

*"...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."*

**(Harry Marsh, Former Director, Contact a Family)**

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## **LISTENING TO PARENTS**

### **Introduction**

Currently various government departments, agencies organisations etc. are trying to find ways of listening to those who use their services. This primarily is due to the government policy which is forcing many of them sometimes for the first time, to consult.

However for years parents of people with disabilities (and people with disabilities themselves) have felt isolated and marginalised from those who are providing services. They were not listened to. In the voluntary sector groups blossomed that facilitated parents having a "voice". It is not surprising then, as a result of this frustration, that many parents are very wary of these new government initiatives, and feel they smack of tokenism.

On the ground, those people directly delivering services to families are also frustrated. Reported unmet need continues to be unmet due to lack of resources or an unwillingness by senior management to take seriously priority needs identified by both parents and those who work with parents.

Research to identify needs has been patchy, and often done on people with disabilities and their families rather than with them. Statistics and empirical evidence seem to take precedence over qualitative research based on individual families. There has been little recognition of individual family experience, this seems too subjective, it is claimed, as many of the findings would be based on personal opinions. Yet within each family story there are common issues and concerns, we have to listen to the story, if we really want to listen to parents.

## **THE STORY**

When the time is right many of use will want to tell our story. This is simply the experiences that we have had when we had concerns about our child for the first time, what we were told about his/her condition, diagnosis, and how this was all explained to us, disclosure.

These stories are important and space must be given for families to talk things out. Often professional **counselling** will be needed to give families this space to talk things over and over again and to help them get things in perspective. In this case counselling is really a listening ear.

Although not always available professionally, many people in the community who really listen can help families by being there and supporting them in any way they can – often this help comes from family members.

There is a deep sense of loss when your child is diagnosed with having a disabling condition. Sometimes this loss and hurt can be deepened if the diagnosis and disclosure are not handled sensitively.

Some parents feel that they are failures and that the condition is their fault, others are hurt that the expectations and dreams they had for their child are shattered.

If their child's condition is terminal (leading to an early death) then the family will naturally become totally preoccupied with this.

At this time shock, numbness, disbelief can often prevent any real information getting through to family members. Indeed the person making the diagnosis and giving the information may be the target of the families frustration, anger and bitterness so he/she may not be listened to at all initially.

An overload of information at this point could possibly lead to even more confusion.

Certainly any questions or queries from the family should be answered and answered sensitively. Information on a specific support or information group should be made available.

Also the name, address and telephone number of another family who have a child with a similar condition – but who are positive about their situation and who have agreed to be a contact family should be passed on if the family want this. A follow up appointment, preferably in the family home should also be arranged as well as a contact number for the family if they have any further queries.

How all this is handled, particularly by the professional health care workers, during this crisis period, will deeply affect the family not just now. Parents still recall clearly the hurt felt by being treated insensitively, others will remember the professional whose sensitive nature guided them through such a traumatic time.

The pain of this period is real and sometimes lasts a lifetime. Families, in this situation, have more than enough to contend with. Sensitivity, a listening ear, empathy (identifying strongly with another person's feelings) are all needed at this time.

Coming through this is going to take time a lot of time, but some families are often locked into the feelings they had around the time of diagnosis and disclosure.

Like an experience of death, everyone's reaction can be different. However after the initial shock and numbness there can come a time of denial – not us, not our family, this is not really happening. Also there can be great anger and bitterness – why us? Why not someone else? Why are other children so healthy? Sometimes deep guilt can set in.

All of this is natural – time and space must be given for an expression of these feelings even though those closest to family members and working with family members may be at the receiving end of a lot of these negative feelings.

From family to family the sequence of events can often be very different, also the time between each event can also be very different. Some children are already known to have a disabling condition before they are born. Other children – for no apparent reason – are born with such a condition. There are also children who have disabling conditions at birth but they are not found to have these until they are older. Yet other children who are perfectly healthy at birth, later develop disabling conditions.

No matter what the sequence, the family will be at the receiving end of a lot of information. This has to be handled with great sensitivity and with at least some understanding and appreciation of the hurt that family members must feel. One main area of confusion is how professionals are seen and how accurate and realistic is the view of their roles. A brief introduction to how parents can be seen as professionals follows in the next section.

## **PARENTS AS PROFESSIONALS**

The Family Information Group takes the opposite view. Each family's experience, although in some ways is unique, also raises many broader issues including those that affect policy.

The paradox is that families need people to work with them in a very individual and sensitive way, yet at the same time, facilitate them to address the more general concerns that affect them.

For example families react differently to their various concerns e.g. education, housing, benefits, access etc. but for many families the policy decisions around these issues can be the same.

Through the experience of having a child/young person/adult with a disability, most parents develop skills and an expertise to deal with all the resultant issues. Very few of them have such expertise at the time of diagnosis.

Of course they may have no academic qualifications to back this expertise up, but it is obvious to anyone who has eyes to see. Indeed in a professional training programme that is competency based (as many now are), many parents show competence far beyond academic criteria, in their everyday experience.

By running a home, looking after the care needs of all the family members (including the person with a disability), dealing with the bureaucracy and appointments, sorting out financial matters – on and on it goes.

The wealth of experience and professionalism gained, is second to none. Parents are professionals.

Unfortunately up to recently, this professionalism was ignored by many. Therefore a number of services that could have met family need were never developed, simply because the planners of services never took parents/families feelings on board. Respite care meant taking people away generally, whereas this in fact is only one form of respite care – some families would prefer a short term break of a few hours. This is one example of not exploring issues further.

Recognising parents as professionals is not saying that they are always right, most professionals are not. Rather it is simply acknowledging the expertise that parents have gained through their own experience of coping with a child who has a disability, and the implications of this on the whole family.

## **RESEARCH**

A number of researchers spend a lot of time trying to engage parents and family members in their work, this has to be welcomed. Their process includes consultation, feedback, and active listening – techniques often underused in the past.

A growing number of researchers are beginning to value the experience of parents and families and seek their views as the foundation of effective research. Whether at local, regional or national level there have to be ways found that can move this process forward.

Action research, research that involves those who are directly involved in situations, has certainly moved the process forward. Often it has been shown that the findings from action research measure up well against statistical empirical evidence – and are not opinionated views. Rather the subjectivity and emotionalism give the research the depth that is often missing from other pieces of work.

However in this context, research is meaningless unless it leads to positive change in the quality of life. When families themselves identify their own needs – this is not an academic exercise – rather it is a statement of reality. That statement of reality then must be addressed by effective action. No longer are services seen as privileges, as given only to those who someone else deems as in need. Services are a right, they are a right for all parents and families but none more so than those who have children/young people with disabilities. The following findings are based on personal experience and on the experiences of other families. They are not based on empirical objective evidence but they should be taken seriously.

## **THE FIGHT**

In the community, there is a tendency at times for people to generally believe that if you have a child with a disability, you will receive the services you need. This is a misconception. The prevalence of this misconception can add even more pressures on a family.

Parents will say that they have to fight for the little services that they are able to access. Frequently this fight is with the various agencies charged to help them: health and social services, hospitals, housing, education, benefits etc. even if we do not know what the "system" is, it often seems to be working against us with red tape and bureaucracies. These take the form of masses of paper work, application forms, trying to get the right person on the phone or behind a desk, procedures that make no sense etc.

Fighting is also necessary when people do not treat parents and families with the respect they are due. When people in certain agencies do not acknowledge the expertise of families, talk down to them, treat them as being insignificant rather than work with them as fellow professionals – how can a fight be avoided.

However for some parents, their energies are spent on looking after their own families – often the demands on their time and resources exclude them from having any voice outside the family. But the issues raised by other families can be very similar.

## **DIAGNOSIS AND DISCLOSURE**

Often it is the point of diagnosis that communications break down between parents and those who work with them. At the time of diagnosis – a very emotive and disturbing time for all parents – there is a lack of support, accessible information and counselling. These gaps have been identified by many parents.

Several medical practitioners, although aware of the trauma that parents are going through, do not seem to realise that there is a point when during diagnosis and disclosure that parents stop listening. Information just does not get through. Ways of addressing this have to be found and a sensitive process of diagnosing and disclosing conditions have to be found which would include follow up interviews at home with appropriate accessible information. Also there has to be a question mark over who gives out the information as many parents are so hurt at the initial diagnosis that they no longer can identify with the person who gave them the 'bad news'.

The locality in which the diagnosis takes place has to be looked at. Several parents raise concerns about being told about their child in open hospital wards, of overhearing conversations between nurses and doctors – conversations about their child's condition (of which they know nothing). Other concerns arise over who is present at the time – several parents were told without their partners. Seldom is there any support or information available on site from the voluntary sector at the time of diagnosis – this is often replaced with a contact card, when really the parent wouldn't mind talking to someone in a similar situation.

Every parent is different. Some want a lot of information at first, some very little. Some want to talk, some don't. There must be a sensitivity around the individual needs of parents, from everyone involved in the family. Counselling can take many forms, depending on the family needs – a listening ear, counselling sessions, therapy. Etc. but these must be worked out in co-operation with the family.

After the trauma of diagnosis and disclosure there has to be ongoing sensitive support for all the family – the child/young person with the disability, siblings, parents and relatives. This support should take into consideration the individual needs of the family – the whole family.

## **BEHIND THE DIAGNOSIS**

Those working with families at this point often appreciate that the families are under severe stress and searching for answers. But sometimes there are no answers.

Often there is not a stage where "people come to terms" with what has happened. Sadly this point is missed by some people who work with families. Training and books refer to a bereavement process where people go through different grieving stages. Sometimes they become locked in a stage. At times some families may "come to terms" with what has happened to their child and themselves and "accept" the situation. Others do not.

It is soul destroying for families to have to deal with people who firmly believe that all the family needs is to "accept" things and then they can be helped.

If it was your child and your world devastated, how would you feel? What if all the plans and dreams that you had were shattered and destroyed by the news of some diagnosis or other. If all the positive aspirations and hopes that you had for your child were smashed to pieces by negative images and thoughts of what your child could not do? Is there space here for "acceptance", "coming to terms".

What makes matters worse is that diagnosis and disclosure are often very negative. It is hard enough to receive bad news but then to be told all the worst things that could happen to your child.

Certainly the diagnosis and disclosure in themselves may be horrific but perhaps a more realistic and balanced view of the future could be painted.

Parents have reiterated over and over again how the doctor's/consultant's picture of the future for their child has turned out wrong. Children as they grow older have dumfounded "the experts" by showing abilities that "the experts" never foreseen.

When parents are vulnerable, at the time of disclosure, a balance has to be found – not to build up unrealistic hopes but at the same time not to totally devastate a family who already at this stage are just hanging on. Children are individuals not conditions, and each one is different. Children are also part of a family and **it is the whole family who are affected** by this news.

There are also many concerns around non diagnosis, families who have never been given a clear diagnosis. Living with this uncertainty can be very soul destroying. Often parents have identified that they always knew there was something "wrong" with their child, long before their concerns were taken seriously by those working in a "professional" capacity. For them too, this living with no diagnosis, battling to be taken seriously, can become very tiring and frustrating.

Certainly there is no easy way to break devastating news. However there are a number of issues, raised by parents, that if addressed could help to alleviate some of the problems around diagnosis and disclosure.

## **THE FAMILY VIEW OF DISABILITY**

It seems obvious, but the family is often forgotten or ignored when a child is diagnosed. The Family Information Group recognises the importance and the influence a family can have and the wealth of experience and professionalism that families develop in these circumstances. Many however remain silent, continuously carrying out their caring role in extreme circumstances without support, help or information.

As they do not raise their voices, often they do not receive the help they are entitled to – these are seen as "copying", although never asked if they are, and just left to get on with life.

Families themselves concentrate a lot of their energy and time on the child with the disability. The specific needs of the child often demands this. However when this happens there is then the added pressure of balancing out time and attention with other members of the family particularly siblings and partners. Although there is sometimes support for the child with the disability, not always, there is little or no support for the family.

Those that plan and provide services to families have, until recently not really involved families. Those in the statutory services sometimes "consult" with families while still retaining all the power and with no obligation to act on the feedback they receive. There still seems to be no way that individual families can actually have their voice heard, unless possible through a complaints procedure.

It seems incredulous that those who provide care and attention to their family, on a daily basis, are not really listened to when that wealth of experience could have such a positive impact.

Of course there are those who will argue that there are avenues for facilitating feedback. "Consumer" health groups, "user" groups, the children's services plan, a diverse number of focus groups etc. Relevant and welcome though these moves may be, there is still far to go before those in senior management on statutory boards, committees and trusts seriously take on board that those who use services must have a say, not a token say, but a real say.

Parents and the wider family can also explore ways that they can become more involved, despite already having the pressures of family life. If some still feel frustrated and exasperated in trying to influence the process, perhaps they should look to themselves and gauge whether they could provide the services they need from their own experienced resources.

This may mean looking outside of statutory funding for support e.g. trusts, grants etc... But there has to be a word of caution, no statutory agency should be let off the hook if they have a legal obligation to provide a service.

Between all of this, there is an opportunity for all involved to work in real partnership, recognising the value of all involved. Resources or the lack of them can be a problem but there are other areas of concern that can be addressed. Furthermore strong vibrant inclusive partnerships can also secure additional resources which might otherwise not be accessible.

By involving families at every stage of planning and providing services, a door will be opened to a more effective sensitive service provision.

## **AFTER THE DIAGNOSIS**

In the weeks and months after the diagnosis, and for most families for years to come, life becomes very different. The old lifestyle that families had before diagnosis become a blue as the focus moves to the child with the disability. Into the family's life there is the constant flow of those who are providing services, at least in the early days, although this may not be true for all families.

For those families who are still reeling from the diagnosis, it becomes very painful to relive all of this experience for each service provider. Also the constant flow of people coming to offer services – most of which are new to the family, can be very confusing and upsetting.

There is an opportunity in this situation to look at the possibility of identifying a person who could co-ordinate these services to families, liaise between the various departments and services, i.e. a key worker.

Often there is great confusion over who provides what, for the family (see the chapter on the role of the other professionals). Even between service providers there can also be confusion. Parents often take it for granted that all these people talk to each other whereas in reality, they seldom do as several of them work for different departments.

Perhaps if there was a key worker who identified who was coming to the family, what exactly their role was and who actually introduced those who provide the services, maybe it would lead to better communication and less possibility of confusion. Difficulties can arise when people are just not sure of what other people are doing.

## **APPOINTMENTS**

Life also becomes a time of appointments. An area of acute concern to many people. It is usually the case that the family has to fit in with whoever is providing the service, rather than the other way around.

It seems little consideration is given as to whether the parents work, or are engaged in family or other activities, if the appointments time is convenient, and what to do with other children in the family.

Seldom can appointments be made in the evening. In this area there needs to be a radical rethink of how appointments are arranged and if there are any ways in which the timing of them can be made more suitable.

**Appointments give families the opportunity to link into those who provide the services.**

For many parents appointments with doctors and consultants etc – are the gateway to other services through referral (where someone can be passed on to another service. Where appointments are held and at what time are two areas that need to be looked at urgently, to assist all those involved.

## **INFORMATION**

Choices are based on the relevant information being at hand in an accessible and appropriate format.

In other words people need to know, what they have to know, in a language that they understand. This just does not happen for a lot of families.

Very often the use of 'big words', jargon, complicated medical terms as well as concepts used in social and health care can put parents off and generally lead to confusion. Questions have to be asked whether such information is really relevant.

There is no doubt that there is a lot of information about, indeed so much so that it can be very confusing. But information that is not relevant to the person who is to use it, nor which is in a form suitable to that person – is not really information at all.

This point is often missed by information providers. Where information is provided, how it is provided, by whom it is provided and in what form – all of these are just as important as the information itself.

The needs of families change, so does the type of information that they require, as does the response from those who provide it.

Parents continuously raise concerns over having to go from one organisation to another, or make a number of phone calls before they finally find what they are looking for, if they ever do.

To save time, avoid frustration and to really provide accessible relevant information, a one stop shop for information is needed. Research is needed to explore how this idea could work in practice, such research is long overdue.

If families can make informed choices then through time, they will begin to have more control over their own lives. The sense of powerlessness felt at diagnosis could begin to ebb away as they begin to have some say in their own lives once again.

## **TIME OUT**

All of us in our day to day living, need a little "time out"/"respite care". A rest from the routine and daily concerns. The pressures of having a child with a disability mean that those concerned need just a little space for themselves, from time to time.

"Respite care" is sometimes, only sometimes offered to families in this situation. A number of families receive no "respite care" from the statutory agencies, others receive very little and some don't want it in the form it is offered. There are families who are very happy with the provision. Very often "respite care" is only offered in emergencies.

Families have identified that what some of them want is a flexible approach to "time out" or "respite care". Perhaps a few hours off to go shopping or out for the evening. Some families want their children to be looked after away from their home but others don't. Some want caring sensitive and experienced staff to look after their children in the family home and not to be taken away.

As with many of the other issues, a sensitive approach will have to be taken to this issue. Families have to be asked what do they need in their own individual circumstances, not the emphasis on what is on offer. A comprehensive and varied time out service, properly funded with sensitive trained workers could go a long way to supporting families and act as a preventative measure to alleviate much of the stress that families feel.

## **OTHER ISSUES**

It would be impossible to go into detail with regard to all the issues raised by parents and the wider family. Indeed what is of concern is that a number of these issues put pressure on a family at the one time and this can create a lot of confusion.

Several of the major concerns have been highlighted, some of the others will be briefly outlined. There are even more issues than these that have been detailed here. The following summary covers some of the issues already covered as well as some others. What has to be highlighted is that these are not isolated issues and concerns, many of them impact on a family at the one time, causing great distress and confusion.

For each parent and each family, the importance of different issues is not always the same. Overall the issues and concerns raised have been identified by parents and families themselves – many remain unresolved.

## **LIST OF KEY ISSUES**

Access / Regress

Attitudes

Benefits

Children's Services Plan

"Consumer Involvement"

Diagnosis

Disclosure

Education

Family View of Disability

Housing

Inclusion

Information

Key Worker

Language

Positive View of Disability

Respite Care/Time Out

Role of Professionals

Services

Support

Training/Development of Carers and Parents

## **OUTLINE OF KEY ISSUES**

### **Access / Regress**

At the simplest level, this is how people get in (access) and out (regress) of buildings, premises or anything that they need access to. Children who use wheelchairs, buggies or walking aids need enough space to get through doors, suitably designed ramps to overcome steps and adequate space when they are inside to move about. As well as ramps often steps are needed for people who can walk a little, for whom ramps may be difficult. Also space is needed for the person who is assisting them, if this is relevant. Once in a building, people need to be able to get out – regress – and this may not necessarily be by the entrance, particularly in public buildings so alternative exits should be found for safety reasons.

### **Attitudes**

Attitudes could be called access of the mind. If attitudes are positive then it is much easier to address physical access or any other issues that arise around disability issues. Children and people with disabilities have to be seen as people first and treated as such, unfortunately this does not always happen. Many people see the disability first and act on their own prejudices first. Others treat children with disabilities as if they do not exist, talking to the parents or carers of the child about the child as if he /she were not there. Many people just do not know how to treat people with disabilities, this is where awareness training could help. Also common sense can prevail, if you want to know how to treat someone with a disability – ask them, if you want to know what the right language is to use, discuss this with them, sometimes it is as simple as that.

## **Benefits**

It is costly to look after someone with a disability. Often what are termed "benefits", are simply your the rights of an adult or a child to have a reasonable quality of life. Indeed many families would argue that the so called benefits have little real benefit when you count up all the costs of caring for someone with a disability. Also there are terms conditions and criteria that apply to each benefit, usually quite a lengthy application form and sometimes very detailed questions. Information on benefits is constantly changing and because the application procedure can at times be complicated, it is best to seek advice before applying from any of the disability organisations, support groups, advice or resource centres or Citizens Advice Bureau.

For adults and children with disabilities the main benefit is DLA (Disability Living Allowance) which is made up of two parts – caring and mobility. Depending on the needs, some people get one part, some the other and some both. ICA (invalid Care Allowance) is a benefit for the carer if he/she meets the correct criteria, there is a limit on what you can earn to be eligible for this benefit. There are other benefits – mainly for adults – and possible tax concessions available, again it would be best to seek advice on these.

Benefits are an entitlement, it is not as if people with disabilities are trying to get something that they do not deserve. It is difficult enough, at times, to care for someone with a disability, these benefits only help you with some of the financial costs – and definitely not all of them. One example would be mobility. If you have a child in a wheelchair, for example, you will probably need the car most of the time with all the additional running and parking costs (few shopping centres have free places) – even for short journeys. The mobility part of DLA will hardly cover someone for all these costs.

For many, including those who work with families who experience disability, this can be a very frustrating and difficult area. This is why it is advisable to get in touch with an organisation that has experience in this field. Benefits are only stepping stones to a better quality of life and as such they should be accessed.

## **Children's Services Plan**

As in most areas of life, planning is necessary. However when it comes to health and social provision for children with disabilities, not all children have a service plan outlining what type of services they are going to get and when. Furthermore work is only beginning in some health boards and trusts to bring together all the various agencies, both statutory and voluntary as well as parents, carers and those who use specific services to help develop an overall plan to meet the needs of children. Such a provision is long overdue.

## **"Consumer Involvement"**

How to involve those who use services into the planning of such services – this is the crux of "consumer involvement". But people see themselves as more than consumers and see those who provide the services as more than just that. Also there is the whole question of consumers and commercialism, in the long term will the people who use services have to pay for them themselves? Consumerism does not seem to take a holistic approach to health and social care that many people want. Certainly it is praiseworthy to involve the "consumers", indeed it is crucial, but for many looking on it has taken a government initiative to drive health boards and trusts down a road they should have been going down anyway, years ago. When individuals who receive either health or social care or both, can influence not only the planning but also the provision of such services, the perhaps then we will have real involvement, even though it may not be consumer involvement.

## **Diagnosis**

For many people it is very important to have a name for their child's condition (diagnosis) based on the symptoms (signs, ways of going on), for others it is not. Also there are many parents who have to wait a long time for a diagnosis, indeed some will never have a diagnosis. For all parents and children this is a very vulnerable time and great sensitivity is needed by all involved.

## **Disclosure**

How this information on the child's symptoms, condition and/or diagnosis is given to families is often referred to as disclosure. A great degree of empathy is needed at this stage by professional staff involved as it is often that at this point that communications between professionals and parents can break down. After the initial shock, many parents cannot take in any further information. Also many parents highlight that a negative picture is often painted at this point, with little or no support available. Disclosing information that is going to dramatically change peoples' lives is not easy, but all those involved must look closely at their practice and see if there are any ways that they can help give more support and help to families.

## **Education**

This is a key issue for many families, particularly when there are young children involved. In the end when all the debate is over, it is really up to individual parents and their children as to what is best for them. There are advantages and disadvantages in different education systems, and these all have to be weighed up before any decision is made. It could be that Special Education is the choice, even though some will argue that this keeps children with special needs / disabilities away from other children but others will argue that such provision meets the particular needs of their child. Some people swear by integrating their children into Mainstream Education (what is usually referred to as primary and secondary education), arguing they want their children taught alongside children who do not have disabilities. However even in this situation some children feel left out if there is not adequate provision to meet their needs. Harder to find is Inclusive Education, where children with disabilities / special needs are fully included in the education system, their needs are met but also all the children learn from each other and value each other whether they have a disability or not. Concerns around the education statement and getting what is best for their child are constantly to the fore for many parents. Clearer information, guidance and better choice for everyone involved is needed in this crucial area.

## **Family View of Disability**

This is the core of the work of the Family Information Group, that disability in a child affects the whole family. There are many views and models of disability: medical model, social model, statutory view, voluntary view etc..., the "family view" is simply one more perspective or view. This is based on the experiences of parents who have children with physical and/or sensory disabilities. From this viewpoint, it is argued that the views of families, including children with disabilities, must be taken on board in the planning and provision of services. However it goes further and advocates that families and children should also be directly involved in these processes as they are the professionals and experts too in certain circumstances.

## **Housing**

The housing needs of children with disabilities and their families can sometimes be very complex, also they can be constantly changing, as the child gets older. In trying to address these issues there is a range of choices for families: public or private rented accommodation, sheltered housing, specialist housing, housing association dwellings, adapted housing, home ownership etc... Many families are limited however by what they can afford, and sometimes even the grants procedure in home ownership – the Disabled Facilities Grant – which is supposed to help families, can prove to be too expensive as parents are means tested (not the child with the disability) and often find they cannot afford the contribution they are assessed to pay. Space, safety, warmth, access are just some of the basic requirements of a family, they are not luxuries and these needs should not just be met in a particular family's home but in homes in general if our community is to be inclusive.

## **Inclusion**

This simply means including everyone, adults and children with disabilities, their families, relations etc... However to be inclusive many of these issues have to be addressed first.

Information

Just because there seems to be a lot of information about, does not mean that people can obtain such information. There are many issues around information that need to be sorted out if families and those who work with families are to be fully informed.

Indeed often the glut of information on certain issues can be more confusing than little or no information at all. Key areas of concern are: who is giving Information has to be accessible, in other words people must be able to get at it, and it should be in formats that people can easily understand (e.g. large print, Braille, audio tape, video, drama, illustrations etc ...).

If it is true, as it is argued, that the key to giving people real power is information then we must all work towards ensuring that the information needs of everyone are met.

### **Key Worker**

In the confusion that can often arise when there is a number of different "professionals", from various agencies, working with families – especially around the time of diagnosis and disclosure, the appointment of a key worker to co-ordinate services to families would be very beneficial. This worker would be able to inform the family of who does what and how to access particular services. Also he/she could inform "the professionals", thus alleviating the family from having to relive the diagnosis and disclosure every time someone new was coming into the family to offer a service. The key worker could also help to build a bridge between the family and the statutory services.

### **Language**

If we listen to adults and children with disabilities and their families, we should be able to learn what is appropriate language to use. Language can hurt and can help to form negative attitudes so it is important to always monitor what we say and print. Sometimes we end up using jargon or big words that no one seems to understand, jargon free language is much more appropriate.

Positive View of Disability

As parents, family members and as people who work with families, we often concentrate on the negative aspects of disability. Some of these attitudes stem from our own viewpoint, or sometimes we can pick them up from negative attitudes at the time of diagnosis and disclosure. However there are children and adults with disabilities who would put many "able-bodied" people to shame because of the ability they show. Much of this ability can be seen in everyday activities rather than in the headline featured feats. Indeed many people with disabilities do not see themselves as disabled at all. It is still possible to be realistic and acknowledge limitations yet still have a positive view of disability. It is in really listening to and watching people with disabilities that we can capture a little of what is meant by the positive view of disability.

### **Respite Care / Time Out**

Everyone needs a break, families with children who have disabilities equally so, if not more. The pressures and strains of looking after and caring for a child with a disability can be phenomenal and many parents' health have been adversely affected. However rather than someone take their child away for a couple of days, many parents would prefer just a couple of hours off to go shopping, out for the evening, or perhaps just to spend with the rest of the family. Flexible child-minding provision which allows the child with the disability to have creative stimulating time, with someone experienced in disability who has got to know the family and in a safe warm environment inside or outside the home would be the ideal.

### **Role of Professionals**

This has been explored in detail already. It is enough to say that all of us who care for children who have disabilities are equally professional whether we are paid, volunteers, carers, parents or family members. If we recognise this then perhaps we can work together.

## **Services**

Services to families need to be integrated, co-ordinated and for all the family – the child with the disability, the siblings, parent/s and relatives. Families should be directly involved in the planning and provision of services, it makes sense that those who use the services will know a lot about them. Service providers must respect family members and be sensitive to their needs.

## **Support**

There needs to be more support for families not just at the time of diagnosis and disclosure but as and when needed. Both organisations in the voluntary and statutory sectors have a role to play in this as well as the families themselves. Support given at the right time can often act as a preventative measure, helping the family through a difficult time, which could mean they will need less support services in the future.

## **Training / Education / Development of Carers and Parents**

The needs of parents and carers around education, training and development are often ignored or overlooked. Many carers and parents miss out on such activities because of the pressures that result from caring for someone.

Often courses on offer do not take their specific needs into consideration when being planned. Skills are needed when caring for someone, practical concerns and issues around advocacy, for example, few courses address these. Some of the criteria relating to certain benefits prevent people from accessing courses e.g. Invalid Care Allowance.

Parents and carers are people too and they also have their own needs, this must be recognised and ways found of addressing these needs.

## **THE ROLE OF THE OTHER PROFESSIONALS**

There are many professionals – from voluntary and statutory agencies who will be involved with you, your family and especially your child who has a disability. At times it can be very confusing. But what is not confusing is that you too as the parent and/or carer of the child are also a professional.

Often you will know more about your own child's condition, about his/her development and growth – more so than any of the other professionals involved.

You know what it can be like in the early hours of the morning when your child calls for attention one more time. Also many parents will tell you that they knew – long before any diagnosis – that there was something wrong with their child and often professionals would not listen to them.

However it is when families are treated as equals by other professionals that the tension and aggression that sometimes can develop in these situations can be eliminated. Building up good relationships with sensitive and caring professionals can then be achieved, in the interests of everyone. But also parents/carers and the professionals themselves have to be clear about their role in the family.

For example if a social worker is seen as "someone who takes children away" – as one recent report found – then it is going to be difficult for families who believe this to work closely and openly with a social worker. If a doctor does not treat a parent with respect and dignity, how can he/she expect the parent to follow the advice given.

In describing the roles of some of the key professionals (other than parents/carers) as much jargon (difficult words and terms associated with professionals) as possible is avoided.

Some professionals will disagree with the description of their role but this description of roles is taken from the family viewpoint, which is not always the same as the professional viewpoint. No offence or criticism is implied.

## **WHO DOES WHAT?**

**CONSULTANT PAEDIATRICIAN** – This is a senior child doctor who specialises in the health of children. Often consultant paediatricians coordinate a variety of services for children, sometimes through a child development clinic. Families are encouraged to bring their child regularly to these clinics to check on their progress. Again the consultant paediatrician can refer families to other services as can the paediatric community nurse.

**DENTIST** – Advice and information is available from the dentist on caring for and looking after teeth.

**DIETICIAN** – The dietician gives assistance on health diets, information on healthy foods and help to give information on a balanced diet. Dieticians do not concentrate on diets for losing weight rather they help families to develop health eating patterns with the proper nutrition although they do realise that we are living in the real world with all the peer pressures and the influence of advertising.

**DOCTOR** – There are various types of doctors, some who work in hospitals in specialist fields, others who work in the community (in practices and health centres) – often referred to as GP's (General Practice) or family doctors. Often it is your doctor (i.e. G.P/family doctor) who refers you or your child to the other services needed. If a more senior experienced doctor (consultant) is needed, often this referral comes from your doctor. Usually it is your doctor that you see first for a check-up when you are pregnant before you see the midwife.

**EDUCATIONAL WELFARE OFFICER** – Although often seen as the key staff involved in concerns around children not attending school – which is one of their functions, educational welfare officers also give information and assistance to families whose child has special needs and/or disability.

**EDUCATIONAL PSYCHOLOGIST** – Helps children with educational development, involved in assessing their needs working closely with the children, parents and teachers. Very much involved in assessments of children with special needs, learning difficulties and disabilities. These psychologist are directly involved in the educational statementing procedure, often providing reports for this.

**HEALTH VISITOR** – Soon after your baby is born, a health visitor (usually based at your doctor's surgery/health centre) should visit you and your baby at home. Through time further contact with the health visitor will be at your local clinic/doctors surgery or possibly at home.

The health visitor is interested in your health as well as your baby's as well as the rest of the family. Like your doctor, she can refer you, your baby and/or your family to other services that may be available. Health visitors usually stay involved with families until the new baby is five years old and starting primary school. Often they are seen as the profession most involved with families and children in those first few years after a baby is born.

A disabling condition can be diagnosed at any age. It can be the parent who first notices that there could be something wrong, or it could be the midwife, health visitor or doctor or perhaps some other concerned individual. Often a referral process takes place until the child is seen by a specialist. It is the specialist who usually makes the diagnosis although other professionals are now taking on this duty. Paediatrics is the field of children's health and often it will be professionals in the field that your child will see.

**MIDWIFE** – The midwife is usually attached to your doctor's surgery and to the hospital which you will be attending during pregnancy and childbirth. Community midwives will visit you in your home before and after the baby is born. The community midwives will continue to visit the mother and baby in the home for a number of days after the birth.

**OBSTETRICIAN (+Consultant Obstetrician)** – The role of this specialist doctor is in the area of pregnancy and childbirth. He/she is usually based in the hospital and if you are pregnant you will have regular appointments with him/her. A consultant obstretician will be in a more senior position within this department:

If the child is born in the hospital then it will be the responsibility of the hospital staff to offer the care and attention that the mother and baby need through doctors, nurses, auxiliary nurses and the other hospital support staff. The midwife and family doctor will continue to support the baby born at home and the baby's mother.

**OCCUPATIONAL THERAPIST** – it is in the areas of daily living and mobility of your child that occupational therapists work. Often they can advise and assist on equipment which could help your child. Particular emphasis is on helping with dressing, washing, toileting and any change to your home (adaptation) that could help your child have better access. Advice and information on various equipment e.g. specialist beds, wheelchairs etc are also available through the occupational therapist. Although a referral is usually necessary and preferred to use this service, contact can be made directly with the occupational therapist in certain circumstances.

**OPTOMETRIST** – Offers advice, information and help on matters relating to eyesight and difficulties over vision including squint and eye movements which give cause for concern.

**PAEDIATRIC COMMUNITY NURSE** – A nurse specialising in children's health who works in the community. Also there are general community nurses and district nurses who also offer support, advice and medical treatment to families. A practice nurse is based in a doctor's surgery/health centre.

**PAMs** (Professions Allied to Medicine) – These are specialist professionals who can offer very specific and individual support to children and their families and include occupational therapists, physiotherapist, speech and language therapists etc. Some of these professionals are based in the child development clinic while others work in the community. Contact is usually through a referral from another professional e.g. doctor, health visitor, or social worker. Also they can work in the community, health centres/clinics, surgeries and in hospitals.

**PHYSIOTHERAPIST** – Assist with helping in gaining independence, retaining independence and/or developing independence usually through a programme of specialist exercises and movements. A physiotherapist also often teaches parents/carers skills in exercise

which they can carry out at home with their children. Also can give advice on breathing exercises and safe lifting and handling techniques. A referral is necessary to use this service e.g. from a doctor, health visitor, doctor, social worker, nurse etc.

**PODIATRIST** – This is a relatively new name used to describe someone who is concerned about your child's feet, previously call a chiropodist. Information, advice and help is given by podiatrists on all aspects of feet care.

Just as there are stages in a child's development, so too there are different stages which certain professionals are involved. Although the family doctor often remains the key medical figure for most families, when the child reaches school age (around 5 years old) there is a shift from the health visitor to medical staff linked with the school. On certain occasions the health visitor may continue to be involved with your child beyond the age of five.

**SCHOOL DOCTOR** (Clinical Medical Officer) – He/she co-ordinates much of the medical care your child will receive at school – medical check-ups etc. Also if your child has special needs around education, it is the school doctor who is responsible for much of the medical information needed to help your child get the most out of his/her education. If an educational statement is needed for your child the doctor will be directly involved with this.

**SCHOOL NURSE** – Links with the school doctor and has responsibility for health and medical matters for your child in school.

**SOCIAL WORKER** – Referrals to social workers can usually be made by individuals themselves by contacting their local health centre or base from which social workers operate. Often they specialise in certain areas of care e.g. children, older people, people with disabilities etc – social workers are often a link to other services and to professionals from other fields both inside and outside the health service. They offer advice, support, information and can often act on behalf of families and their children. However limited resources often prevent many social workers from offering the full range of services they know are required to meet the needs of families and their children.

**SPECIAL EDUCATIONAL NEEDS OFFICER SENCO** – This is a specialist teacher, appointed by the school to take a special interest in children who have special educational needs, learning difficulties and/or disability. They are very involved in the educational statementing procedure.

**SPECIAL NEEDS OFFICER** – Employed by the education board to co-ordinate services to children with special needs/learning difficulties, disabilities, have the power to make decisions on whether a child should receive an education statement or not.

**SPEECH AND LANGUAGE THERAPIST** – As well as giving children help in areas of speech and language development, therapists are interested in all areas of communication. Information on aids towards communication, including computers and computer software, is available from staff. A referral is usually necessary.

**TEACHER** – For many children and their parents, the teacher is the first professional that they are in contact with while their children are at school. He/she may be the first person who becomes aware of your child's educational needs and sometimes medical needs. Also the teacher can refer your child for more specialist help, if this is needed. Increasingly more teachers are receiving training and education about special needs and disabling conditions.

There are other professionals involved with families but this list includes some of the most common.

## **CONCLUSION**

If anyone is serious about gaining a full picture of how disability affects families then they must listen to the parents and the families involved. Too often these voices have been overlooked or ignored.

Of course there are other voices to that have to be listened to – the children and young people with disabilities, their siblings, other family members, those who work with families from the voluntary and statutory sector etc. But this listening cannot be a form of tokenism.

Parents and family members save government a lot of money, by their constant care and attention. To recognise the value of parents/carers and family members is a first step in acknowledging their "professionalism". As equals, there is an opportunity for those who provide services and those who use services to work in real partnership positively.

By listening to parents/carers the lives of all those involved in disability issues will be enriched. As we aim towards a more inclusive society, we cannot ignore the families most affected by disability.

Addressing the issues up front, supporting families in the community and gradually wearing down the negative attitudes and misconceptions around disability, these are the positive moves needed to change our community and to include parents/carers more fully in our future. These are not vague wishes or aspirations, rather they are fundamental rights which we must all act on.

Listening to parents, can be the starting point. Acting on what they say will be the measure of our commitment to a more sensitive inclusive community. The choice is ours. It is time to choose.