry out an objective study. I have my own experiences, which inform and colour the way I see things.

Of course, these in turn can have a detrimental affect on research findings and analyses unless measures are taken to thwart this. But I am part of the research, not an objective observer.

On a personal level, I would have to go one step further and state that I am really in there with the others. I do not have to try and enter their world; I am already there.

Indeed, it is the demands of the research and the underlying questions which determine the research approach. Also, at a practical level, my experience of working in focus groups and one-to-one with parents is that the stand-back objective approach, treating people as objects of analysis, just would not work. Many families locally will tell you that they are *researched out*.

To gain the trust and confidence of the parents involved in this research, the researcher will have to be sensitive, empathetic and honest, and I believe it will help if the researcher has been through experiences similar to those of the parents. The focus of this research is on one of the most traumatic times that a parent ever has to go through.

In a presentation by **Harry Marsh (2000)**, former director of Contact a Family, he summarised what many parents feel but seldom acknowledge:

'It can be rather painful for some parent carers to see academia, government and national charities slowly catch on to the messages they have been crying from the rooftops for many years.'

This research acknowledges the value of personal experience that parents have obtained through caring for their child with a disability.

This theme permeates the work of the Family Information Group and has been the cornerstone of its series of events under the title “Professionals Together”. This series brought together voluntary and statutory workers with parents in workshops discussing common themes as fellow professionals. **(Appendix 2)**

Also, my own experience has been highlighted as the starting point of this research. I acknowledge that every effort would be made to monitor my own subjectivity on this issue by constantly reflecting on what I am doing and by scrutinising my approach to parents and the questions that I may ask them. On a personal level, I appreciate that at times this will be very difficult, as there are strong emotions and feelings involved.

As a further cross check, a small number of professional service providers will be asked for their views (this will be outlined a little further in the next chapter).

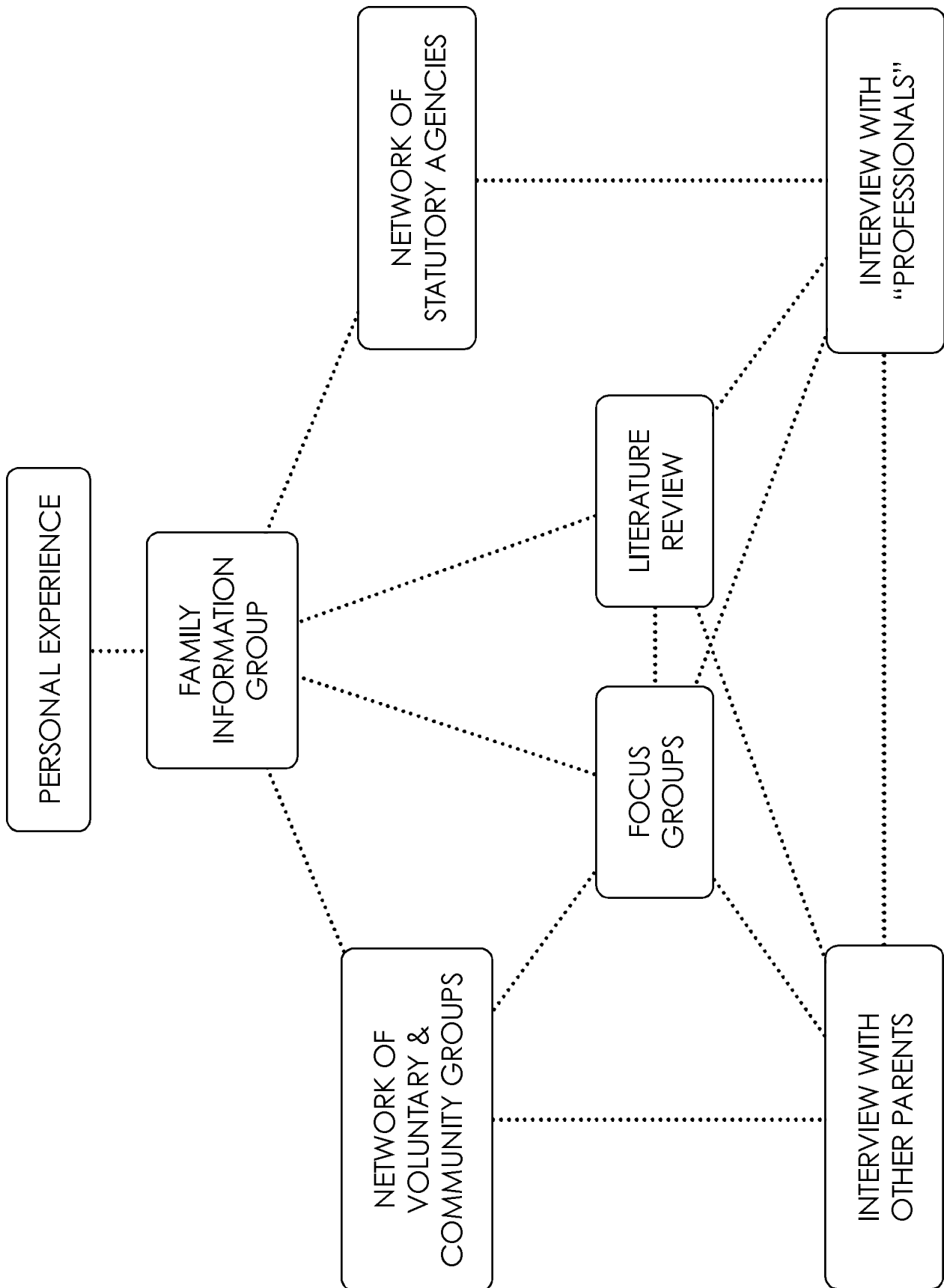
The final piece of the jigsaw will be the literature search. This search will include books, periodicals, presentations and journal entries. This is outlined opposite in a flow chart.

There has to be an acknowledgement from the author that he knew some of the parents. However, as this was through the work of the Family Information Group and its network, it has to be stressed that the individual experiences of the parents around diagnosis and disclosure would not necessarily have been known. All participants were selected from the Group’s network of parents, groups and voluntary and statutory agencies on the basis of who would be most willing to participate. This would be based on past experience and referral.

From all of this, I will draw out themes, which have a bearing on this research, to be discussed and analysed. This is quite a challenge, but if common themes do emerge, it will certainly validate the individual experience and confirm the sentiments of Harry Marsh, to which I have already alluded.

Through this method, the intention is to get right into the heart of the subject. At times, it will be as important to note *how* things are being said just as much as *what* is being said.

If a clash of interests does emerge, between my own personal perceptions of some people who work professionally with parents and



## ***Family Information Group***

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the reality of their actions, this may cloud my own judgement as to whether I can even consider including them.

I have acknowledged my subjectivity and the potential limitations that may arise. However, there is also the other side of the coin. My experience will hopefully give me the insight and sensitivity that is needed to carry out an effective research task.

Indeed, I would argue that this methodology might be the only way to extract the information needed that will make this piece of work effective. If this research does raise pertinent questions then it could just be the beginning.

In the drive towards change, the Family Information Group has action research as its tool or methodology. Drawing on the experiences of families, it uses this knowledge and information to try and effect change. This pursuit of change happens at various different levels – from attitudes to political policy.

By its very make up, ie families of children with physical and/or sensory disabilities, there is inherent in the group the tendency towards action research. The living experiences of these families are the touchstone on which the desire for policy change nurtures and grows.

Through sharing their stories, the individual life experiences can be collated: apprehensions around isolation and exclusion can be addressed; and action can be planned and carried out with the common themes and/or issues being the catalyst needed to raise political and community awareness.

Also, if certain themes do emerge, there is the possibility that this qualitative study could lead to a quantitative study covering many more parents to test out and validate the findings of this work.

There are four key areas to this research: first, my own personal experience; secondly, the views of other parents; thirdly, a comparison of parents' views mirrored against the outlook of those who work with parents both in the statutory and voluntary sector. Finally, there is the analysis of the literature.

I have already outlined in detail my own personal experience. Also, I have tried to show how, even though my experiences are totally subjective, I want to carry out this work in as scientific a manner as is possible.

I would also argue that this research matters to me and therefore I will be critical of myself in order to try and ensure that, in fulfilling the correct criteria, this piece of academic research will have the potential of creating change.

The approach to parents has to be sensitive because of the nature of the study. To gain the relevant information, I decided to use small focus groups with in-depth, one-to-one interviews in a semi-structured manner with a questionnaire. These took place in various venues, eg someone's home, in a day centre and in a youth club. Contact was made with people known to me through my work, although I certainly would not be aware of the nature of their child's diagnosis.

Contacts were also made through local groups known to the Family Information Group, although I would not know the personal background of most of these parents. The nature of this research requires a certain degree of trust between those who are participating and myself as the researcher. In previous consultancy work, I found that by liaising with someone I knew, it was of great help in trying to contact people that I did not know – primarily because a degree of trust was already built up with the intermediary. That is why I used this technique on this occasion.

Focus groups took place in Creggan Day Centre and in the Old Library Trust Community Building. There were three separate meetings exploring the issues that parents themselves were identifying. This research was carried out by a number of groups, including our own, to gather information for a proposed "parenting" course, when it became very clear that parents did not feel that current courses met their needs.

The experience of working in these focus groups – along with my own experience and listening to other parents – has informed and somewhat dictated my approach to this research. Mention has already been made to the qualitative approach and the reasons for it. The need for sensitivity goes without saying in situations like this.

However, because of the nature of the subject, I found that there has to be some type of structure and some degree of control. From listening to parents in focus groups, from my own reading of other research and indeed on reflection on my own experience, I compiled a semi-structured questionnaire, believing that this would be the best way to collate the relevant information.

In the focus groups, I found that this approach proved to be very positive, at least for one parent. This was confirmed by the parent, when

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approached about the research, who immediately replied that she hoped that I would have questions to ask to stop her rambling on.

For the parents, both the individuals and the focus group members, I have compiled a questionnaire. **(Appendix 1.)** This questionnaire records details of the family as well as a summary of the diagnosis and the disclosure, including information on who was there, how it was conducted and space for any comments. I helped parents complete this form. Assurances were given that no personal details linked to real names would appear in the research.

It was thought that using focus groups with parents unfamiliar with our Group's work, or me, would give some support to the individual parents. Also, it would help parents who were a little shy of coming forward with their experiences. In the first focus group, the parents were familiar with each other as they all belonged to a rural support group for parents of children with various disabilities. All six participants were mothers; there were no male participants and the meeting was held in a local youth club.

The main aim of the session, which lasted one hour and thirty minutes, was to facilitate the completion of the questionnaires. Also, it gave the opportunity for participants to express their views and opinions in depth. It was obvious that the diagnosis and disclosure had impacted most of the parents. At one point, I found it necessary to end the recording, as one of the mothers became upset.

I knew none of the parents at the second focus-group session; this took place in the school at which the children with disabilities attended. Four people were present: three mothers and one father. Two of the participants were married to each other. Again, the emphasis was on completing the questionnaires and giving the opportunity for parents to express their views and opinions.

A local day centre hosted an individual interview with a parent. I knew this parent through a course that our Group co-facilitated, but the individual circumstances of this family were not known to me. The interview, which took the same format as the group interviews – tape recording of discussion, semi-structured questionnaire and informal discussion – lasted approximately ninety minutes.

Finally, another, separate individual interview took place with a parent known to me through our own Group and through work we had been

doing in the community. This interview followed the same pattern as the others and lasted approximately forty-five minutes.

By engaging a variety of parents in different settings, I hoped to gather a variety of information that would enhance this research.

Although these parents were not picked at random, I do feel that as most of their personal experiences were not known to me, there is a degree of objectivity, rather than just picking parents whose experiences fit in with one theory or another.

Also, as the topic is so personal and, to many of the parents, very emotional and painful, it was important that the parents either knew me or trusted the person who was referring them to me.

I have nothing but admiration for these parents, who allowed me to share with them some of the most devastating experiences a parent can face, in the hope that someone would listen and take on board their views. Despite having a role as a researcher, I am also a parent as I have emphasised before.

In this context, it was very frustrating listening to parents locally, reflecting views and experiences that have been highlighted in other research exercises and in literature related to this topic, and yet little seems to have changed. The taped information primarily lends a certain degree of depth to the feelings expressed. At times, it was harrowing.

## **LITERATURE REVIEW**

### **Introduction**

It is necessary to review the literature that impacts on this research. Of course, the materials at hand are only a fraction of what is available, primarily local and regional, as well as coming from Great Britain, Ireland and USA.

However, I hope to draw from these reports, findings, legislation etc, themes that will inform this research. Information on the literature is at the end of this report.

The literature around rights particularly, eg disability, race, human, equality, children etc, certainly shows a movement in recent years towards enshrining values in law and protecting those who have been marginalized in the past and in the present.

There has to be, however, a touch of realism injected into this process. Still, many people feel excluded and are unaware of their rights, and indeed some of the legislation does not cover some of the basic rights.

There is also a dilemma. As a parent of a child with a disability, I sometimes reel in anger and frustration while reading a lot of this research. This is because much of it reflects my own and others' first-hand experience. **(Beresford [1995], *Expert Opinions*, Policy Press Publications.)**

There are questions often raised about the validity of certain types of research and whether the findings are as important when emanating from action research. However, everyday experiences often become the tools whereby researchers develop their theories.

All research should be able to be challenged, tested and verified against what is real, whether in the academic, social or actual world being studied. There are many perceptions; only one reality.

Yet it is when we can turn this around, through action participatory research, that we feel in control and can possibly effect change. The dilemma for me, as a parent and as a researcher, is: can change really be possible?

To be honest, initially, I had thought of doing this research to prove a point, to prove that my own experience was more universal. Yet when I began to think about fitting it within the restraints of academic research, I started to look at the possibility of being more objective and being more open to positive experiences.

The more I delved into the literature around this subject, the more I realised that most of it reflected my own views and experience, as well as those of the parents I had contact with through the research.

I was genuinely surprised at this, or rather at the extent of the literature which affirmed my own opinions and those of many of the parents I work with.

The dilemma, however, is that what we are researching is real people's lives, including my own. It is not some abstract theoretical perspective that needs analysis; it is a snapshot of life at a time when most people are at their most vulnerable.

But when the literature search, and the experience of parents, and your own experience are pointing towards the same themes and issues – many of them unresolved – questions have to be asked, and the more you reflect, the more painful it becomes.

The themes and issues are real for all those involved.

At this point, it would be constructive to identify some of the key themes which emerged:

- For most parents, the experience of diagnosis and disclosure, or, to be more exact, the way they were given the news, is very vivid in their memories. The negative way in which the news was delivered to them is a central theme;
- The reliance on the medical model of disability, rather than the social model, is very prevalent;
- Insensitivity towards parents and a lack of respect for them and their knowledge by those who work in a “professional” capacity;
- Lack of support for parents and family members;
- Absence of relevant accessible information;

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- Services are often unco-ordinated;
- There is no strategy or written guidelines for carrying out the diagnosis and disclosing this information.

Participatory research means I am in there somewhere. Literature analysis, as will be seen in the following pages, is reaffirming what has been expressed, sometimes in great pain, by the parents. As a result, I am left with more questions than answers. How is it that so many people know so much about the difficulties for parents over diagnosis and disclosure and yet little seems to change?

In the review, we have to remember it is real lives that we are looking at. Because I am part of those families' lives, I find it very difficult to understand why those who read the literature have never really acted on it, since so many parents today face the same barriers and negative attitude that prevailed years ago. Furthermore, I then begin to question myself and wonder whether there is a possibility of effecting change through this research.

## The Legislation

In recent years there has been an increasing amount of literature detailing new laws and outlining legislation that affects our everyday experiences. Often the process of consultation around such matters is seriously flawed, as those most affected do not seem to have any real input. In certain circles, “consultancy” is a bad word. Also, at times, the proposed legislation does not cover as wide an area of concern as first thought. So, often there are “get out” clauses.

This said, it has still to be acknowledged that the movement, through legislation, to protect and enshrine rights has been a very positive move in trying to combat discrimination and negative attitudes.

In education, the **Education (NI) Orders 1986 and 1987** not only affected education, but also raised the profile of children with disabilities for almost the first time, as there was a strong move away from patronising care to education and social development. This was followed some years later with the **Education (NI) Order 1996**, which provided a legal framework for the assessment and development of educational plans for children with special educational needs. The theme of young people with disabilities having rights, enshrined by law, was clearly emerging.

One of the most radical moves to not only protect, but also to develop and nurture children with disabilities came through the **Children’s (NI) Order 1995**. The implications of this piece of legislation have not yet been fully implemented. Recently, the development of the Children’s Services Plan at Health-Board level is a process by which the rights and needs of children are beginning to be addressed. Two main themes emerge from the literature around this order: first, the emphasis is on including those who use services in the decision-making process; secondly, and of great significance and importance, children with disabilities are seen as children first. Many see this as a direct move away from the “medical model of disability” to the “social model of disability”. This will be addressed further in the literature review.

The **Disabled Persons (NI) Order 1989** and later, the **Disability Discrimination Act 1995**, enshrine in law the rights of people with disabilities. However, these rights are not fully inclusive. For instance, there are access rights to transport vehicles, but not to actually accessing those vehicles. Furthermore, rights of access to premises providing goods and services are not to be fully implemented until 2004. Indeed, the law on discrimination in employment does not apply to organisations with fewer than fifteen employees.

Again, we see a move through legislative literature to enshrine rights in law. This could also be interpreted as recognition that in society there is discrimination against people with disabilities, a theme that is reflected in some of the social research.

More recently, the **NI Act 1998**, particularly Section 75 of this act, and the subsequent establishment of the Equality Commission have raised public awareness of the promotion of equality of opportunity for all. This theme is coupled with the whole concept of inclusion, which also refers to those who use services. Again, the notion of Human Rights and the proposed Bill of Rights for NI and the **Carers (Recognition and Services) Act 1995** further solidify the issue of rights with regard to disability.

Also, there are all the consultative papers issued by government departments (*Fit for the Future; Well into 2000; Policy into Practice etc*), which try and solicit views that are supposed to affect policy. However, in real terms, unless attempts are made to facilitate an inclusive consultation process, again, all we will have will be tokenistic responses from a select few.

Finally, on a more global scale, the **European Convention on the Protection of Human Rights 1950** and **The United Nations Convention on the Rights of the Child 1989** reflect the theme of children first, not disability, and that children have rights of their own and that these have to be respected. This further highlights the theme that children have to be listened to and that their voices should be heard. Such themes are central also to the **Children's (NI) Order 1995**, already referred to.

## **The Literature Review**

The trend, reflected in many recent research documents, is to give prominence to the views of parents and those who have disabilities. Classic examples of this are the publications coming from the Policy Press of the Joseph Rowntree Foundation. This type of research hits you up front, as a parent, because it is so tuned into the experiences of parents.

In government discussion papers (relating to Health and Social Services), again, there is an emphasis on the role of parents and the need to engage those who use services in a realistic and meaningful partnership. The discussion papers and the legislation are beginning to impact the community and open up the possibility of real positive change.

At a more practical level, the voluntary group, **Scope**, deals directly with the issue of diagnosis and disclosure. Certain recommendations are made which will be discussed later. I hope that the findings of this research will form the basis of a more constructive approach to what is a very painful experience.

Reports emanating from other groups also have a significant role to play in highlighting different themes, such as the importance of accessible language, the negative view of disability in the wider community, the need for relevant information etc in their reports. These themes form the backdrop to the whole process of diagnosis.

Various other themes emerge, such as: the importance of a clear diagnosis and the necessity of having the diagnosis handled with a great deal of sensitivity; the difficulties over the lack of information and resources; the necessity for a key worker; and the idea that parents should be involved in the planning and provision of services, to name just some of them.

Difficulties arising over inter-agency work, as well as the involvement of statutory and voluntary organisations, were also highlighted as areas of concern – particularly with the emphasis in the Children's Order of a more holistic approach to service provision. The need for respite care and information for families was also voiced.

Other issues, such as the necessity to listen to children and young people with disabilities, were flagged up. However, the most important aspect of the Order – treating children with disabilities as children first, which underpins the whole ethos of the Order – featured very strongly in research materials.

In academic research, it has to be remembered that the expertise and experiences of the families on whom the research is being carried out are as important and as valuable as the researcher's.

The earlier work of the co-author of this report (into support for families who had children with cerebral palsy in the nineties) is significant, as it highlights many of the core themes noted in the literature review. These themes are: the need for a clear diagnosis; the coping personality and the need for respite care. A subsequent study in 1997 highlighted additional themes around inter-professional working, concerns over the integration of health and social services, the role of information, counselling (or rather the lack of it) and the need for support for self-help groups.

As one of the few works targeted at families in Northern Ireland, it will be interesting to see if their findings are reflected – almost ten years on from the initial study – in this current research. Hopefully, the difference in this current research is that it is up-to-date, will cross disabilities and will not be based on one locality, such as a specific clinic.

Furthermore, the work carried out by **Scope** (referred to earlier), which studies in-depth diagnosis and disclosure, is another piece of work that needs highlighted in this review. Although it will be looked at in more depth in the body of this research, it is very noteworthy in that it is one of the few pieces of work which comes up with both a strategy and template of good practice in the field of diagnosis and disclosure.

As hinted at earlier, there are other pieces of literature which support the observations of parents, and indeed my own experience, and which clearly find that many parents experience negative disclosures.

For many, what is termed sometimes as “breaking the bad news” begins the process that leads to a very different life. This “bad news” can often affect the whole family, not just the parents.

It is this crucial point in a number of parents' lives, the time of the diagnosis and disclosure (how the information is relayed to the parents), which is central to this research. It is not so much what the “bad news” was; rather it is how it was told and everything else associated with this. As **Beckman** and **Beckman Boyes (1993)** express it:

‘The news that a child has, or is at risk from, a development disability is often among the most frightening and confusing pieces of information that parents will ever receive.’

From the parents' comments (see appropriate section), it is obvious that many of those interviewed were less than happy with the disclosure. As far back as the early 1970s, researchers were highlighting this experience of dissatisfaction of parents – **Finlay and Dallimore (1971)**.

Also, from some of the comments of those involved in the statutory sectors (see appropriate section), certain criticisms and recommendations have been made which indicate that, from their perspectives, some of the disclosures were not handled as well as they might.

As a parent and researcher, I could put forward a number of arguments for why this happens. Some of those providing the diagnosis will argue that there is no easy way to deliver bad news. This is true; but there are some ways that are better than others. If the concentration is on the medical condition of the child because many of the providers of information at this point are from a medical background, then it is not very surprising that “the medical model of disability” prevails, ignoring the social implications for all the family that a “social model” would recognise.

In his research, **Michael Farrell (1999)** vividly acknowledges the difficulties some professionals have with breaking bad news:

‘This challenge tests, in a very intense way, the ability of health professionals to engage with patients and family members in a meaningful, sustained and therapeutic way.’

Part of this phenomenon of distancing from the person being diagnosed, is referred to as “professional distancing” by **Carpenter (2000, p4)** who goes on to warn of the dangers of this approach:

‘It ignores the feelings of families [and can] be as damaging as over-involvement.’

In the discussions with people from the statutory sector as part of this research, one participant raises his own concerns over how cold and distant some health professionals can be (see appropriate section). Also, through my own work, from time to time, this whole area of professional distance has regularly been raised.

Our Group has tried to address this issue by bringing parents and those who work in the voluntary and statutory sectors together to discuss common themes. This is done under the heading of “Professionals Together”.

There is another kind of distance too. Many parents can identify with the sentiments of the parent in **Carpenter and Herbert (1995)** who points out the value of 24-hour care that he and some other parents give their children:

'But to live with a child with a disability twenty-four hours a day brings lessons that no professional course of training can hope to teach.'

Barriers do exist between those who provide the services and those who use them (see our Group's report *Bridging the Gap {2000}*) and these barriers are often accentuated at the time of disclosure. **Manuel (1996)** rhetorically asks the question of professionals as to whether they really understand the range of emotions experienced by families. He goes on to put forward the proposition that sometimes they assume they know. **Mc Conachie (1997, p135)** is very critical of professionals and of their ability to give support to parents, particularly in the early days.

This lack of support for families and a scenario of disjointed service provision, as well as the absence of a key worker to co-ordinate services, have long been bones of contention for our Group.

At the time of diagnosis and disclosure, there are many emotions, particularly anger, fear and denial. There is a predominant theory that this experience is similar to a bereavement process with distinct stages (**Kubler & Ross, 1969**).

However, listening to parents, I sense a degree of frustration when it is perceived that support and help can only be given when parents "accept" the situation. Indeed, there are some unsubstantiated reports that sometimes negative messages are sent out by professionals at the time of disclosure to make parents accept very difficult situations, long before they may be able to, if they have to at all.

It is obvious from the literature review, from my own experience, from the experiences of parents (see appropriate section) and from those who work in the statutory and voluntary sectors (see appropriate section), that often the disclosure of the diagnosis has not been handled well by those who are working in a professional capacity. This has been happening in the past, in the recent past and very probably at present. Yet still, there have been no dramatic changes.

From time to time our Group and I have advocated change. Some of these changes are reflected in literature: the sensitivity of showing the

correct body language in non-verbal communication; disclosing the news gently, slowly, with the emphasis on the correct choice of words and with a high degree of empathy.

As parents themselves have highlighted, the location at which the diagnosis is actually given is often remembered, so it is important that it is conducive to a supporting atmosphere. An overall synopsis of some of the changes that could be put in place is available in **Scope's** publication, *Right From the Start*.

The literature review has shown us that, for years, there have been difficulties around diagnosis and disclosure. This seems to stem from a lack of understanding and appropriate training for those who work professionally with parents.

Also, there appears to be a medical model of disability which seems to ignore the whole impact of disability on the rest of the family. In the Recommendations' Section, I will be putting forward some ideas for consideration in relation to this.

## **PARENTS TALKING**

As a parent, the process of listening to parents was very difficult at times. There are still many raw emotions, and, for most, the time and place of diagnosis remains very vivid in their minds. Generally, there was an acknowledgement that “bad news” is not easy to break. However, over and over again, the way the news was told to them was criticised.

As explained earlier, there was a semi-structured interview. The questionnaire was compiled by myself, following on from my own experience and having listened to other parents in focus groups in the past and trying to take on board the research studies carried out by Huw Griffiths, his co-authors and colleagues (**Bamford, Griffiths and Kernohan, 1991**). A tape recorder was used, mainly for background information, but at times it was intrusive and I had to switch it off.

At the outset, I explained to the parents that all personal details would be held in confidence and pen names would be used in the actual research findings. Also, I informed them that the information they were disclosing is to be part of my research work for the academic Masters Degree at Magee. I outlined my own misgivings as to whether any of this would lead to change for other parents.

The parents were very willing to share even those moments when their world was pulled apart for the first time. Most talked candidly and openly about the diagnosis and disclosure, at times very much in pain at recalling such a traumatic experience. Witnessing this pain was, at times, disturbing, and I was a little apprehensive in case these inquiries brought my own emotions to the surface.

Personally, I felt very privileged that the parents trusted me with their stories, and this is not a cliché. I appreciate that I have to deal with my own frustrations of feeling unable to effect change, despite what now seems to be overwhelming evidence that, for a number of parents, diagnosis and disclosure have not been handled very well, to say the least.

Listening to parents, there are certain themes and issues that arise. Ironically, many of these have also emerged in the Literature Review, even in those pieces of academic research of which most people in the community would not be aware.

Furthermore, some of the suggestions made by parents to try and improve the situation around diagnosis and disclosure are reflected in

the comments of those who work in the voluntary and statutory sectors. My own personal views concur with many of the observations of the parents interviewed.

It was not just what the parents said that is significant, but the way they said it and the clarity with which they recalled those moments that transformed their entire lives.

In many of the interviews, the pain was real, as was the hurt that was caused by what can only be called insensitive remarks on the part of the “professional” involved. This was not just true of parents of older children, but of some of the younger ones too.

One theory, already mentioned, is that the negativity of the diagnosis and disclosure – how it was so badly handled by the “professional” involved – not only caused pain and hurt, but has often led to a severe breakdown in communications between parents and those who work with them, which takes years to recover from, if ever. It is not within the remit of this research to explore this phenomenon, but it would provide a good basis for a different piece of research.

Before looking at the findings, it is important to recall that twelve parents were interviewed in total. Two groups were used, one of which was an established group; the other was just a grouping of individuals. In one of the groups, there was a husband (the only male) and wife. Two individual interviews also took place. All parents were asked to complete the questionnaire and I was there to give help or clarify any matter. Drawing on previous work with families, my own experience and work carried out by other researchers, the content of the questionnaire was targeted at some of the main issues that seemed to keep cropping up.

## **PARENTS TALKING – THE FINDINGS**

The most disturbing finding was that seven out of the twelve parents felt that they were treated insensitively during the diagnosis and disclosure of their children by the person giving them the news. Of the other five, one parent noted that a follow-up diagnosis was poorly expressed, one felt that it was handled OK, whereas the other three felt that it was sensitively carried out, but that other key areas of support were missing.

When all these facts are taken into consideration, it seems that one parent felt that the handling was all right: eight parents had great reservations about the first or second diagnosis; and the other three, although happy enough about the handling, were not happy with other areas of concern at that time.

Four of the parents had concerns over who was present at the time of diagnosis; in all of the cases except one, the husband was missing. In the other one, the husband was given the diagnosis before his wife knew, as she had been sedated, and she was subsequently told on her own, against his express wishes. It still seems that sometimes the news is being broken to parents without the partner being present.

Two of the parents were unaware of anything that worried them about their child before the diagnosis, whereas the other eight all felt something was wrong before the actual diagnosis. This subtly highlights the expertise of some parents.

None of the parents were offered counselling, and only one parent indicated that enough information had been given. Six of the parents stated that they did not receive enough support or information, and any information they did receive, they could not fully understand.

Of the other six, four felt that they understood any information given to them and two felt that they did get support. When it came to follow-up, eight of the parents stated that there was none.

With regard to where the diagnosis took place, eight took place at a hospital, three happened in a health centre and one at a Child Development Clinic. Not one of the sessions involving a diagnosis and disclosure took place in the parents' home.

At a local level, what are parents really saying? Having spent some time with them, it is very clear to me that quite a few of them have been impacted in a very negative way by the manner in which their child's

diagnosis was disclosed to them. It has to be stressed, at this point, that we are discussing the way the information has been presented to them, and not the actual diagnosis itself. If just one or two parents had been disgruntled, out of admittedly a small sample, then maybe excuses could be made.

The feelings reported by the parents were very negative and raw:

'Upset . . . angry . . . that such a strong diagnosis was made without being adequately assessed.'

These are the words of Philomena, whose four-year-old son, Liam, was diagnosed as having a mild form of autism last year, having been originally diagnosed at the age of two with Severe Learning Difficulties. Philomena went on to say, 'I would have liked the disclosure to be handled more **humanely and in stages.**'

Mary simply stated, 'Not enough thought of **impact of diagnosis.**' She went on to highlight that there was **no-one else there** at the time to give information, **no telephone** offered to contact home (her husband was not present) and no real **explanation** given. Mary's son, Daniel, is four years old and was diagnosed at nine months as having "undetectable genetic syndrome".

Ciaran, the only father to participate, has a seven-year-old daughter, Ann, with Angelman Syndrome. At the initial diagnosis, when Ann was two years and six months, he **felt no real tests or full investigations** took place, and he goes on to say 'We received absolutely **no information,**' and had to go on and **find out the information for themselves.** Ciaran recommends:

'There should be a **consultation period** involving parents, doctors with a full **overview of the syndrome,** and a **back-up service.**'

Ciaran's wife, Rose, comments that after the diagnosis and disclosure, she felt very alone with Ann and did not know what to do to help her. She went on to suggest:

'I feel that when you get news like that, **someone who knows our situation should have been with us.**'

She adds that it could have been their local consultant.

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Other comments by some of the parents give a snapshot of how they felt at that time:

Brenda (whose child, Tom, is fifteen and has Sotos and severe behavioural difficulties): 'I felt relieved, knowing what was wrong. I still had my doubts. **I had to go looking for advice and information** on this.'

Danielle (whose child, Clare, is nine and has Vipiper Traunevy Weber Syndrome) similarly felt relieved but: ' . . . **still confused as what was to happen next**. We felt left in the dark after the diagnosis, **no more information** was given. Her **file has been closed since diagnosis**.'

Ursula (whose son, Aaron, is seven and has Down's Syndrome) was very **angry** that her husband was told while she was in a state of sedation after giving birth, and then she was wakened to be told, **against the wishes of her husband**, while he was away breaking the news to the wider family. 'I felt I had been dealt a **bad blow**.'

Martina was "**shell-shocked**" when she discovered that Denise had Choreoathetoid Cerebral Palsy. Denise is now six. Martina also felt that the **length of time for the referral** to the Child Development Clinic was **too long**.

Sandie (whose son, Seamus, has no conclusive diagnosis and is ten) expresses deep anger when recalling the **description of her son** by the doctor; the expression he used was, 'Your son is retarded.' Sandie went on to say how she felt ' . . . as if my whole **world had fallen apart**.'

Breige was ' . . . **devastated** at the time . . . ' when she got the news that Dylan, now six, had Down's Syndrome. She got a lot of support from another family in a similar position, but looking back at the disclosure felt ' . . . it could have been **more positive about the future**.'

Mary (whose child, Paul, is now nine and has Nystagmin's Albinism) also has another child, Patricia, aged four with the same condition. When talking, Mary relates how **everyone just expected her to get on with things** when Patricia, a twin, was born, because she already had a child with a similar condition. The acknowledgement of Paul's condition was just given in a conversation with a nurse shortly after he was born. Mary went on to say:

**'The consultant should pick an appropriate time and place to tell both parents and back up disclosure with support. We would have liked more positive support.'**

Finally, Jane simply says: 'I felt **totally distraught** at the news that Peter, now aged ten, had Hydrocephalus Cerebral Palsy and was blind' Later, at a second disclosure, she recalls: 'I was told to go home and forget about Peter, because he would be **like a vegetable** and no school would ever accept him.' There is little else that can be said.

The views above, expressed by parents interviewed in Derry and the rural village nearby, almost mirror the findings of this report's co-author, ten years ago, when he and his colleagues looked into support for children with Cerebral Palsy. Similar concerns, highlighted by the research of 1991, included: the lack of help and support, especially during the first four months; not enough carer support; no information being available; and no indication of where to go for help.

For some of the parents of children with varying disabilities, little has changed, and all the children, except one, referred to in this research were born since 1991. Indeed, one child was as young as four years old when this current research took place.

## **SUMMARY OF PARENTS' FINDINGS**

As a parent, recalling the Literature Review and reading the accounts of the parents interviewed locally, it is obvious that some parents come through the experience of diagnosis and disclosure with hurt and pain caused by the way these were handled as much as by the diagnosis itself.

Of course, every parent is different, and not all of them have such negative experiences. But as long as reports such as these emanate from even some parents, then all of us involved in this work have to look at these situations and seek answers.

There will be those who argue that the bereavement process associated with diagnosis prevents real communication at this time. This is no excuse for attempts not to be made to communicate effectively.

From the comments of the parents in this study, we can draw a picture of how some consultants and doctors treat parents of children with disabilities.

At times, they seem to have no real sensitivity, empathy or, indeed, understanding of the impact of diagnosis on the whole family.

Often, they seem to want to get the diagnosis and disclosure over and done with quickly – they do not seem to consider the possibility of gradually breaking the news in stages – and then follow up on this. Many parents feel the language they use to describe conditions, and their negative outlook, is very offensive.

Parents often seem to be left in the dark with little or no information, having to follow things up themselves in whatever way they can.

It has to be pointed out that many parents will be in a state of shock and/or confusion after the initial diagnosis and be unable to take in very much information. As a result, innovative follow-up information, written and/or verbal, should be available.

At times, no thought seems to be given to practicalities at the time of disclosure: for instance, who should be there, where should it take place, is there a telephone available (for parents to contact relatives), how do parents get home, are refreshments available, what follow-up or back-up service is there, who else can support the parents at this time?

There seems to be a consensus that, at least, certain practical arrangements should be put in place to address many of the issues raised by parents. Indeed **Scope**, through their research *Right From the Start*, already referred to, have compiled a list of prerequisites to disclosure. **(See Appendix 3.)**

In listening to parents, there also comes to the fore the negative way in which some parents are treated by those delivering the news. I remember once discussing with a consultant the whole area of information provision at the time of diagnosis. I explained that I believed parents could not really take in information after the shock of the diagnosis and disclosure. She argued that she still gave parents information despite this.

Therefore, we have a real situation where, possibly, people giving information believe it is getting through and people receiving information believe they are not getting any because of shock and/or feelings of devastation. This requires further investigation, perhaps with a quantitative survey carried out among those who work in a professional capacity and involving parents.

Finally, parents need to leave the situation of diagnosis and disclosure with some form of realistic hope, not with a pipe dream or a nightmare. **Their child is an individual, not a syndrome or condition or a medical problem to be solved or abandoned.** As already said, sensitivity and empathy are needed, as is training that starts to look at the individual child, respects the parents and gives support to the whole family.

Perhaps then, the nightmare stories around diagnosis and disclosure will begin to fade away. Perhaps then, working in partnership for a holistic approach to health and social care will start to become a reality. If not, in another ten years, researchers will be mirroring these findings. Surely it is time to act?

## THE PROFESSIONAL VIEW

An in-depth study into the practice of those who work professionally with parents and families is beyond the remit of this current work. It would be suggested, however, that such a study would be very informative to this debate around diagnosis and disclosure. It might even be more productive if it was an internal study in case an external one was seen as a threat. Information is needed on current practice as well as any ideas on how to improve it.

This was the starting point for a limited number of interviews, five in total, that I carried out among those who work professionally with parents and families, both in the voluntary and statutory sectors.

There are no interviews with medical staff, as, pointed out earlier, I felt strongly that there was a personal conflict of interest, and, as I compiled the information from the parents, a professional conflict too. I could not marry up potential answers from those who work in the medical field with my own experience and those of many of the parents. This is for another piece of research, not this one.

From the network of people I am in contact with, I approached five people to illustrate what goes on in the process of diagnosis and disclosure. The five are: a development officer for a charity that works with families who have children with various disabling conditions; from the voluntary sector, a community health visitor; a school principal; a manager of a day centre; and an assistant programme manager for a disability team, all working in the statutory sector. They were all asked, on tape, to outline the diagnosis and disclosure procedure as they saw it, and then to make any comments or suggestions to improve it. **(See Appendix 6.)**

From the information collated, there emerged a scenario where the parent, GP or other medical or social practitioner, first identified something wrong with the child. This alert then set in motion a referral system that usually led to a consultant or other specialist.

All of them revealed that the process of diagnosis and disclosure varies from parent to parent, and from “professional” to “professional”.

Maurice (manager of a day centre) felt there is a need for research into diagnosis from parents’ experiences. He identified **the need for someone, who would be an advocate for the parents**, to be present at

the diagnosis and disclosure. As well as having concerns about the lack of information available, he went on to say that many GPs and consultants, as well as the medical profession in general, lack sensitivity.

Also, he recognised the breakdown in communications –he feels communications are very important – as a result of a badly handled disclosure. ‘Circumstances surrounding the diagnosis and disclosure can set a family off in a very negative way of thinking, or can totally brutalise them in terms of the experience, and they will probably **find it difficult to work with professionals in the future.**’

Maurice concluded with suggestions that there should be training for “professionals”, that they should listen to what parents say, that they should understand that diagnosis is a process, often a gradual one, and that parents and children should be treated as individuals.

Sinead (Community Health Visitor) gave an in-depth analysis of why there is often this division between parents and “professionals”. She outlined how human beings often **lose their humanity when the work demands that they must cover their backs.** Also, the emphasis is on protecting yourself; this is paramount, everything else can then follow. Sinead described the difficulties of trying to change the system from within, which can be very tiring and frustrating.

Larry (Assistant Programme Manager for Disability) gave a clear breakdown of the diagnosis and disclosure procedure. He went on to emphasise **the social model of disability** as being the more positive. Larry went on to praise the progress that has been made with the introduction of the Child Development Clinic with its multi-disciplinary approach to disability.

With regard to how parents feel after the diagnosis and disclosure, Larry states: ‘The reality for parents is that they leave the consultant’s room or office and they leave very, very confused.’ This has serious implications for information provision. He goes on to acknowledge the **very negative way in which disability matters are treated**; he also highlights the need for everyone to be treated as **individuals.**

David (principal of a local school) has a lot of experience in working with children with disabilities. He outlined the process involved in referring parents and their children when someone is worried about a child and/or young person with a disability. Again, this process echoed others already featured.

He found that this subject was an ' . . . area needing an awful lot of improvement'. Because so many professionals are involved, David suggested that a **key worker** could possibly address the difficulties that arise; he emphasised the need for empathy, good communication (verbal and non-verbal) and genuineness.

He reflected: '**I think it is very important that “professionals” are taught how to effectively communicate with the people that they are working with and serve.**'

Nora (development officer for a charity) was very concerned about **how parents were treated by the medical profession**. Some parents relayed very negative experiences to her such as “professionals” treating parents as if they are paranoid, or slowing down the process of diagnosis and disclosure with a wait and see policy.

She went on to give details of various support mechanisms that could ease a little the impact of diagnosis and disclosure. Examples are: contacting parents in advance to suggest they bring someone with them; offering counselling and other support mechanisms; arranging follow-up appointments; offering the services of a good social worker; having **written guidelines**; and explaining the range of activity within each disability.

Reflective practice is a tool used by many people who work professionally. In the case of those who are employed in health and social services teams (and in the voluntary sector), it can be a very powerful tool – facilitating change – if senior management can respond positively.

With those who work professionally, we can see patterns emerging as to why there are sometimes difficulties over communication. These do not excuse bad communication; rather, they give us a basis from which to advocate change.

It seems the medical model of disability, and the attitudes of the medical profession in general, do not seem to take on board the **social implications of diagnosis and disclosure**.

If these are not real considerations, it is very easy to see why certain consultants and doctors believe that they impart information to parents, and why parents do not believe they receive it. There are two different realities present at the time of diagnosis and disclosure. **Only training**

**and education, influenced and perhaps carried out by parents, could possibly change this.**

Also, **self-protection** and the **philosophy of not getting emotionally involved** seem paramount in many medics' thinking. This does not mean that every individual from a medical background feels like this, but, generally, there is some truth, according to these research findings, in these assertions.

It seems that the process of disclosing a diagnosis could be slowed down, perhaps into stages, maybe even in the parents' homes and often in a more realistic but positive tone, focusing on the individual child and parents, rather than the syndrome and/or the condition. This research has found that **communication between parents and those who work professionally is very poor.**

From these discussions with those who work professionally with parents and families, there is a recognition that often parents are not treated with the **respect** that they are due. Indeed, in certain cases, they are not valued at all. These findings concur with what the Family Information Group has been discovering over the past few years – as highlighted in their series of discussions "Professionals Together". **(See Appendix 2.)**

Relevant information, in suitable formats presented in a sensitive way and at an appropriate time, has been referred to over and over again. **Information is often not getting through** at the time of diagnosis, because many parents are traumatised. This is a very serious concern that needs to be addressed, not just dismissed as par for the course.

Those working with parents also raised the issue of **lack of support for parents** at the time of diagnosis and immediately afterwards. One suggested the inclusion of an independent advocate for parents right from the start. Medical support for the child, as a follow up, is not real support for the parents.

**Practical arrangements** must be reviewed and there needs to be discussion around who should be there. Would the home environment be more appropriate? Very basic things such as the provision of refreshments, access to a phone, physical arrangements made to ensure the parents get home safely, the language used, counselling services etc.

In the final analysis, what is needed is **caring, empathetic, human, sensitive practitioners, who acknowledge the value, experience and dignity of parents and their children, and who use positive, yet realistic, accessible language to convey the diagnosis.** Coupled with this, we require a **systematic supportive follow-up** service to all the family. To achieve this, a protocol or template is needed that informs this whole process, and a training and education process (informed and co-hosted by parents) is essential if we are to develop a different way of doing things that addresses everyone's needs. These are the thoughts of those who work as professionals, and, personally, I would agree.

## CONCLUSION

This has been a long journey for me. Although it seems at the end, I am only really starting. Through this research, I have discovered a wealth of information and experiences from other researchers, people working professionally and, most importantly of all, the parents themselves.

My findings could be summarised in the phrase: **'It has been going on too long.'** Some will argue about all the changes in society – in the words and phrases used to describe disability – in the new equality, disability and human rights legislation, or how we are more informed now with so much information available in different formats.

In reality, however, today there will probably be at least one parent, sitting in a room somewhere, whose life has been turned upside down, not just with the news her child has a disabling condition, but shocked and devastated by the way the news has been given to her, which has devalued her as a person, and disempowered her. If there is, then it is one parent too many, and all the research in the world is not going to impact her. It has been going on too long.

What I have discovered, through this piece of work, is that my personal experience as a parent going through this process was not unique. The hurt, pain and alienation that I felt, and the anger at the way our son's disclosure was handled, were not just peculiar to me. Nor were they peculiar to some of the parents interviewed, or to the many people who have contributed to research programmes through the years (featured in the references).

For those who work professionally with parents, it is clear that they too are aware that diagnosis and disclosure are often not handled very positively, or they would not have put forward so many suggestions to improve the process. All of the contributors who work professionally, as all the other interviewees, were open, honest and willing to voice their opinions on this matter.

When I started, I really believed I would be very open to hear positive stories, to hear about bad news being broken in a sensitive and, supportive way. There were very few of those types of stories.

My personal story was the starting point, the intrinsic reason for carrying out the research. Not an academic exercise, rather a journey deeper into myself and into the lives of others.

The academic criteria forced me towards other researchers and writers – reluctantly, at first. Later, as writer after writer seemed to confirm the issues, and as stories of injustice and unnecessary pain and anguish mounted, I began to feel angry and frustrated.

I began to realise that it was not just me, not just other parents, but also those who have studied these situations for years; all of us have known how parents have been treated, yet little has changed to improve this.

When this was also confirmed by those who work professionally with parents, I began to question the validity of my own piece of research.

Finally, watching the pain of the parents I interviewed as they recalled those terrible moments, those private moments when words are not adequate to express the depth of pain and sorrow, I knew I had come full circle.

All our voices have to be heard, and, if no-one listens, it should not stop us from speaking. Change will not come as a result of this work, and even though this had been originally the motivating factor, I have learned that too many other unheard voices have already spoken.

Sometimes life is unfair. It is unfair when your child faces an uncertain future. Tinged with the negativity of a badly handled disclosure, your own future seems uncertain also.

It is equally unfair when change does not result from the learning that many parents can offer to those who work professionally, learning that they seem to spurn, preferring the false elitism of a professional medical practice that often has lost touch with reality.

In this research there is no real conclusion. As pointed out earlier, the Family Information Group adopts a community-development approach to all its work. **(Appendices 2, 4 and 4.)**

By its very nature of consulting and working with those most affected by the issues, often there are no conclusions; rather, there is a process that eventually can lead to change. The same is very true of the community network of parents.

Almost four years of this work has taught me that there are no overnight changes and often no conclusions. Frequently, what happens is someone manages to open the door to change a little. Someone else then comes along to push it more ajar.

Through time, this process, bit by bit and with the help of others, can lead to the door being forced fully open. If that happens, real change can be effected, but it takes a lot of little voices.

Voice after voice has to be raised, time after time, until, eventually, someone listens. This is just one more voice. But I am not despondent. My faith lies in the parents: their children with disabilities; siblings and other family members; and with those possessing the sensitive skills to work with them. Each in turn will find their voice.

This research has shown how you can bring together what at times seem very different types of practice, and how each can support the other.

Therefore, it demonstrates the value of everyone: professionals, parents, researchers, academics, writers, commentators etc, but it also shows the importance of the individual and the individual's experience.

It is heartening to recall that silence of isolation, that feeling of being marginalized, that deep sense of hurt and pain; to recall and reflect upon it in the light of this work, where so many people shared very similar experiences. There can no longer be isolation.

Our lives go on and we learn more from each other, more than from the textbooks or information leaflets. Many of us, including myself, have been taught very hard yet positive lessons from the experience of having a child with a disability. Our experiences, as parents, are real and raw, and, just as we can learn, so others can learn from us.

Sometimes the wall of silence will be broken, as each additional voice eats at the very foundations of elitist practice as those who work professionally see that there is another way, learned from the experiences of parents, then, at some future date, we will make progress; until then, we can only offer our views from our reality. It is born out of the frustration of dealing with people who sometimes are so fixed in protocol and procedure that they seem to miss the humanity of the situation.

Yet there is also the awareness that before our son was diagnosed, we had no concept or interest in disability. Furthermore, there is recognition that there are many good, genuine and sensitive people, some of whom deliver the "bad news".

If this research is about anything, it is about raising awareness. Raising awareness of what it is like to be faced with the challenges that many

of the parents in this research faced. Perhaps that awareness will then lead to positive change.

By trying, with great difficulty, to use the tools of the academic world, I hope that further questions will be asked and the recommendations will be studied and acted upon.

For me, my reality is at home; my field of study, the circles I work in. When the books are put away, it is not the questions that engage the academics that challenge me.

The recommendations outlined, if addressed, have the potential of enhancing the quality of life for all the family. There is very little new in them. But perhaps what is a little different is that the authors of this report can verify, from personal experience and previous research, that positive changes in these areas would make a vast difference to families. Such changes are long overdue.

## **RECOMMENDATIONS**

- Training and education of those who work professionally in communication skills, with emphasis on empathy, sensitivity and listening to others, ie, counselling skills.
- 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 families. 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. This permeates most of the recommendations.
- Further research, both qualitative and quantitative, should be carried out into the practice of diagnosis and disclosure and findings acted upon.

## APPENDIX 1 – QUESTIONNAIRE TO PARENTS

### PRIVATE AND CONFIDENTIAL

#### BACKGROUND DETAILS – PARENT

Name \_\_\_\_\_ Male  Female

Address \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Tel: \_\_\_\_\_ Date of Birth \_\_\_\_\_

Married  Single  With Partner

In paid employment  Full time/Part time

Occupation \_\_\_\_\_

Partner in paid employment \_\_\_\_\_

Full time/Part time \_\_\_\_\_

Occupation \_\_\_\_\_

#### DETAILS OF CHILD WITH DISABILITY

(If more than one child with disability, give details of all disabled children)

Name \_\_\_\_\_ Male  Female

Disability \_\_\_\_\_

Date of Diagnosis \_\_\_\_\_ Date of Birth \_\_\_\_\_

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**FAMILY MEMBERS**

Number of children \_\_\_\_\_ (including child with disability)

Ages of all children; state if male or female

\_\_\_\_\_

Total number of people living at home, including yourself \_\_\_\_\_

**CURRENT SITUATION**

How often do you go out and socialise? \_\_\_\_\_

List three people or organisations who give you support at present:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

List three main services you get for your child:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are there services you need but do not get? Give details:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**DIAGNOSIS AND DISCLOSURE**

Were you concerned about your child before diagnosis?

Yes  No

Who was first to know? \_\_\_\_\_

Where did it take place? \_\_\_\_\_

Who was present? \_\_\_\_\_

Do you feel it was handled well? Yes  No

Comments \_\_\_\_\_

\_\_\_\_\_

Is there anyone you would have liked to be there but was not?

Yes  No

Give details \_\_\_\_\_

Did you receive enough information at the time of diagnosis?

Yes  No

Did you understand the information given? Yes  No

Do you feel you got enough support? Yes  No

Was there any follow up? Yes  No

Briefly, in your own words, explain how you felt:

\_\_\_\_\_

Was counselling offered? Yes  No

Details of any positive points: \_\_\_\_\_

\_\_\_\_\_

Details of any negative points \_\_\_\_\_

\_\_\_\_\_



## **APPENDIX 2**

### **“Professionals Together” Discussion Series**

Many carers of people who have disabilities have, over the years, developed a certain expertise and professionalism in that role; this is often ignored or dismissed by others. It is also very true of parents of children with disabilities – the main focus of the Family Information Group’s work in Derry.

In an attempt to redress this, the Family Information Group initiated a discussion series at the end of last year. I hope that this will give an opportunity for parents, and those from the various sectors who work with families, to meet and discuss issues. Also, by recognising all those involved as “professionals”, the organisers felt that a mutual understanding of each other’s role will develop.

The first presentation in the series **“Professionals Together”** gave people an opportunity to hear about the work of the national charity Contact a Family.

Over twenty people turned up; the audience was comprised of parents, representatives of voluntary groups, and health and social services employees. Everyone, particularly the parents, was astounded at the lack of information and knowledge about an organisation that has so much to offer.

Contact a Family specialises in areas such as diagnosis, situations where there is no diagnosis, family support, information, referral to appropriate support groups and specific information on many conditions, including very rare ones.

It was clear from this first session that there is a need for such an informal forum. As a result, Martin McCafferty, Manager of Creggan Day Centre, offered his premises for further sessions and for a conference in May 2000.

## **APPENDIX 3**

### **Recommendations from *Right From the Start*, by Anne Leonard (1996), London, Scope.**

- Respect for the child and the parents
- Guidelines for “professionals”, drawn up in consultation with parents, for those involved in diagnosis and disclosure
- Privacy, at the time of disclosure
- Parents told together, if possible
- Plenty of time available for questions, at time of diagnosis and later
- Written information as a supplement to verbal information
- Full information should be available
- Language used in information provision should be understandable
- Ethos of empathy should prevail
- Staff training should incorporate awareness training about issues concerning disability
- Appointment of a Facilitator for children with disabilities

## **APPENDIX 4**

### **Aims of the Family Information Group**

- 1 To collect information that could be relevant to families of children who have children with physical and/or sensory disabilities. To break down this information into a format suitable for both families and professionals in the field of disability. Then to publish such information; eg, information on housing, disabled facilities grant procedure, shopping, access, education and any other areas of interest. It is intended, as much as possible, that information will be accurate, up to date, relevant and understandable to those who wish to use it.
- 2 To listen to family members and ensure that their perceived needs are identified and highlighted to the appropriate authorities.
- 3 To raise awareness in the community of the FAMILY aspect of Disability.
- 4 To seek family representation at all levels in bodies, groups and organisations that serve the needs of children who have physical and/or sensory disabilities.
- 5 To enhance the quality of life of children with physical and/or sensory disabilities and of their families.
- 6 To develop, train and educate family members so that they can help themselves and participate fully in the lives of their children.

## **APPENDIX 5**

### **Objectives of Family Information Group**

- 1 Publish information bulletins on disability related issues; eg, housing, education, access, shopping etc, for families, professionals and voluntary workers in the field of disability.
- 2 Collate information from families through an outreach family contact service and (with agreement from families) present this information to the appropriate authorities; eg, family's perceived needs.
- 3 Work with professionals and voluntary workers to ensure relevant information can be directly or indirectly presented to families in a confidential manner.
- 4 Through co-operation with training/education agencies, such as WEA, Forum for Community Work and Education and St Columb's Park House, ensure that the training and education needs of family members are addressed in a realistic and relevant manner.
- 5 Work closely with other groups and organisations in the field of disability and related areas to ensure there is no unnecessary duplication in order to facilitate the development of an integrated approach to areas of concern.
- 6 By developing contacts with statutory agencies, ensure that the voice of families has a real impact on the planning and provision of services for children with physical and/or sensory disabilities.
- 7 Involving family members in raising awareness of the family view of disability through the media, conferences, seminars and presentations, and in the training of professionals, voluntary workers and people who should be aware of disability issues.

## **APPENDIX 6**

### **STRUCTURE OF DISCUSSION WITH THOSE WHO WORK WITH PARENTS**

OUTLINE OF PURPOSE OF RESEARCH – TO OBTAIN DIVERSE VIEWS OF THE PROCESS OF DIAGNOSIS AND DISCLOSURE OF CHILDREN WITH DISABLING CONDITIONS

REASSURANCE OF CONFIDENTIALITY – NO USE OF REAL NAMES

#### **INFORMATION**

NAME

OCCUPATION

EMPLOYER – STATUTORY OR VOLUNTARY

DISCUSSION OF THE PROCESS OF DIAGNOSIS AND DISCLOSURE – IN OWN WORDS AND DRAWN FROM OWN EXPERIENCE OF IT

BREAKDOWN OF DIFFERENT ELEMENTS AND/OR REFERRALS

ANY COMMENTS ON THIS?

ANY SUGGESTIONS TO MAKE THE PROCESS BETTER?

## **APPENDIX 7**

### **GLOSSARY OF TERMS RELATING TO CONDITIONS**

#### **Albinism**

reduced or absent pigmentation, often affecting skin and/or eyes

#### **Angelman Syndrome**

neurological disorder, associated with developmental delay and with facial appearance and behaviour

#### **Cerebral Palsy**

a disorder of movement and posture due to damage or failure in development of part of brain concerned with movement

#### **Down's Syndrome**

a chromosomal disorder, giving rise to specific physical features. Cognitive difficulties; some have heart conditions

#### **Duchenne Muscular Dystrophy**

a progressive muscle-wasting condition for which there is no cure or treatment

#### **Learning Disability**

function at a level lower than their chronological age

#### **Sotos Syndrome**

associated with large head, accelerated bone maturation, delayed development and language problems

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Below is a list of the sources for this research material. In this revised publication, not all these sources have been used. This bibliography is included for those people who have a keen interest in what other research exists on this topic.

It is both frightening and frustrating to record the many people over the years who have addressed the subject of diagnosis and disclosure and yet to still realise there are many others.

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