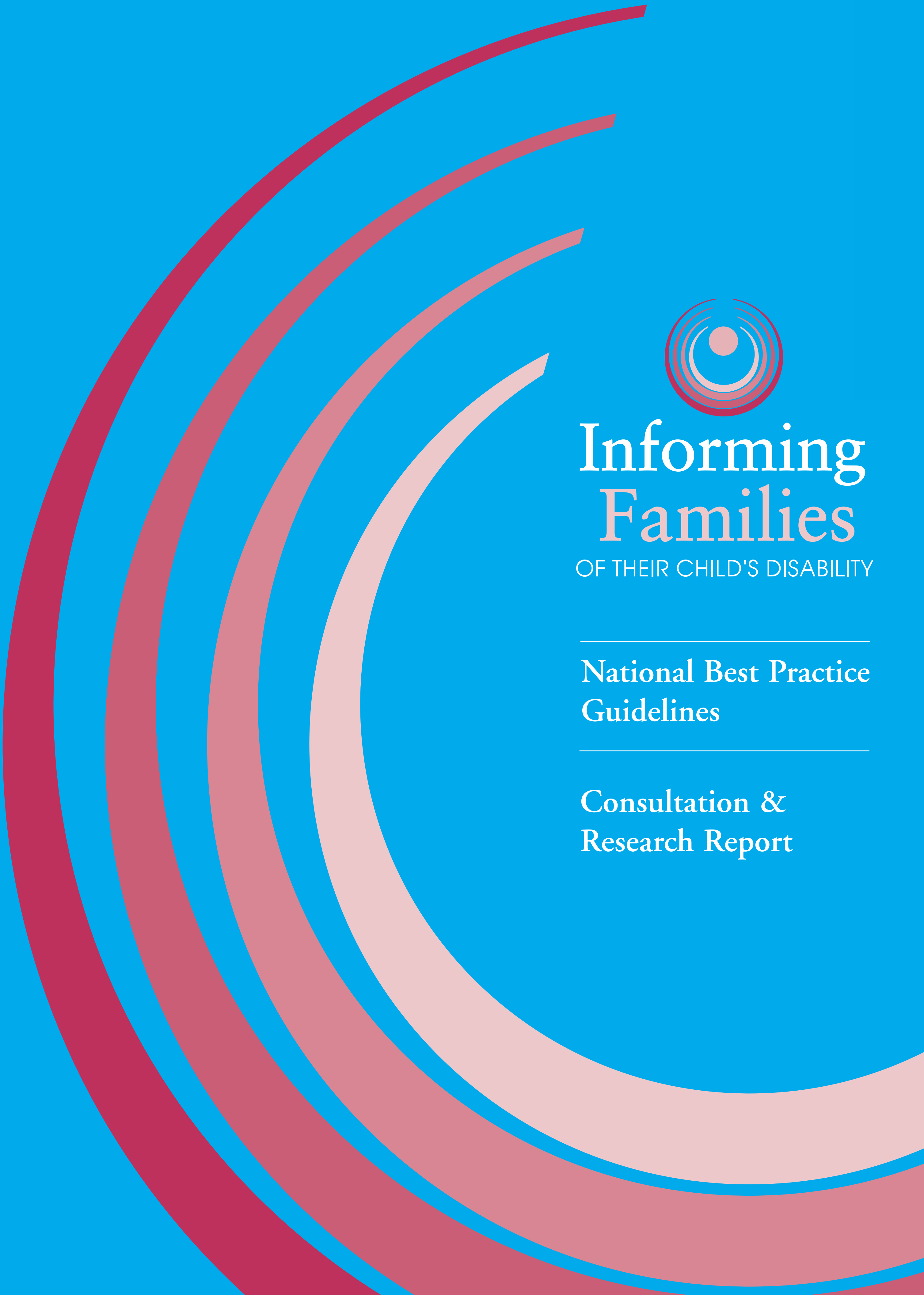

Informing Families
OF THEIR CHILD'S DISABILITY

National Best Practice Guidelines

Consultation & Research Report

Informing
Families

Informing Families of their Child's Disability

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Consultation & Research Report

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FOREWORD

In response to a proposal by the National Federation of Voluntary Bodies to mark the European Year of People with Disabilities 2003, the Health Services National Partnership Forum agreed to provide funding for a project which would make a real difference to people with disabilities in Ireland and particularly to their families who support them.

Having consulted with families and people working in the Disability Sector, it was agreed that the development of National Best Practice Guidelines for how families are told of their child's disability would be a significant way to mark the year, while also leaving a substantial legacy by way of addressing an important issue which has remained unaddressed over many years.

Having distressing news disclosed to us in a manner which lacks sensitivity or in an environment which is inappropriate causes additional stress at what is likely to be a difficult time. The central aim of this project is therefore the development of evidence based national best practice guidelines, education and training on appropriate procedures to inform families of their child's disability when communicating a diagnosis or concern. The intention of the guidelines is to ensure:

- Improved outcomes for families being told of their child's disability, through the implementation of best practice; and
- Improved support, guidance, education and training for professionals in the important and sensitive task of delivering this news.

The development of our National Best Practice Guidelines is the product of rigorous research carried out over the past two and half years. I am delighted to present this report which sets out in comprehensive fashion the research carried out and the exhaustive consultation which formed an essential part of the project.

We were convinced from the outset that a collaborative approach between families, carers, professionals and health service providers represented the best way forward and we constituted our Project Steering Group accordingly. We are delighted that this approach has borne fruit and that guidelines have been endorsed by all involved.

What is important now is that these guidelines are implemented in full in all the relevant care and support settings. We are very optimistic that they will support best practice in this important area and will make a real and positive difference in the lives of families when they are told of their child's disability.

The completion of this project would not have been possible without the input and support of many people, too numerous to mention by name here, but nonetheless whose contributions are gratefully acknowledged by the National Federation of Voluntary Bodies. Foremost in our thoughts in this regard are the many families who shared with us their very personal stories. I would also like to acknowledge the valuable contributions of the many professional staff with whom we consulted. I wish to formally thank Dr. John Hillery and the other members of the Project Steering Group and also Dr. Suzanne Guerin from University College Dublin for her expert guidance of the research methodology. We are extremely grateful to the Health Services National Partnership Forum for its financial support and most importantly for making its expertise in the form of Tess O'Donovan and Marie O'Haire available to us on an ongoing basis throughout the Project. Finally, I would like to pay special tribute to Alison Harnett, our Project Co-ordinator, whose tireless work, commitment and professionalism, have made these very important guidelines a reality.

Brian O'Donnell,
Chief Executive, National Federation of Voluntary Bodies

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LIST OF ABBREVIATIONS

- ASD – Autistic Spectrum Disorder
- CAMHS – Child and Adolescent Mental Health Services
- ENT – Ear, Nose and Throat
- EPSEN – Education for Persons with Special Educational Needs Act, 2004
- ERHA – (former) Eastern Regional Health Authority
- GP – General Practitioner
- HSE – Health Service Executive
- HRB – Health Research Board
- HSNPF – Health Services National Partnership Forum
- IEP – Individual Education Plan for Children
- NICU – Neonatal Intensive Care Unit
- NIDD – National Intellectual Disability Database
- NCHD – Non-Consultant Hospital Doctors
- NPSDD – National Physical and Sensory Disability Database
- OPD – Out-Patients Department
- PHN – Public Health Nurse
- RNID – Registered Nurse – Intellectual Disability
- RFTS – Right From The Start
- SCBU – Special Care Baby Unit
- SHO – Senior House Officer
- SpR – Specialist Registrar

The following terms have been used within the report for ease of analysis and reading

The term 'parent' is used in this report to indicate guardians of the child and respondents to the national parent questionnaire survey which included parents, adoptive parents, foster parents, and grandparents.

The term Trainee Doctor was used to record references to doctors in training throughout the report which included Non Consultant Hospital Doctors (NCHD's), Senior House Officers (SHO's), Registrars, and Specialist Registrars (SpR's).

The term Ultrasonographer was used to refer to Midwives and/or Radiographers performing obstetric ultrasound examinations.

EXECUTIVE SUMMARY

Introduction

In 2004 the National Federation of Voluntary Bodies, with support from the Health Services National Partnership Forum (HSNPF), began a project to develop national best practice guidelines for how families are told of their child's disability. The project was initiated in response to feedback from many parents to National Federation member organisations, that the news of their child's disability had been conveyed insensitively or in inappropriate environments; and that their experience of being told the news had caused additional distress at the time of disclosure. Similarly, feedback from professionals delivering the news indicated that they felt there was an absence of training and clear guidance available to support those undertaking the sensitive and challenging task of giving a family the news that their child has a disability. The development of the guidelines was guided by a Steering Committee chaired by Dr. John Hillery (President of the Medical Council of Ireland 2004-2007 and Consultant Psychiatrist with intellectual disability service providers Stewart's Hospital and St. Raphael's, St. John of God Hospitaller Services). The Steering Committee has representation from key groupings such as parents, disability service providers, the HSNPF, the Health Services Executive, the Department of Health and Children, the Royal College of Physicians of Ireland, the National Federation of Voluntary Bodies and nominees from the professional bodies and trade-unions of various disciplines involved in informing families.[1]

Project Aims

The aim of the *Informing Families Project* was to develop evidence-based National Best Practice Guidelines, education, and training; on **appropriate procedures to inform families of their child's disability** when communicating a diagnosis or concern. The fundamental goals of implementing these Guidelines are:

1. **To ensure improved outcomes for families being told of their child's disability, through the implementation of best practice**
2. **To provide improved support, guidance, education and training for professionals in the important and sensitive task of delivering this news**

The scope of the project included the disclosure of a child's diagnosis of physical, sensory, intellectual, or multiple disabilities, and autistic spectrum disorders. The Guidelines that were produced relate to the diagnoses of a child's disability whether that takes place during pregnancy, at birth, or in the case of a diagnosis which evolves over time. The Guidelines relate to disclosure of diagnosis in hospital, community and disability service settings.

Methodology

In order to ensure that the guidelines would be informed by wide ranging consultation and partnership with all key stakeholders and that they would be grounded in evidence-based research, the Informing Families Steering Committee directed the undertaking of a comprehensive consultation and research programme. This process included:

Stage 1

- A review of relevant national and international literature, and an examination of the national policies relating to this area.
- Initial exploratory research with families and professionals.

Stage 2

- Seven consultative focus groups with parents of children with disabilities (physical, sensory, intellectual, multiple disabilities and autistic spectrum disorders) from around Ireland.
- Consultative focus groups with 15 disciplines of professionals involved in communicating to parents the news that their child has a disability, or in supporting them immediately thereafter.

Stage 3

- A National Questionnaire Survey disseminated to 584 parents of children with disabilities
- A National Questionnaire Survey disseminated to 1588 professionals in 27 disciplines who provide the news to families of their child's disability, or support families who have just received a diagnosis

The consultation and research strands explored disclosure practice across the range of hospital, community, and disability service settings in which parents may receive the news of their child's disability. Each of the stages undertaken informed and led to the next stage, and the results of the consultation and research in the literature, focus groups and national questionnaire survey were collated and analysed to produce the National Best Practice Guidelines for Informing Families of their Child's Disability.

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[1] Please see Page 166 - Appendix III – Steering Committee Membership.

Findings

The findings of the consultation and research undertaken during the Informing Families Project indicate the need for specific supports to be put in place in order to support consistent and universal implementation of best practice guidelines for how families are informed of their child's disability:

- Government Strategy and Policy documents from the past 17 years call for the introduction of specific measures to support best practice in how families are informed of their child's disability. The measures relating to how families are informed of their child's disability largely remain unimplemented.
    a. Needs and Abilities (1990)
    b. A Strategy for Equality (1996)
    c. Towards an Independent Future (1996)
    d. Quality and Fairness (2001)
    e. Disability Act & Sectoral Plans (2005)
- **The importance of the disclosure process is clearly outlined** in the International research, which indicates that the way in which families are given the news of their child's disability has an impact on levels of distress and anxiety for the family, has a bearing on the attachment process, and can influence parent-professional relationships thereafter (Cunningham, 1994; Sloper and Turner, 1993). Cunningham also indicates that dissatisfaction with disclosure is not inevitable and that **the introduction of good practice increases parental satisfaction with how they are told of their child's disability** (Cunningham, 1994). The disclosure process has implications for the child, for the family, for the staff members communicating the news, and for managers of staff members engaged in the process. Poor disclosure practice can impact on the welfare of the child when inadequate information leads to delays in accessing support (Hatton et al, 2003), and can also increase the risk of litigation (Fallowfield and Jenkins, 2004). Staff members may experience challenges in terms of the emotions and stresses that can be associated with communicating difficult news to the family. The provision of training and debriefing opportunities can be positive supports for staff members in this regard (Abel et al, 2001; Barnett et al, 2007).
- Analysis of the *Informing Families Project* national questionnaire survey indicated that levels of parental satisfaction with disclosure reported in the current study are in line with those found in the international literature, and indicate that practice in Ireland appears to lead to a similar levels of parental satisfaction to those experienced in other countries. What is very encouraging, also, is that the levels of dissatisfaction found in the current study are significantly lower than those reported in previous studies. These results demonstrate that **there is a basis for good practice already in place in Ireland with many parents experiencing the disclosure process in a supported way, and many professionals currently employing appropriate strategies to ensure that parents receive the news in the best way possible.**
- However, both the focus groups and the national questionnaire survey found that there were parents who expressed significant levels of dissatisfaction with how they were told, and professionals who expressed an urgent need for further support and training to assist in the application of best practice. These results clearly demonstrated that **when there are deficits in practice the consequences for parental distress can be significant, and when professionals do not feel adequately trained or supported, it increases the stressful nature of the emotionally challenging task of communicating difficult news.** Clearly then, there is a strong rationale for implementing guidelines that aim to ensure a more consistent approach to supporting parents and professionals.
- Through the focus group consultation with families of children with disabilities, parents spoke of the impact caused when poor practice caused additional stress at the time of diagnosis. Parents in the focus groups who were dissatisfied with how they had been told the news noted inappropriate physical environments in which the news is delivered, a lack of appropriate communication, a lack of continuity of care, and inconsistent provision of comprehensive, accurate and up to date information, as the areas requiring the most urgent need for improvements.
- Existing Irish research (Redmond, 2000; Western Health Board & Brothers of Charity Galway, 2003) and the findings of the Informing Families research indicate that there are significant **deficits in the information** currently provided to parents. There is a need for co-ordination of the information available to professionals for supply to parents, as a lack of ownership of information in local settings is currently leading to many parents receiving out of date leaflets, or not receiving recommended literature due to professionals not knowing it is available. The findings of the research indicated that deficits include a lack of information in mainstream settings about the services available in disability service settings; a lack of information in languages other than English; a lack of guidance on appropriate Internet sites for parents seeking information about a particular diagnosis; and dispersed and confusing information regarding benefits and entitlements. There is a need for widespread and equitable access to accurate, up to date and appropriate information and interpretation services.

- Parents and professionals indicated the clear need for **continuity of care** to be provided within service settings (e.g. where more than one medical or social care team are involved in providing the diagnosis) and across settings (e.g. when families are discharged from hospital settings into the community, or are awaiting referral to Early Services). **A named liaison person** is required to provide continuity of care and co-ordinate the team approach in these situations, to avoid the very distressing vacuum that many parents and professionals described following discharge before reaching Early Services, and the mixed messages that were often received when internal teams did not effectively communicate.
- The findings of the focus groups and national questionnaire survey of parents and professionals indicated that in Ireland there are professionals from many disciplines and experience levels, working in many different service settings, who first inform families that their child has a disability, or provide support during the process of this disclosure. The data gathered from the various consultation and research strands confirmed the involvement of professionals:
  - From hospital, community, and disability service settings
  - Working in medical, nursing and allied health professional fields
  - Whose levels of experience range from newly qualified to having over 35 years of experience
  - And whose frequency of involvement ranges from less than once per year to over 35 times per year.

  The broad range of disciplines involved, many of whom are in mainstream rather than disability-specific services, means that clear planning and ownership of tasks within the disclosure and support process; interdisciplinary training; and a structured approach to dissemination of best practice is necessary.
- Previous Irish research (Doyle, 2004) indicated an absence of consistent guidelines or local policies in place to guide professionals breaking the news to families that their child has a disability. The results of the focus groups of the *Informing Families Project* and the professional questionnaire support this finding and indicate that professionals working in disclosure of disability or supporting families who receive the diagnosis would welcome clear guidelines and training in best practice.
- Existing strategies in the UK for implementing best practice when informing families of their child's disability were found through evaluation to have lacked effectiveness because one third of key staff members were unaware of the guidelines (Fallowfield & Jenkins, 2004), indicating the need for a comprehensive communications strategy to accompany the dissemination and implementation of best practice guidelines.

Conclusions

International experience, and the non-implementation of existing policy recommendations, indicates that if Best Practice Guidelines are published and circulated without the back-up of a clear implementation strategy, the recommendations will remain just that, and the needs identified clearly over the past 17 years will remain unaddressed.

This report therefore recommends the implementation of the following evidence-based best practice guidelines, and the undertaking of a coordinated, adequately resourced approach to implementation which is integrated across hospital, community, and disability service settings.

The National Best Practice Guidelines for Informing Families of their Child's Disability fall into two sections; Guiding Principles and Best Practice Recommendations. The Guiding Principles apply regardless of the circumstances of disclosure. The Recommendations are non-prescriptive, and in addition to being informed by the above principles will require adaptation to the circumstances of disclosure, including:

- Hospital / community / disability service setting / family home
- Ante-natal diagnosis[2] / diagnosis at birth / evolving diagnosis
- Physical / sensory / intellectual / multiple disabilities and autistic spectrum disorders
- Unexpected event / predicted disclosure following assessment or tests

These guidelines adopt a person-centred approach whereby the child and the family are at the centre of the measures undertaken at the time of disclosure and in the ongoing parent-professional relationship.

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[2] Joan Lalor et al (2007) have conducted Irish research into the specific elements of practice that relate to disclosing a concern or diagnosis during pregnancy. A further reading list in this regard can be found on page 164 of the Reference section.

INFORMING FAMILIES OF THEIR CHILD'S DISABILITY NATIONAL BEST PRACTICE GUIDELINES

Guiding Principles

Whilst every disclosure event is unique, the *National Best Practice Guidelines for Informing Families of their Child's Disability* have identified that the following Guiding Principles should be applied in every case.

1. Family Centred Disclosure

Disclosure must be family-centred and tailored to the emotional and informational needs of each individual family. The family should be provided with choice and options in the support that they receive during the disclosure process (e.g. family-friendly appointment times, private accommodation, contact with other families, counselling, etc.).

2. Respect for Child and Family

At all times it is necessary to demonstrate respect for the child and family. This should include using the child's name, acknowledging and supporting the family's dignity, emotions and reactions, and respecting cultural and linguistic diversity.

3. Sensitive and Empathetic Communication

Sensitive communication that is open, honest, empathetic and understanding is essential. Whilst unavoidable difficulties in implementing best practice in other areas may be understood by parents, blunt or insensitive communication invariably leads to significant and lasting dissatisfaction.

4. Appropriate, Accurate Information

Meeting the family's information needs is a key priority that influences subsequent levels of parental stress and satisfaction. It is essential to pace the information in accordance with the needs of the individual family; (including how recently they have received the diagnosis, any current medical needs, and potential levels of distress or shock) to provide sufficient information whilst avoiding information overload.

5. Positive, Realistic Messages and Hope

Realistic, positive messages and hope should be given with the diagnosis - not merely the worst case scenario. The emphasis should be on the child first, and the disability second. Encouraging staff members to support parents who wish to celebrate their child may include disability awareness training and an exploration of various definitions of hope which parents find appropriate and helpful (e.g. reassurance that support and help are available).

6. Team Approach and Planning

Informing a family of their child's disability is a process rather than a once-off event. Preparation, planning, team work, close communication between staff members and liaison between agencies/service providers is essential to successful implementation of best practice.

7. Focused and Supported Implementation of Best Practice

Support for implementation of the Guidelines is required at all levels, including management, to ensure that planning takes account of the need for appropriate physical environments; provides for information ownership; and facilitates agreed protocols for dealing with different disclosure scenarios.

The Guidelines are non-prescriptive, and in addition to being informed by the above principles, will require adaptation to the circumstances of disclosure, including:

- Hospital / community / disability service setting / family home
- Ante-natal diagnosis / diagnosis at birth / evolving diagnosis
- Physical / sensory / intellectual / multiple disability and autistic spectrum disorders
- Unexpected event / predicted disclosure following assessment or tests

Recommendations for Informing Families of their Child's Disability

1. Setting/Location and People Present at Disclosure

In relation to the location and the people that are present, the Guidelines recommend that:

1.1 The diagnosis is given in a private place with no interruptions. The room in which this takes place is:

- Quiet
- Free from interruptions
- Comfortable and user-friendly
- Available for the family to spend time in, absorbing the news after the consultation
- There is a kettle, phone, tissues, tea, coffee and water available

Within the hospital setting there is a need for private rooms to be made available in both in-patient and out-patient settings. Ideally, the consultation does not take place in a room that the family will be using again such as the labour ward or ultrasound scanning room, as this may leave parents with a negative association with this room for the future.

1.2 The diagnosis is made verbally (not in writing) and in person (not over the phone).

1.3 Both parents are present when the diagnosis is given.

1.4 If it is only possible to have one parent present, the option is given to have another family member or friend present to provide support.

1.5 When a parent hears the news alone, arrangements are made as soon as possible to inform the other parent and close family members.

1.6 If the parents are very young, it may be appropriate to invite extended family members such as grandparents as support for the parents.

1.7 The news is given by an appropriately trained staff member who is responsible for delivering and confirming the diagnosis.

1.8 A second professional, preferably known to the family, is present and remains to support the family after the initial disclosure.

1.9 The number of professionals present is limited and does not greatly outnumber the family members.

1.10 No extra staff are present purely for training purposes. *(Any staff members in training that are present should also have a role in providing further care to the family).*

1.11 If the news of a child's disability is given close to the time of birth, it is important that the parents have seen the baby before the diagnosis is given, and if at all possible the parents are given the opportunity to spend some time with the baby before any disclosure takes place. *This can facilitate the parents in identifying with their infant as a child first and the disability as secondary.*

1.12 It is critical that the parents can see the baby when they are being prepared for difficult news. *(This is necessary to avoid any misunderstandings that may lead to assumptions that the child has died.)* If the baby cannot be present, the parents should first be sensitively reassured that the difficult news to be imparted does not mean that their child has died or is dying.

1.13 If a baby is being cared for in the intensive care unit, the parents are facilitated to visit as soon as possible after the diagnosis is given, including facilitating a mother who herself may be recovering from surgery such as a Caesarean section.

1.14 Unless the diagnosis takes place close to the time of birth, it is not recommended that the child should be present for the disclosure, so that the parents have an opportunity to absorb the news and express their emotions.

1.15 Parents are given time alone together to absorb the news in private, if they wish. They are made aware that there is a staff member who they can contact for support at any time.

1.16 Whilst respecting the parents' need for privacy it is also important to ensure that the parents are not isolated after being given the diagnosis – if parents wish, a staff member should engage with them at this time to sit and spend time with them.

2. Communication

In relation to the communication of the child's diagnosis to the family, the Guidelines recommend that:

2.1 The news is communicated with:

- Empathy
- Sensitivity
- Honesty
- Respect
- Compassion
- Understanding

2.2 It is important that positive, realistic messages are conveyed, and hope is given along with the diagnosis. Positive messages can include describing support and assistance that will be available to the family and focusing on the individual child as a person, with the disability secondary. *Rather than listing all possible negative implications of the diagnosis and presenting only the worst case scenario, parents have indicated that where possible it is helpful to be informed of the range of possible outcomes of the disability or condition, and the percentages of children who experience different aspects of the syndrome.*

2.3 Staff members giving the news use language that is:

- Simple
- Understandable
- Straightforward
- Appropriate

2.4 Prior knowledge of parents is assessed before explaining a diagnosis. *(Parents have suggested that open questions such as 'Have you any concerns?' or 'What have you heard so far?' are helpful, but closed questions such as 'Does he look like anyone else in the family?' are not.)*

2.5 Any medical terminology used is clearly explained, along with the implications and significance of any information given about the child's diagnosis.

2.6 Explanations are given at a level parents can understand, taking into account socio-economic, linguistic and cultural factors.

2.7 Listen to parents. *Listening to parents allows for communication to be tailored to the individual needs of the family.*

2.8 Parents are encouraged to ask questions.

2.9 Staff members check that parents have understood what has been discussed.

2.10 The child is shown respect; the child's name is always used, and they are not referred to by their diagnosis. *For example, instead of saying 'this Down Syndrome baby' staff members say 'Ben, who has Down Syndrome'.*

2.11 The appointment is **not** rushed. *Families and professionals agree that informing parents of their child's disability should be seen as a priority, and consequently adequate time must be allocated, including time for the parents to ask questions and express emotions without interruption.*

2.12 Pagers and mobile phones are switched off.

2.13 Team members reinforce the information already given at appropriate times so that families have several opportunities to absorb and clarify information provided.

2.14 Staff members are aware of their body language and how this can be interpreted by parents. Avoid whispering in front of parents, or giving negative non-verbal signals that could raise concerns with parents before the news has been communicated to them.

2.15 Parents' concerns are acknowledged, treated seriously and followed up.

2.16 The reaction of parents is acknowledged, supported and taken into account when communicating with the family. *(Parents will have different reactions and different coping mechanisms. Some may feel the need to 'walk away' for a period of time to come to terms with the news, others may be in shock and take in very little, still others may wish to have significant interaction, information and support from staff members.)*

2.17 Dismissive, impatient, aggressive or judgemental language is never used when speaking to parents or children.

3. Information and Support

In order to meet the information and support needs of parents at the time of diagnosis, the Guidelines recommend that:

3.1 Parents are kept up to date at all times, with honest information. *This includes acknowledging any uncertainty that exists about the diagnosis, and explaining any suspected diagnoses that are being investigated. There should never be a large gap between what parents know about the diagnosis and what professionals know or are investigating. Building trust with parents is a priority, particularly since the initial diagnosis may be the beginning of a long term parent-professional relationship.*

3.2 At the end of the initial consultation, parents are offered factual, accurate, up to date, relevant written material on the disability, support groups, entitlements and benefits, and on the Early Services that will be available for their child.

3.3 Information on support groups for specific syndromes is particularly important to parents and is therefore provided when at all possible. Where support groups do not exist in Ireland, contact with such groups in other countries is investigated and facilitated.

3.4 The amount of information provided is tailored to the individual parent's needs - avoiding information overload for parents who may feel overwhelmed, and meeting the information needs of parents who seek further details.

3.5 Care is taken in the timing of the delivery of news so that the consultation takes place at the appropriate time; taking into account for instance in a neonatal diagnosis that the mother may be recovering from the birth or surgery.

3.6 A contact number for a member of the staff team is provided to the family at the initial diagnosis, which they can use if they have questions or concerns.

3.7 A follow up appointment is **always** scheduled before the consultation is over so that the family leave with a plan, knowing when they will next have contact with those who provided the diagnosis, and giving them an opportunity to prepare questions and raise concerns. This appointment takes place no longer than two weeks after the diagnosis is given.

3.8 Parents are given a written summary of the consultation and receive copies of all correspondence between professionals relating to their child's diagnosis.

3.9 Next steps are carefully outlined and explained to the family – including any tests that will be carried out and any referral to other agencies.

3.10 Parents' preferences are sought and facilitated, including how much information they wish to receive, whether they would like to have visitors or support in limiting visitors while they come to terms with the news, whether they would like input from pastoral care teams. *Meeting this recommendation will include listening to parents during the consultation to assess whether they are overwhelmed by information already received or are seeking further information.*

3.11 The family are provided with guidance on appropriate Internet sites which contain relevant and accurate information for their child's particular disability. *This can avoid unnecessary anxiety when parents read information that may not be relevant to their child's particular case.*

3.12 The option of counselling is made available to families following the diagnosis, if appropriate.

3.13 The option of meeting the parents of other children with disabilities or similar diagnoses is offered following the diagnosis, where appropriate.

4. Culture and Language

In order to provide the diagnosis in a way which respects cultural and linguistic diversity, the Guidelines recommend that:

4.1 A formal interpreter is provided if the parents have limited English proficiency, and the role of the interpreter is explained.

4.2 Family members/friends are **not** nominated as interpreters. Formal interpreters should be used, as the use of family members/friends is inappropriate.

4.3 The interpreter is briefed on what will be discussed prior to the consultation so that he/she is prepared when the news is given.

4.4 The cultural and religious backgrounds of all families are acknowledged and respected.

4.5 When families from diverse cultural backgrounds are being given a diagnosis of their child's disability particular attention is paid to gaining an insight into the meanings that each family assign to disability. Accurate information is provided to explain the diagnosis and dispel any unhelpful misunderstandings of the disability that become apparent.

4.6 The written information given to parents is in their first language. *The information being explained to parents during disclosure of a child's disability can be quite complex and this is further complicated when there is a language barrier to be overcome.*

4.7 At a national level equitable access to appropriate professional interpretation services is provided, with interpreters available in person to attend consultations in which parents are inforrmed about their child's disability.

4.8 At a national level widespread access to written materials in languages other than English is provided to staff members, for supplying to parents.

4.9 The Informing Families Project recommends that further research is undertaken into how families of children with disability should be supported at the time of diagnosis to ensure culturally competent care.

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5. Organisation and Planning

Interdisciplinary team working, preparation for the different circumstances of disclosure that may occur and strong team communication are important when informing families of their child's disability. The Guidelines therefore recommend that:

5.1 Staff members consult with one another and prepare individually and as a team prior to the consultation with parents. *Providing a diagnosis of disability to a family is a priority task, and therefore calls for adequate time to be allocated, along with good planning.*

5.2 All staff members who may come in contact with the family liaise to ensure that no conflicting information is presented to the family and that all members have the same picture of what has already been told to the parents, to ensure that families are not inadvertently told new information without adequate preparation.

5.3 Staff members share information, so that parents do not have to give the same history or information to many different people.

5.4 As family circumstances vary, the team share information on how best to facilitate each family.

5.5 Care is taken at staff shift changeover times to alert staff members coming on duty that a family has been given the news of their child's disability.

5.6 A liaison person is assigned to the family to provide support and information from the time of diagnosis until such time as the family are being supported by appropriate early intervention services. Some of the key aspects of the liaison person's role include:

- Providing a single point of contact for the family
- Providing information to the family on entitlements and benefits, and services and supports available
- Providing assistance with paperwork and applications for services if required
- Ensuring that an 'Informing Families' checklist is completed and that all tasks relating to best practice in the disclosure process are carried out
- Providing a central point of contact to support services and organisations for the supply of up to date information to the interdisciplinary team
- Providing a co-ordinating role within the interdisciplinary team, to ensure that information is shared and coherent communication takes place with the family (including, if necessary, team conferences with the family) and ensuring that at least one person is present at the initial disclosure who will be available to meet with the family again to provide continuity of care and information
- The liaison person should have appropriate training to understand the needs of families of children with disabilities.
- The liaison person will have a key role in disseminating best practice guidelines for informing families of their child's disability.

5.7 Written information is provided between professionals when referring on, detailing what parents have already been told, so that parents are not inadvertently given significant news without adequate preparation. Written information back to the referring party is also provided, to keep all parties up to date on the child's diagnosis. This needs to be sent to the parents, the GP (with parent's consent) and the referring party. Information is also written on the child's chart in the hospital setting, to ensure that all team members are kept up to date

5.8 Birth Notification to the Public Health Nurse includes information about how the family has received the news of their child's disability.

5.9 Preparation and planning at a local level is required to ensure the availability of private settings in which to communicate the news; to ensure that staff members have available accurate, up to date, relevant written material for supplying to parents; and to plan the team communication and response that should take place when a child is diagnosed with a disability.

6. Training, Education, and Support for Professionals

In order to provide appropriate training, education and support for professionals who undertake the task of informing families of their child's disability, the Guidelines recommend that:

6.1 Staff members are trained in best practice for informing families of their child's disability.

6.2 The training provided includes:

- communication skills training
- disability awareness training
- cultural awareness and diversity training
- listening skills
- skills to guide staff members on appropriate responses to reactions the news may cause, including shock
- reflective practice
- counselling skills

6.3 Role playing/experiential training forms a central part of training

6.4 As this can be a distressing area for professionals, it is important to have two staff members present at the sharing of the news.

6.5 Appropriate support is given (identified locally) including debriefing and mentoring by senior staff members for those in training.

6.6 There is an input from parents into training provision.

6.7 There are many disciplines across various settings who are involved in informing families of their child's disability. Good linkage across these disciplines and settings is central to a positive experience for parents. Therefore, interdisciplinary collaborative skills training should be provided to **all** members of staff who may be involved in communicating to families the news of a child's disability, or supporting them thereafter.

6.8 An ethos of continuous quality improvement is promoted, with quality assurance and feedback mechanisms put in place to evaluate practice in how families are informed.

7. Referral

The topic of referral pathways for a child diagnosed with a disability is an area beyond the scope of the current project and is an area in which further research is recommended. However, a small number of specific recommendations in relation to referral were brought forward through the various strands of consultation and research of the Informing Families project:

7.1 Parents are referred to Early Services as soon as possible.

7.2 Parents are given information about the service they are being referred to.

8. Dissemination

Professionals in the focus group consultation discussed the necessary actions that would be required for successful dissemination and implementation of the Guidelines. Their suggestions included the following:

8.1 Management buy-in at all levels for implementation of the Guidelines.

8.2 Various formats of information to be provided including leaflets, booklets, checklists and laminated sheets containing the Guidelines - displayed in staff areas in Primary, Community and Continuing Care (PCCC), disability and hospital service settings.

8.3 Training to be provided as detailed above.

8.4 Direct communication of the Guidelines through professional bodies, trade unions and academic faculties.

8.5 The Guidelines to be provided as part of hospital orientation/induction.

8.6 The Guidelines to be included in hospital accreditation processes.

The formats for training and dissemination most widely chosen by professionals in the course of this research were *'training course with peers'* and *'interdisciplinary training course'*.

These guidelines adopt a person-centred approach whereby the child and the family are at the centre of the measures undertaken at the time of disclosure and in the ongoing parent-professional relationship.

The father of a baby boy is told on the day of the birth that the baby has to go to the intensive care unit to have his blood sugars monitored:

"The nurse meets me at the door, takes [the baby] in, leaves me in the waiting room, it's tiny, about the size of a confession box. I'm standing there for about ten minutes, getting worried at this stage because it's the intensive care unit. The nurse walks back out and hands me his clothes. So I nearly dropped dead on the spot. The clothes that I dressed him in three hours ago when he was born. She handed them back to me and said 'Sit down there the doctor will be out to talk to you.' Don't panic… Where's the baby, don't panic…. I was pacing up and down… I walked out to walk into the intensive care unit because at this stage I'd had enough, then I walked back then another foot then eleven foot. I was just about to go in and say 'What the hell's going on,' when the doctor walked out. I said, 'Is he alright?' He said 'He's fine'. 'How are the blood sugars?' 'Yeah the blood sugars will be fine but there's something else.' I said 'What is it?' Then he pussyfooted around. I said 'Tell me what it is. I need to know. If you tell me I can start dealing with it. If you keep me guessing I'm going to be thinking the worst.' So he said, you've noticed his eyes haven't you?' I said I hadn't seen anything wrong with them. He said 'Well it looks to me like Down Syndrome'… I said 'What's that?' He said 'Well now he mightn't have, we have to do tests to confirm.' I said 'What percentage do you think?' And he wouldn't tell me. I said 'Look doc, do me a favour tell me what percent …in your opinion, I'm not going to hold you to it, I'm just looking for a guide.' He said 'I'm 80%.' I said 'Grand. He has Down Syndrome. Now what is it?'"

Father, Informing Families Parent Focus Groups

CHAPTER 1
INTRODUCTION

In 2004 the National Federation of Voluntary Bodies, with the support of the Health Services National Partnership Forum (HSNPF)[3], began a project to develop **national best practice guidelines for how families are told of their child's disability**. The project was initiated in response to feedback from many parents to National Federation member organisations, that the news of their child's disability had been conveyed insensitively, or in inappropriate environments; and that their experience of being told the news had caused additional distress at the time of disclosure. Similarly, feedback from professionals delivering the news indicated that they felt there was an absence of training and clear guidance available to support those undertaking the sensitive and challenging task of giving a family the news that their child has a disability.

Project Initiation

The project work began in April 2004 with the employment of a Project Co-ordinator. A Steering Committee was formed to guide the study and to facilitate contacts for research[4]. It is chaired by Dr. John Hillery (President of the Medical Council of Ireland 2004-2007, and Consultant Psychiatrist with intellectual disability service providers Stewart's Hospital and St. Raphael's, St. John of God Hospitaller Services), and has representation from key groupings such as parents, disability service providers, the HSNPF, the Health Services Executive (HSE), the Department of Health and Children, the Royal College of Physicians of Ireland, the National Federation of Voluntary Bodies and nominees from the professional bodies and trade unions of various disciplines involved in informing families[5].

Project Aims

The aim of the Informing Families Project has been to develop evidence-based National Best Practice Guidelines, education, and training; on **appropriate procedures to inform families of their child's disability** when communicating a diagnosis or concern. The fundamental goals of implementing these Guidelines are:

1. **To ensure improved outcomes for families being told of their child's disability, through the implementation of best practice.**
2. **To provide improved support, guidance, education and training for professionals in the important and sensitive task of delivering this news.**

It was agreed by the project team, and in discussions with the Department of Health and Children, that the scope of the project would include the disclosure of physical, sensory, intellectual and multiple disabilities, and autistic spectrum disorders.

As disclosure can take place in a variety of locations and settings, (and indeed across settings in many cases) the research and consultation explored practice across the range of hospital, community, and disability service settings in which parents may receive the news. It is intended that the Guidelines will be applicable in this variety of settings and will take account of the liaison that must take place across settings when parents need to access services which cross organisation and sectoral boundaries.

In order to ensure that the Guidelines would be informed by wide ranging consultation and partnership with all key stakeholders, and that they would be grounded in evidence-based research, the Informing Families Steering Committee directed the undertaking of a comprehensive consultation and research programme. This process included:

Stage 1

- A national and international literature review

Stage 2

- Seven consultative focus groups with parents of children with disabilities (physical, sensory, intellectual, multiple disabilities and autistic spectrum disorders), from around Ireland.
- Consultative focus groups with 15 disciplines of professionals involved in communicating to parents the news that their child has a disability, or in supporting them immediately thereafter.

Stage 3

- A National Questionnaire Survey disseminated to 584 parents of children with disabilities
- A National Questionnaire Survey disseminated to 1588 professionals in 27 disciplines who provide the news to families of their child's disability, or support families who have just received a diagnosis.

These elements took place in stages, each of which informed the stages which followed. The development of this programme of research and its methodology is set out in further detail in Chapter 3 of this report.

All above strands of consultation and research were analysed and collated to form the National Guidelines presented in this report. The National Guidelines will be implemented at a local level in the Cork region on a pilot basis starting in 2007, the learning from which will be rolled out nationally from 2008 onwards with the support of the HSNPF and the HSE.

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[3] For further information on these two organisations, please see Appendix I on Page 165 of this document.

[4] Please see Page 165 - Appendix II - Steering Committee Terms of Reference

[5] Please see Page 166 - Appendix III – Steering Committee Membership

"Giving the diagnosis of disability in a child to parents is a difficult and complex task that few relish. Done well it can reduce parental dissatisfaction and anguish; it can establish positive and important parent-professional relationships at a crucial time."

(Cunningham et al, 2002, p.500)

CHAPTER 2
LITERATURE REVIEW AND NATIONAL POLICY CONTEXT

2.1 Introduction

The following literature review provides a broad overview of the national and international research regarding the disclosure of the diagnosis of a child's disability to parents. It concentrates on areas such as the communication of the news of disability; parental satisfaction with disclosure; aspects of best practice identified through existing guidelines; evaluation of best practice; and parents' and professionals' experience of the disclosure process.

The review was guided by searches conducted through resources including Cinahl, PubMed and ProQuest, and through research material recommended by the Informing Families Steering Committee. Much of the literature available for this review has been found to be based on opinion and theory rather than empirical data, a finding that is echoed in previous authors' literature searches (Doran, 1999; Doyle, 2004; Girgis & Sanson-Fisher, 1998). This is an area in which there is a relatively low level of empirical evaluation of recommended practice (Baird, McConachie & Scrutton, 2000).

Irish Research

The literature search did not yield a significant amount of recent Irish research into how families are informed of their child's disability. There are a number of studies of a general nature regarding the provision of early services (e.g. South Western Area Health Board & Rush, 2003; Western Health Board & Brothers of Charity Galway, 2003); studies which investigated themes related to the disclosure process (e.g. *The Needs of Carers of Fragile Babies and Young Children with Severe Developmental Disability*, Redmond, 2000) and various relevant descriptive, discussion or theoretical pieces (Kealy, 2004; Mulrooney & Holland, 2004). However there has been just one significant recent Irish study which specifically explored the disclosure of disability to parents. This study; *Report of the Maternity and Intellectual Disability Review Group on Integrated Patient Care* (Doyle, 2004), was conducted by the then Eastern Regional Health Authority (ERHA) and examined practice within the maternity hospitals and early intervention services in the former ERHA region. This study has not been replicated to date in other areas of the country.

Government strategy and policy documents have specifically and frequently referred to practice for how parents are informed of their child's disability and have made recommendations for the introduction of measures to improve outcomes for families. This chapter concludes with a review of these strategy and policy documents.

2.2 Importance of the Disclosure Process

> You will never forget the words. For as long as you live, through the sad times and the happy times, those words will always come back to you. Those first words the doctor spoke to you, telling you that there was a problem with your child. The way you accept and the way you begin to deal with the situation starts with those first words you hear.
> (Krystyna Swirydczuk in Davis, 1993, p.34)

The manner in which parents are informed that their child has a disability impacts upon the way the news is received and accepted (Price, McNeilly & Surgenor, 2006), and can have an important bearing on the attitude of parents throughout their child's life (Review Group on Mental Handicap Services, 1990). Parents may learn of their child's disability at the maternity hospital, or the news may come as an evolving diagnosis based on assessments following suspected developmental delay (Doyle, 2004). Regardless of the setting it is vital that those delivering the news do so in a sensitive manner, giving the facts truthfully and positively, providing support, accurate information, and showing respect for the child and the family (Cunningham, 1994; Doyle, 2004; Right from the Start, 2003; Sloper and Turner, 1993). The literature indicates that it is essential that staff members responsible for disclosing the news are supported in this sensitive task, through training, support and clear guidelines (Right from the Start, 2003).

Theoretical Context

The *Informing Families Project* and *Guidelines* are rooted in the context of the **Social Model** of disability, which relies on one simple notion; disability is not about an individual condition, rather it is about how society supports a diverse humanity to have equal access to all that society has to offer. (Oliver, 1990; Union of the Physically Impaired Against Segregation, 1976). The social model creates the movement from the individual being the problem to society being the problem. Oliver (1990) describes the problem as being located in society and the cause of the problem as being the systematic lack of inclusive provisions within society. Tom Shakespeare (2006) describes the most recent position on the social model debate as moving towards recognising a more complex interactional relationship between impairment and disability, and supports adopting a broader international frame of inclusive rights – while at the same time acknowledging the crucial importance of the social model position in it's time (Shakespeare, 2006).

At a service provision level, normalisation theory (a close cousin of the social model) transferred into common use in Ireland through the 'Pass Programme' in the 1980's, through the work of John O'Brien (McCormack, 2004). At an international level Degener & Koster-Dreese assert that disability was reconceptualised by disability activists:

> … as a different state of being rather than a tragic deviation from 'normality', and as a social status vulnerable to discrimination by non Rights and Disabled Persons, (Degener & Koster-Dreese, 1995, p.15)

This becomes important in the context of disclosing a child's disability, when we consider that many parents are given only negative messages at the time of disclosure (discussed later in this chapter), which may be partly attributable to beliefs held by professionals that the disability being diagnosed is a tragedy.

Hilton Davis, in his guide *Counselling Parents of Children with Chronic Illness or Disability* (1993), indicates that the provision of social and psychological support to families should be considered as a key objective for professionals, along with the physical care provided to the child. Davis describes **disclosure as being the beginning of the adaptation process**, noting that if it is done badly it increases parental distress unnecessarily, and can reduce the amount of information that is absorbed and understood. If done well, however, *"it may enhance the parent-professional relationship ever-after."* Listening to parents and providing the news in a sensitive and respectful manner can provide the means of developing a model partnership with families;

> Good disclosure practice prevents much distress for parents, and can form the beginning of positive parent-professional relationships, facilitates the attachment process, and when combined with family support services over the first years, reduces levels of anxiety and stress. (Cunningham, 1994, p.99)

Given the importance of the disclosure process in facilitating the adaptation process, it is important to briefly examine theoretical perspectives relating to how families adapt to the news of their child's disability. Early theories of adjustment to having a child with a disability concentrated on perspectives of grieving. These theories, such as the **stage theory of grief** put forward by Kubler-Ross (1969) suggested that parents who are presented with the diagnosis of a disability at birth or in the early life of their child begin a learning process that involves coming to terms with the 'loss' of the normal child and the normal parenting role they had expected. The time of diagnosis is a confusing and emotionally overwhelming period which involves high levels of anxiety. Following this initial crisis of discovery there is a slow unfolding learning process about the significance of the diagnosis which affects parents and professionals in different ways. Although not viewed as a linear process, the stage theory has been considered as relevant as parents of a child with a disability move from one stage to the next until finally towards acceptance of their child's condition. Acceptance, as defined in the stage theory of grief, was considered to be reached when the parents presented a realistic view of the child's disability both in terms of type and degree. Unresolved grief, in the context of this theory, was considered as a lack of acceptance of the child's disability.

However, it has now been accepted that the theories put forward by Kubler-Ross are an over simplification of the complicated experience that accompanies parent a child with a disability. Alternative models such as cognitive and phenomenological theories are more helpful in understanding grief and loss in terms of **adaptation to changed circumstances**. Featherstone (1980) suggests that it may be more helpful to talk in terms of **adjustment and readjustment** as age and circumstances change, rather than grief, and professionals need to be cautious in applying theories of grieving as fact. Suggesting parents need counselling for example may not be appropriate in every case; what is often needed is a trusting stable relationship that offers choices in support, and understanding about change and loss reactions when the individuals are ready. Being able to support the parents when they are angry, fearful, blaming, or depressed is essential to the relationship of partnership with the family. Being able to recognise the emotions and the relevance to how the news is told and continue to work through the difficult times is a key facet of this partnership. Education about loss and grief combined with communication skills training and an adequate system of support, debriefing and professional supervision are essential for maintenance of high-quality child, family and staff care.

Perhaps the most relevant theoretical framework relevant to this study is **Bowlby's Attachment theory**. Bowlby maintained that the goal of the attachment system is protection at times of danger which is achieved by seeking proximity and contact with the primary caregiver to ensure safety and survival at times of fear distress anxiety and abandonment (Bowlby, 1969). Distress signals such as crying either bring the sensitive carer to the child or the child to the carer who acts as the secure base. As well as acting as secure base sensitive caregivers also help children regulate and manage arousal and distress, including physiological arousal. Thus the child builds up an understanding of their own and other peoples' emotions, intentions and behaviours.

Bowlby's theory suggests that the more open, reflective, emotionally attuned and communicative the carer is about the child's behaviour and mental state, the more the child feels understood and psychologically secure. It helps the child make sense of their own and other peoples' behaviour and mental states. This lays the foundation for psychosocial strength.

Bowlby indicates that parental sensitivity, emotional attunement, congruence, and responsivity with young children largely depends on parent's ability to accurately recognise, understand and interpret their children's behaviour, body language facial expressions and speech. These classifications have implications for the psychosocial adjustment of the child and their parent-child relationships in later life. Carers who are sensitive and responsive to their children's communication signals tend to have securely attached children (Vaughan & Bost, 1999). However although caregiver factors have been felt to be important in determining a child's attachment organisation, child factors that affect levels of parents stress (which in turn affects the carers sensitivity and emotional availability) have also been thought to play a part. There is evidence that there is increased risk of parental stress in looking after a child with disabilities, often based in problems of communication, understanding and interpretation (e.g., Johnson et al, 2003).

Stress associated with care giving also activates parents' attachment-based defences including any unresolved attachment issues. Moran, Pedersen, Pettit & Krupka (1992) found that for a group of developmentally delayed children, mean levels of sensitivity and security of attachment were relatively low. There is a growing body of evidence that supports the broad thesis that children with a wide variety of congenital conditions and disabilities are more likely to be classified as insecurely attached (e.g., Andrew, 1989; Moran et al, 1992; Huebner & Thomas, 1995; Clements & Barrett, 2002). **However the disability alone is unlikely to be the only risk factor**. The dynamics that affect attachment are the result of transactions between both parental and child characteristics and when both parties bring vulnerability factors to the transaction, then there may be high rates of insecurity (Howe, 2006).

Critically, parents feelings about the disability, and their acceptance of the news of how they were told about the disability can affect the attachment process. For example, Barnett et al (1999) explored whether parental reactions to a diagnosis of a neurological problem in their child was affected by whether they had resolved their feelings about their child's condition. Children whose parents were classified 'unresolved' with respect to their child's diagnosis were nearly three times more likely to be rated as insecure than those whose parents were classified as 'resolved'. Marvin & Pianta (1996) used a theoretical model based on attachment theory to examine whether parents had resolved their reaction to their child's diagnosis of cerebral palsy. For many parents the disclosure time had been a traumatic experience. They argue that unresolved states of mind decrease parental sensitivity and emotional availability and increase the risk of disorganised parent-child attachments. They found that parents who had resolved their grief reaction and who held more realistic mental representations of their child and the implications of their care giving role were more likely to have securely attached children. In contrast, unresolved parents experienced conflict and distress as their care giving system was activated by their child's attachment behaviour. This increased the risk of insecure or insecure/disorganised parent child interaction.

The research reviewed, for example Howe (2006), suggests that **the presence of a disability on its own does not simply predict an insecure attachment**. Parents with unresolved losses and traumas including those surrounding the diagnosis of the disability itself, however, are particularly at risk of becoming emotionally unavailable as their child's attachment needs unconsciously activate unprocessed mental representations of the self, leading to higher levels of disrupted attachment processes. The implication of these findings on attachment suggests that at risk 'mother-disabled child' dyads need early identification, guidance and support (Piñata et al, 1996).

Children born with a disability to parents whose own states of mind with respect to attachment are unresolved are more likely to be insecurely attached. Therefore it is vital that professionals provide clear explanations of the nature and character of the child's disability and how it is likely to affect the child's ability to communicate needs and emotions. **Helping parents understand their child's disability increases their resilience and improves the sensitivity of their interaction**. It is vital to support parents through resolving issues of loss and trauma including the diagnosis of disability and to help parents reflect on and reprocess attachment issues relating to their own childhood experiences (Howe, 2006).

In general good family harmony, reliable social support and improved and better co-ordinated services by key agencies appear to reduce maternal stress, increase sensitivity and improve children's feelings of security (e.g., Mitchell & Sloper, 2000; Williams et al, 2002; Sloper et al 2003). **Lewis (2003) notes that a critical time for parents who have a child with a disability is when they are first told of the child's condition. Parents who receive sensitive support at this time are more likely to accept their child and as a result are less likely to be distressed and more attentive and positive toward their children than parents who are not helped through the early days (Lewis, 2003, p. 304).**

Marvin & Pianta (1996) also found that many parents feel intense distress in first learning that their child has a disability. Parents may need help in resolving and integrating the conflicting representational models they might have of the healthy child they were hoping for and the child with disability they actually have (Pianta et al, 1996). Failure to resolve the conflict between the expectation and the reality increases the chances of children feeling insecure. Parents value clear easily understood and sympathetically delivered information about their child's condition (Sloper & Turner, 1993) and this will be discussed in greater detail later in the chapter.

The key to a successful outcome is the ability of the parent and child to communicate effectively and reciprocally and this will require expert advice and training. If parents feel unable to understand the child and his or her needs they become less psychologically available. Parents of children with a specific type of disability benefit from advice guidance and support about the developmental interactional and communicational aspects of their child's condition. Therefore children with different disabilities will pose different parent-infant relationship challenges (e.g., Lewis, 2003).

The psychosocial support that the family receives at the time of disclosure can affect access to support and intervention for the child. Parental acceptance of the diagnosis is strongly linked to their *understanding* of what they have been told. If appropriate and accurate information and support leading to understanding the nature and extent of the disability are not provided during the disclosure process, the family may not accept the diagnosis, and subsequently may not become aware of benefits and formal support services that their child or family may require, or may not believe that interventions are necessary or appropriate for their child (Hatton et al, 2003). Increased levels of dissatisfaction with disclosure have also been related to increased levels of litigation. Families who were dissatisfied with the disclosure of their child's disability were significantly more likely to sue than those who were satisfied (Baird et al 2000; Fallowfield & Jenkins, 2004).

Attachment, disability, parental stress and caregiver sensitivity remains an under researched field. Children's development and security benefit when parents feel supported and they are helped to understand their child's condition. In addition to its role in facilitating the attachment process, this report examines other important areas of the disclosure process, including the development of positive parent-professional relationships, and providing the basis for outcomes leading to increased parental satisfaction.

2.2 Parents' Experiences

For the reasons outlined above it is clear that the disclosure process is a very important step in the family's adjustment to their child's disability. The literature shows that while many parents hear the news in a positive and supportive manner, there are also many cases where the news is disclosed in less than ideal ways. Those imparting the news may have views of disability that are negative or ill-informed:

> [The doctor]… said that he was handicapped. When I asked what type, his answer was that he is mongol and they are all the same. I dreaded going to see him. I thought I might see a monster. But he was lovely; he fed well and was very good. (Parents Future Planning Group, 2000. p8)

The feeling that medical professionals see disability in a very pessimistic light is a common thread running through many of the stories told by parents. Throughout the literature, however, parents frequently call for a diagnosis that is truthful and positive (e.g. Leonard, 1999; Sharp, Strauss & Lorch, 1992).

Parents can often feel, particularly in the case of an evolving diagnosis, that their concerns are not being taken seriously, or that they are not given full information, and that they are therefore 'left in the dark', which is distressing and isolating. (Baird et al, 2000)

> Parents spoke of the depression that came with the sense of helplessness when they were not listened to. Feelings of isolation were accompanied by (often disproportionate) fears when their suspicions that something was wrong with their baby were not recognised and responded to. (Leonard, 1999. p12)

In the initial period after disclosure and particularly following discharge from hospital, there can be a lack of co-ordination between hospital or community services (Redmond, 2000) which can leave parents feeling very alone.

> …we expected someone to be in contact with us but no-one did (…) we walked out of the hospital when our baby was diagnosed and nobody told us what to do or where to go next. (Western Health Board & Brothers of Charity Galway, 2003 p.15)

This report; *Review of Early Childhood Services, Brothers of Charity Galway Services*, recommends that there be a single liaison person that families deal with in accessing information on diagnosis and services. This person should also assist the family in the transition period after discharge from hospital.

In discussing ways of telling the news that have been positive, some parents mention honesty, directness, and an empathetic manner as important factors.

> He told us, gently and sensitively – that tests had shown that our child had brain damage, caused probably by a tiny brain haemorrhage, and that an operation was not recommended…. He told us to rear her as normal as possible and only in time would we know the extent of her handicap. We never had any problem with the forthright manner in which we were told. We still believe this was best. (Mulrooney and Harrold, 2004, p.47)

2.3 Professionals' Experiences

Various studies have indicated that the news of a child's disability is most commonly provided by Paediatricians or other consultant doctors. Cunningham, Morgan & McGuckan (1984) found that 88% of parents were told by a Paediatrician, in Pearson et al (1999) the percentage was 87%. Both of these studies were carried out in the UK. In a Swedish study by carried out by Hedov (2002) 85% of families were told by a Paediatrician. The most recent available study also comes from the UK, and deals with the disclosure of Down Syndrome only (Downs Syndrome Association, 2006). This report found that when the diagnosis was given during pregnancy 41% of parents were told by Midwives and 40% by Obstetricians. When the diagnosis was given after birth 71% were told by Paediatricians, 11% by Midwives, and the remainder were told by various other disciplines or had guessed themselves (Downs Syndrome Association, 2006).

There is a large body of literature describing the role played by nurses in reinforcing and clarifying the information that parents receive, encouraging appropriate settings and fostering sensitive, effective communication (Ahmann, 1998; Narasanayamy, 2003; Price et al, 2006). One major limitation of the literature is that it concentrates largely on the experiences of professionals from medical and nursing backgrounds, and does not widely report the perspectives of other members of the multidisciplinary team who also play a key role, such as those identified by Doyle (2004), e.g. Social Workers, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Psychologists, etc.

The international research indicates that the process of communicating the diagnosis of a disability to a child's parents is difficult for the professionals involved, and one that can bring the professional's own emotions to the fore. Consequently those providing the diagnosis may find themselves feeling sad and upset, and perhaps thinking of their own children (Hasnat & Graves, 1999). Clinicians have expressed the view that the process of disclosing difficult news is of significant importance, but many feel inadequately trained to do it (Phipps & Cuthill, 2002).

Having the communication skills required to break news is one of the key aspects of disclosure that can leave professionals feeling a lack of confidence (Abel et al, 2001). An Australian study found that while 64% of interns felt competent with their technical skills, only 35% of the same group felt competent about their interactional skills, including breaking 'bad news' (Campbell & Sanson-Fisher, 1998). Hasnat and Graves (1999) found that of a group of 26 paediatricians studied, 50% noted that providing the diagnosis of the child's disability had left them sad or upset, 23% reported feelings of detachment, 12% felt fearful and experienced anxiety and uncertainty, and 8% indicated that they felt drained. It is not surprising therefore, given these feelings, that some professionals may use distancing tactics when discussing emotionally charged topics (Phipps & Cuthill, 2002).

2.4 Dissatisfaction with Disclosure is not inevitable

The theme of whether dissatisfaction with disclosure is inevitable receives much attention in the literature (Cunningham et al, 1984, Cunningham, 1994; Doyle, 2004; Pearson et al, 1999; Sloper and Turner, 1993). There is a need to dispel the view that dissatisfaction with disclosure is attributable to parental dissatisfaction with the diagnosis itself (and therefore that 'there is no good way to give bad news'), in order to move forward with implementing practice which aims to improve parents' satisfaction with the way in which the news is communicated.

Through a study of the then existing literature, from the 1960's to the 1990's, Cliff Cunningham (Cunningham 1994) found that between 40% and 80% of parents expressed dissatisfaction with the way in which they were told of their child's disability. He found that the reasons for dissatisfaction came from a number of key areas; firstly the manner of the person giving the diagnosis (e.g. insensitive, or using language that was difficult for parents to understand). Secondly, a lack of, or problematic information, including contradictory or inaccurate information, and finally organisational aspects, such as delay in giving the news, lack of privacy, co-ordination, etc.

However, through his own work with families, Cunningham found that parents who had been given the news in a positive way felt no need to recount the event of disclosure for cathartic reasons, and that they maintained positive relationships with the professionals who disclosed the news. He also found that when kept fully informed of reasons for delay, or organisational issues, parents understood the pressures that come to bear on professionals. He concluded that it was not inevitable for parents to be dissatisfied with the disclosure process, and set out to prove this theory by introducing in one catchment area an 'ideal service' with a Consultant Paediatrician and Specialist Health Visitor trained in a model of good practice developed by the researchers using the existing literature and interviews with parents (Cunningham et al, 1984). A group of 15 families who experienced disclosure through this 'ideal service' was studied, against a control group of 25 families in adjacent districts where no additional intervention was introduced. The results showed that no statements of dissatisfaction were expressed by the parents who received the 'ideal service'. Only 25% of the control group expressed similar levels of satisfaction. This indicates that 75% more parents were dissatisfied in this study, when no specific intervention to provide good practice was present.

One particularly interesting aspect of this research is that there was a breakdown in providing the 'ideal service' for four families, during a time when the hospital registrars changed and the consultant was on leave. All four families reported dissatisfaction with the disclosure process and one family had their infant fostered. This points to the key importance of developing and communicating written policy and guidelines in locations where disclosure takes place; developing contingency plans for staff turnover or absence; and providing training for all staff that may be involved in sharing the news.

The sample size for Cunningham's study was small and related specifically to the disclosure of diagnosis of Down Syndrome, and therefore a degree of caution needs to be exercised when generalising from the results. However this study provides very useful insights and is considered a seminal report in the area; it was referenced in a very large proportion of subsequent studies on the topic of informing families of their child's disability. Hasnat and Graves (2000) studied the practice of 26 paediatricians in Australia using Cunningham's model and identified the possibility that satisfaction in Cunningham's study may have been associated with the particular Paediatrician giving the news. However, it is clear that the provision of a positive service in the Cunningham study was related to improved satisfaction with disclosure. Other studies support the assertion that dissatisfaction is not inevitable. Sloper and Turner (1993) empirically investigated determinants of parental satisfaction with disclosure of disability and concluded that:

> Mothers appeared to be able to forgive instances where the disclosure was delayed or the husband or baby were not present, so long as they could understand and accept the reasons for this, and factors such as uncertainty over diagnosis were explained. On the other hand, if they felt that the disclosure was handled unsympathetically or little information had been given, they were likely to be dissatisfied, even if told early. (Sloper and Turner 1993, p 320)

The same study found no significant associations between satisfaction and variables internal to mothers, such as personality or coping strategies and concluded: *'Thus it seems unlikely that dissatisfaction was caused by general factors. Parents appeared to respond specifically to the particular situation'* (p.822). There is some variance of opinion on this matter, however, with Baird et al (2000) attributing significance to parent variables such as levels of maternal depression, but Quine and Pahl (1987) finding no correlation between internal factors of psychology and personality, and levels of parental satisfaction.

An Irish study which examined Paediatrician's disclosure practices, albeit through a study with a small sample size, also points to satisfaction being attributable to the practice applied: *'Mothers that were not happy with the way they heard about their child's condition had paediatricians that applied the least amount of guidelines put forward from the policy papers'* (Doran 1999, p.38). Improving levels of satisfaction observed over time (Pearson et al, 1999) further suggest that dissatisfaction with disclosure is not inevitable, and may be improved through the introduction of best practice.

2.5 Elements of best practice identified in the literature

Having discussed the importance of the disclosure process, and the evidence to suggest that successful implementation of good practice improves outcomes for parents, it is necessary to examine the elements that define best practice. There is much agreement in the literature on measures that should be taken at the time of disclosure to provide the best outcomes for families. Given the widespread agreement on the principles of good practices (and on many of the specific procedures that should be followed in delivering a diagnosis of disability), two studies have been chosen as the basis to represent an overview of the findings of the literature for the purposes of this report. One set of recommendations comes from an international perspective and one from the Irish viewpoint. These studies were chosen on basis of their clear detailing of best practice in this area, and their relevance to the situations in which informing families of their child's disability takes place in Ireland. The recommendations from both have been collated in order to present a view of the most commonly quoted best practice. Additional sources from across the literature have been added to further elucidate and clarify the findings of these two reports.

"Right From The Start" (UK) and ERHA *'Integrated Patient Care'* (IRL) reports:

From the international perspective, the *Right From the Start* (RFTS) group in the UK began investigating and developing best practice for informing families of their child's disability in 1994. They produced resources for disclosure including an audit tool, a template of best practice and a CD-ROM and video. A key benefit of using the RFTS report in summarising the recommendations is that it specifically references and builds on key studies that evaluated best practice guidelines through research such as Cunningham (1984 and 1994); and Sloper & Turner 1993, which are commonly cited in the existing literature. In addition, this report captures the breadth of the process of informing families of their child's disability, while many other sources concentrate on one specific aspect of the disclosure process, such as information provision, cultural competence or communication skills, etc. The principles underpinning the *Right From the Start* Template for good practice (2003) are:

- Valuing the child
- Respecting parents and families
- Preparation
- Tuning in to the parents – effective communication
- Providing practical help and information
- Support for professionals

Looking, then, to an Irish perspective on the topic, as mentioned above the former Eastern Regional Health Authority undertook a study entitled *Report of the Maternity and Intellectual Disability Review Group on Integrated Patient Care* (Doyle, 2004) that examined the way in which parents in the maternity hospitals in the ERHA region are informed of their child's intellectual disability, and made 23 specific recommendations for best practice. A key benefit of referencing the ERHA report in summarising the recommendations is that it makes reference to the process of informing families of their child's disability as it relates specifically to the Irish context, such as the manner in which birth notifications are managed, and the disciplines involved in the process in this country.

There is much similarity with regard to the recommendations for best practice contained in both reports. The recommendations from the two studies can be categorised for the purposes of this report as follows:

- Setting/Location and People Present at Disclosure
- Communication
- Provision of Information and Support
- Culture and Language
- Referral
- Organisational and Planning Requirements
- Training, Education, and Support for Professionals

These categories have emerged through the various phases of research of the *Informing Families Project* as a useful method to group themes in the disclosure process, and have been used throughout this report for ease of comparison between sources. Recommendations in these categories emerged at each stage of the consultation and research programme, and they allow for a wide-ranging and complex process to be broken into manageable steps. For each category a discussion of relevant themes from across the literature sources is presented, followed by a summary of the recommendations from the ERHA and *Right From the Start* reports, with additions where necessary from other authors.

2.5.1. Setting/Location and People Present at Disclosure

Themes

The way in which the news of their child's disability is first given to parents is remembered clearly, often for many years (Leonard, 1999). Some parents recall the setting, the words and the people present in vivid 'flashbulb' detail (Cunningham, 1994). This indicates the importance of creating the best possible environment and conditions for disclosure.

Aspects of best practice relating to the setting of disclosure are staples of best practice guidelines that appear throughout the literature. There is unanimous agreement that the news should be given in privacy, with adequate time allowed for questions and without interruptions, and that both parents should be told together. If parents are not told together it creates an additional stress on the parent who already knows and is anxious about their partner being told, and some parents are left to tell their partner themselves (e.g. Doyle, 2004; Downs Syndrome Association, 2006; Girgis & Sanson-Fisher, 1998; Nash, 1995; Phipps & Cuthill, 2002).

There is a little more diversity of opinion in relation to the people present during disclosure. It is agreed that parents should be told together (Hedov et al, 2002; Pearson et al, 1999; Price et al, 2006). However the question of whether the child should be with the parents while the diagnosis is communicated is one area requiring further analysis. Some emphasise the positive outcomes of having the child present; Cunningham states in relation to the diagnosis of Downs Syndrome;

> Having the child present allows the professional to convey value and worth by touching and referring to the baby. (Cunningham, 1994, p.91)

Others note the risk that the absence of the child may even lead to parents thinking that the child is dead or dying, if diagnosis occurs soon after birth (Doran, 1999). However Price et al (2006) state that uncertainty exists about the presence of the child during the meeting;

> …it may appear inappropriate given the reactions experienced by the parents at the time of being told the bad news… Although debate continues and a distinct lack of evidence around this question is apparent, many health professionals choose not to include the child in the initial discussion, giving parents time to assimilate their feelings and vent their emotions, before talking to their child. (Pg. 116)

A trend that does appear to be consistent throughout this debate is the suggestion that the baby should be present if the diagnosis takes place close to birth, while the parents of an older child may benefit from the opportunity to absorb the news and openly express emotions and reactions without the child being present.

Many studies indicate that a support person should accompany the professional who discloses the diagnosis of the disability (Gatford, 2001; Phipps & Cuthill, 2002). Ideally the support person should be known to the family (Girgis & Sanson-Fisher, 1998). The presence of a support person can have a twofold benefit in supporting parents and assisting the professional giving the news. *'[The support person]…may take notes on behalf of the parents during the meeting which may be helpful for parents in reviewing the main points covered at a later stage'* (Price et al, 2006 p.118). If possible the additional person present at disclosure should have a role in supporting the family that will continue beyond the initial telling, as their presence will strongly emphasise to the parent that the disclosure is merely the beginning of a supportive process and that there are positive things to be done (Cunningham, 1994).

Recommendations from the Literature

- The news should be given in a private, comfortable setting.
- The news should be given by an appropriately trained professional with knowledge of the guidelines. It is recommended that a second professional, preferably known to the family, should be present to support the family after initial consultation. No additional personnel should be present.
- Both parents should be present. If it is only possible to have one parent present, the option should be given to have another family member or friend present to provide support. When a parent hears the news alone, arrangements should be made as soon as possible to inform the other parent and close family members.
- If the diagnosis takes place close to birth, parents should be given some time with the baby before any disclosure takes place. This can help with the bonding process and allow the parents to identify with their child first and the disability as secondary.
- When diagnosis takes place close to birth, the baby should be present if possible. If it is not possible, the baby should be referred to in a respectful way at all times. The child's name should be used; it is important that professionals see the child first and their disability second. When sharing the news of the additional needs of an older child consideration should be given as to whether they should be present. (If the baby cannot be present, the parents should first be sensitively reassured that the difficult news to be imparted does not mean that their child has died or is dying*)[6]
- Time and space should be available to the family to reflect, and they should be able to meet with a member of the team if they wish. The ERHA report recommends that the hospital should explore the possibility of offering overnight stay to the father (or person of the mother's choice).

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[6] The presence of an asterisk* beside a recommendation, or a section of a recommendation contained in brackets, indicates that the recommendation emerged from the literature but was not specifically present in the ERHA or RFTS reports.

2.5.2. Communication

Themes

As discussed above, Sloper and Turner (1993) found the manner in which the diagnosis is communicated to be a key determinant of parental satisfaction. Empathy, sensitivity, and honesty have been mentioned in a number of studies as important elements of positive disclosure practice (Girgis & Sanson-Fisher, 1999; Hatton et al, 2003; Price et al, 2006). In discussing empathetic communication, Davies (2003) describes it as the ability of a clinician to understand needs from a parent's perspective and thus to respond sensitively to those needs. A lack of sensitivity can have a range of negative consequences (Fallowfield & Jenkins, 2004), including a delay in diagnosis if insensitivity leads to the dismissal of parental concerns (Leonard, 1999; Davies, 2003).

> An insensitive approach increases the distress of recipients of bad news, may exert a lasting impact on their ability to adapt and adjust, and can lead to anger and an increased risk of litigation. (Fallowfield & Jenkins, 2004, p. 312)

The literature stresses the need for those communicating the diagnosis to be aware that the responses of parents to the diagnosis of their child's disability and the amount of information that parents are able to absorb and understand, are affected by many factors. These factors include previous family history; educational, socio-ecomonic, cultural and linguistic background; and the shock that many parents will experience (Ormond et al, 2003, Gatford, 2001). Parents will be likely to make use of a variety of coping mechanisms, including at one end of the spectrum wishing to learn as much as possible about the diagnosis, and at the other end of the spectrum denial or avoidance of what they have been told (Price et al, 2006, Phipps et al, 2002). People who use avoidance strategies may cope less well if these strategies are taken away (Girgis & Sanson-Fisher, 1998). Therefore positive communication with families must involve an individualised approach, which takes account of the particular needs of each family and the responses and coping mechanisms which need to be supported for those individuals (Ormond et al, 2003, Gatford, 2001).

Effective communication also takes account of the meaning which the receiver places on the information provided, since the news communicated can mean different things to different people (Buckman, 1984). For instance in relation to the provision of an evolving diagnosis, the term 'developmental delay' may be used. While this is a term that may be familiar and well understood by professionals, it has been noted that the term may give parents an unrealistic expectation that the condition is a set-back, a delay implying perhaps indicating ultimate arrival at a specified goal and that the child will catch up with peers. It is proposed instead that at an early stage the terms 'developmental disorders', 'difficulties', 'problems', but not 'delay' should be used. (Williams & Essex, 2004). Of course, the goal of early intervention is to *'prevent or minimise developmental problems'* for children and therefore effective early intervention will mean that some children do not need ongoing intervention in later years (Guralnick, 1997). However the importance of this example is to illustrate the need for professionals to ensure that the messages communicated have been understood, and the requirement for simple, clear language that avoids medical or technical jargon (Phipps et al, 2002; Price et al, 2006).

A hugely important aspect of positive disclosure practice identified throughout the literature is the communication of hope when giving the diagnosis. Parents who received counselling following the diagnosis of cystic fibrosis in their infant expressed the wish for positive messages that contained optimism about the future (Ormond et al, 2003). As discussed earlier, parents have indicated that positive messages should be communicated, rather than a catalogue of all potential negative outcomes (Leonard, 1999), and that empathy and sensitivity is hugely important (Mulrooney and Harrold, 2004).

Recommendations from the Literature

- The news should be given as soon as possible and care should be taken to avoid giving negative non-verbal signals before concerns have been shared with parents.
- Language used should be plain, understandable and avoid the use of medical jargon or terminology. Explanations should be given at a level that parents can understand, to build their confidence, taking into account socio-economic, linguistic and cultural factors.
- The manner of the professionals providing the news should be empathetic, sensitive and honest.
- Discussions about the child should be kept positive and predictions should be avoided.
- Parent's reactions vary widely and cannot be predicted. Parents should be listened to, supported and empowered, and their concerns treated seriously.
- During the disclosure process the parent should be given opportunities to ask questions, and professionals should ask parents to explain what they have heard in their own words to ensure that understanding is as intended.
- A follow up session should be arranged as soon as possible. Contact details should be provided at the first meeting and parents encouraged to make contact to ask further questions if they arise.
- Adequate time should be set aside, including time for the parents to ask questions and vent emotions, with no interruptions – pagers should be switched off.

2.5.3. Provision of Information and support

Themes

Michael Guralnick (1997), in his evaluation of the effectiveness of early intervention, described a 'crisis of information' which many families experience when faced with the news of their child's disability. This crisis of information, according to Guralnick, includes questions about the child's behaviour, ways that the parent's own care-giving activities may need to be altered, the meaning of a particular diagnosis in terms of developmental expectations for their child, and the nature and effectiveness of therapeutic services provided by professionals. Guralnick describes this information crisis as one of four major risks to the family system in the context of a child's disability; and consequently to the development of the child. One of the key aspects of good disclosure, and a counteraction to the information crisis described above, is the provision of information on services, entitlements and sources of support for parents (Doyle, 2004; Right From The Start, 2003).

Having a child with a disability may be a significant source of stress for families and can place immense pressure on the dynamics and relationships within a family (Speedwell, 2003; Pelchat, 2004; Phua et al, 2005). This is a time that the family need to have maximum support and minimum extra stresses (Redmond, 2000). A lack of information can increase pressure on the family as time and energy are invested in seeking details about services and entitlements. The evidence suggests that in Ireland this information is often provided in a haphazard fashion, leading parents to search for information from a disparate range of sources, at a time that is already very stressful (*Commission on the Status of People with Disabilities*, 1996; Redmond, 2000). In its' study of the first information provided to families of children with disabilities, the former South Western Area Health Board (2003) found that 66% of families received no information pack, 30% said that the information that they had received was not clear, and 36% stated that the information they had received had not come in good time. **Clearly then, there is a wide gap between the recommendations for best practice contained in the international literature, and current practice on the ground in Ireland**.

As detailed above there is a need to respect parents reactions and coping mechanisms, which may include a wish to avoid receiving information at the beginning as part of their coping mechanism, or may lead to parents wanting to have as much information as possible. Miller & Mangan (1983) characterise those who seek information as 'monitors' and those who wish to avoid information as 'blunters' and indicate that the amount of information provided should seek to identify parental characteristics and preferences at the outset. Since parents may not be aware of the range of information that can be provided, one device that may assist appropriate pacing of information is to outline the areas that can be covered, thus allowing for individual family choice (Girgis & Sanson-Fisher, 1998). Family choice is also indicated in the types of support that are offered following disclosure. One study (Sawyer & Glazner, 2004) found that while two-thirds of families would strongly welcome being put in touch with other parents, one third would 'definitely not' wish to do so.

An area of particular importance for the provision of quality information is for those parents whose child receives a diagnosis that evolves over a period of time. For these parents there is often a long period of anxiety and uncertainty before a firm diagnosis is made (Quine and Rutter, 1994). The information received by many in this group has been reported by many parents to be inadequate and confusing (Quine and Rutter, 1994; Redmond, 2000).

An increasing number of parents now turn to the Internet as a source of information following the disclosure of a diagnosis, and many sources on the Internet have a poor level of accuracy when benchmarked against best practice (Speedwell, 2003). The ERHA report on Integrated Patient Care (Doyle, 2004) supports the theory that many families are using the Internet as a source of information immediately following disclosure. The report identifies that this can prove problematic if families access information that is not reliable, accurate or perhaps not fully applicable to their child's diagnosis. There is a therefore a need for professionals to direct parents to sites providing balanced, relevant and comprehensive information (Downs Syndrome Association, 2006).

Recommendations from the Literature

- Information provision should be staged and the diagnosis or concern should be shared honestly and sensitively, taking into account any other treatment the child is having.
- Information should be reinforced at appropriate times to enhance parental understanding.
- Next steps should be outlined - such as what tests will be carried out, help that is available etc.
- Parents should be offered factual written information on their child's condition. This may include leaflets, magazine articles and books.
- Parents should be provided with information on peer groups, advocacy groups and self help agencies
- After diagnosis the parent needs to be made aware of the services available to the child and family.
- The family should be provided with guidance on appropriate Internet sites which contain relevant and accurate information for their child's particular disability.*

2.5.4. Culture and language

Themes

As Ireland becomes more culturally diverse the increased need for culturally competent care and support is self-evident. The cultural needs of individuals accessing health care services have been identified as

> …the need for equal access to treatment and care; the respect for cultural beliefs and practices, including religious, dietary, personal care needs, daily routines, communication needs, and cultural safety needs. (Narayanasamy, 2003, p.185)

Different cultures may have different understandings in relation to cultural health beliefs, and this can include various interpretations of disability (Gatford 2001; Hatton et al, 2003). For example, a recent Zambian report describing myths and misinformation about disability indicates that some communities in that country look upon a disabled child as *'a curse or a punishment from God'* (Zambian State, 2007). In other cultures some disabilities can be viewed in an extremely positive light. Levinsone & Gaccione (1997) list several cultures where people with certain types of physical impairment are highly valued and believed to have special powers or abilities. Reynolds-Whyte & Ingstad (1995) also note how, in many cultures, blind people are more likely to become learned religious men, storytellers or singers, such as *Surdasi*, the blind singers of India. The consequences of such views, particularly those that see disability in a negative light can be very serious for family members. Gatford (2001) found that the mothers of children with disabilities from various ethnic communities were particularly isolated for a number of reasons; some had been left by their partners who blamed them for the birth of a child with a disability; whilst others were isolated through their difficulty in explaining the child's condition to family members and kept 'themselves to themselves' for fear of rejection from friends. Hatton et al (2003) found that satisfaction levels with disclosure amongst South Asian families in his study were as low as 14.7%. He suggests that it is helpful if parents are given a broad understanding of the disability and how it occurs so that they can counter unhelpful myths amongst their family and friends. This study also found that poor parental understanding the diagnosis led to delays in accessing benefits and formal supports.

> Parents made links between the way the disclosure process was handled and their understanding and acceptance of their child. (Hatton et al, 2003, p.183)

The most obvious limitation to understanding (and therefore acceptance) is language. The literature strongly advises against the use of family members or friends as interpreters, indicating that family members or friends may provide inaccurate information due to embarrassment, may *interpret* rather than translate, and that the professional may be unaware of whose views are being expressed (RFTS, 2003; Narayanasamy, 2003). Further complications may be experienced if both parents are not told together, as one parent is left trying to interpret for their partner information which they themselves find difficult to understand (Hatton et al, 2003).

Staff members may need to develop both *cultural-specific* and generic cultural competence in order to fully support families from a diversity of backgrounds (Narayanasamy, 2003). It should also be born in mind that not all members of any given group will possess the same cultural attributes and ideas, and the principle of individualised care must therefore be maintained. (Phipps & Cuthill, 2002). Without understanding the cultural meanings that different groups assign to disability, there is a danger that the support provided at disclosure will not be specific enough to cater for the family's needs, and will not be adequately individualised (Gatford, 2001). Culturally competent care requires professionals to be aware of their communication in areas such as body language, eye-contact and proximity as well as ensuring assistance for non-English speakers. (Narayanasamy, 2003)

Recommendations from the Literature

- Cultural difference should be acknowledged and respected.
- Use of an interpreter should be offered for family members with limited English proficiency, and the role of the interpreter explained. Under no circumstances should a family member or friend be expected to take on this role.
- Written information should be provided to non-native speakers in their own language.
- When families from diverse cultural backgrounds are being given a diagnosis of a disability particular attention should be paid to gaining an insight into the meanings that each family assign to disability. Accurate information should be provided to explain the diagnosis and dispel myths or unhelpful understandings of the disability.*

2.5.5. Referral

Themes

The supports and services which are put in place following disclosure are a key element of providing hope with the disclosure of a child's disability, in terms of reassuring parents that they will not be left alone and that there is help available. In Ireland, current practice in informing parents of child's suspected or diagnosed disability, as well as the initial referral process to early intervention services is not standardised across sites (Western Health Board & Brothers of Charity Galway, 2003; Doyle, 2004). Prompt information regarding choices of support available, and referral to these services (if parents wish to engage with services) is an essential step at this time.

> Many mothers refer to having had to care for their child without services and assistance to which they were entitled as they did not know they were available. (Redmond, 2000, p38)

A detailed examination of existing referral procedures is beyond the scope of the current report, which is focused on the *informing* of families rather than on the supports that are provided thereafter. It is therefore recommended that further research and consultation take place to ensure seamless referral between hospital, community and disability services.

Recommendations from the Literature

- The ERHA report stresses the need for a referral process to be put in place – agreed between the maternity hospitals and Early Services.
- Early contact should be made between hospital-based and community services.

2.5.6. Organisational and planning requirements

Themes

> Parental satisfaction, defined as the perception of needs or expectations being met or fulfilled, is an important indicator of quality in health care. (Phua et al, 2005, p.432)

Interagency co-ordination and collaboration, along with a family-oriented approach and individualised programmes, are key indicators of best practice in the provision of high quality Early Intervention services (Hanson & Lynch, 1995). Interagency collaboration is a particularly pertinent requirement of a positive disclosure process in relation to the diagnosis of a child's disability, due to the combination of professional disciplines and agencies that are often involved (Western Health Board & Brothers of Charity Galway, 2003; Redmond, 2000).

At a local level, it is essential that planning for the disclosure process takes place. Some of the key requirements of the planning process include the nomination of one person with overall responsibility to develop and maintain good practice; written procedural guidelines; training for all staff members in the basic skills required and the procedures agreed; and regular review meetings of staff to monitor procedures (Cunningham, 1994).

Pearson et al (1999) indicate that parents should have a choice of who attends an appointment when disability and special needs are highlighted. This of course will require that the disclosure is planned. In order to reduce the risk of alarming parents by telephoning them to indicate that both parents should attend an appointment, the Downs Syndrome Association (2006) suggest that wherever relevant (e.g. when tests are undertaken), parents should be asked at the first appointment to indicate how they would like to be informed, and perhaps suggest a time and date that both parents are free to attend to receive results.

Recommendations from the Literature

- Staff members should have time to consult with one another and prepare individually and as a team prior to consultation with parents. As family circumstances vary, the team should share information on how best to facilitate each family.
- A checklist and written guidelines should be developed and used by professionals giving the news.
- The ERHA report recommends a link worker to be provided between maternity hospital, primary care team, Early Services and the family.
- A record of the initial discussion should be made available to parents in written or in audio form, always in their first language, and a record should be sent to the GP also.
- Parents should be made aware of their right to seek other professional opinions.

- Currently in Ireland, birth notification to the Public Health Nurse does not contain information on the child's diagnosis or how the family have received the news. The ERHA report stresses that the birth notification given to the PHN when a child has a disability should contain some details of how the family have heard the news. The person responsible for filling out the checklist should ensure this happens.
- A wall map should be developed - showing the services available and the communities which access these. This can help timely follow up and sharing of information.
- A Directory of Services and Entitlements (e.g. Access West, *www.accesswest.ie*) should be developed between primary, secondary and tertiary services to facilitate timely referral and inter-agency working. The Ombudsman has recommended that parents are informed of entitlements, especially Domiciliary Care Allowance, by the professionals who provide first information to parents.
- Hospitals should provide signposting to services during the neonatal period. The hospital should put parents in touch with services in the child's area. The **Citizen's Information Board** (*www.ciboard.ie*) provides profiling of services. Discussion should take place with all stakeholders to avoid duplication of effort.

2.5.7. Training, education, and support for professionals

Themes

The process of imparting difficult news has been shown to be a stressful undertaking for those undertaking the communication, and it is therefore very important that professionals are provided with support and training in communication skills (Sharp et al, 1992; Barnett et al, 2007; Abel et al, 2001). Emotions such as sorrow, guilt, identification, and feeling a failure are all possible outcomes from breaking difficult news and a lack of communication skills training in this area is acknowledged as a major factor contributing to burnout and psychological morbidity (Fallowfield & Jenkins, 2004).

> … in the absence of much effective training [doctors] may adopt inappropriate ways of delivering bad news and coping with the emotional fall-out. (Fallowfield & Jenkins, 2004, p.312)

Hammond et al (1999) surveyed 180 Obstetric Ultrasonographers in Canada, regarding their experiences of providing 'bad news'. **Those working with clear protocols experienced less stress than those working without protocols.**[7] The importance of providing experiential training alongside any protocols or guidelines introduced is illustrated by the example of a US study which showed that in spite of the availability of guidelines for breaking bad news, 16 of 18 families who received such news did so in a haphazard way, leaving them shocked and upset (Ablon, 2000). In order to adequately support professionals, debriefing and reflection should also be built into disclosure planning as an integral part of the process (Price et al, 2006). Barnett (2007) found that a majority of Consultants surveyed believed that communications skills training in relation to communicating difficult news was useful and expressed a willingness to undertake experiential approaches in learning.

A difficulty that arises in the current context and a crucial point to address going forward is that many training courses which are provided in communication skills are lacking in clear educational theory, are not evidence-based, and do not have clear outcome or efficacy measures (Fallowfield & Jenkins, 2004). In order for training to take account of the experiences and needs of parents, it is important that there is parental input into the training development and delivery (Western Health Board & Brothers of Charity Galway, 2003).

Many parents already express their satisfaction with how they have been told, for example two thirds of parents in a study by Garwick et al (1995) indicated that professionals had presented accurate information in a sensitive way. However, this is not the experience for all parents. In a recent study of disclosure practice for ante-natal diagnosis and diagnosis at birth, the Downs Syndrome Association in the UK found that some professionals have outdated or prejudiced views about people with disabilities (Downs Syndrome Association, 2006). As discussed above parents favour positive, realistic messages to be communicated along with the diagnosis. Ill-informed views can have a negative impact on the tone of the messages communicated (Cunningham, 1994). It is important, therefore, that along with training in communications skills, cultural diversity training, and breaking news guidelines; professionals involved in disclosing the diagnosis receive training in disability awareness (Downs Syndrome Association, 2006).

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[7] Joan Lalor et al (2007) have conducted Irish research into the specific elements of practice that relate to disclosing a concern or disability during pregnancy, and a further reading list in this regard can be found on page 164 of the Reference section.

Recommendations from the Literature

- Professionals need to be confident, well prepared to share the news, and flexible to adapt to parents' needs. Staff members need to be aware of the adaptive process that parents will experience.
- The provision of communication skills training should be targeted at all staff members who may potentially be involved in raising a suspicion of a disability. Consideration should be given to the development of a collaborative communications skills training programme which builds staff confidence and improves sensitivity and efficacy.
- Staff members should have time to consult with one another, and prepare individually and as a team prior to consultation with parents. As family circumstances vary, the team should share information on how best to facilitate each family.
- Parental views on the provision of the first information and support should be examined and their views incorporated into any potential training programme.
- Those imparting the news should seek to identify, acknowledge and try to address inequalities between parents and professionals.
- As this can be a distressing area for staff it is important to have two senior members present at the sharing of the news. Appropriate support should be given (identified locally) e.g. debriefing with medical social worker, or other experienced professionals in the field. In the ERHA region weekly meetings between neonatology, ultra-sonography and social work were found to be very helpful.
- Inter-professional practice, mutual support and sharing good practice should be promoted.
- An ethos of continuous quality improvement and auditing of practice should be promoted.

2.5.8. Dissemination of guidelines and best practice

Themes

In order for best practice guidelines for the disclosure of a child's disability to be effective in a given location, their introduction must be accompanied by a strong implementation and dissemination strategy. In Cunningham's 'ideal service' which produced positive outcomes for families, a breakdown in the service provided occurred when key staff members were not present, indicating the central importance of documentation and dissemination of good practice to all staff members and contingency plans for staff turn-over or leave (Cunningham, 1994). An audit of a large health authority in the UK that had used the *Right from the Start Template* (2003) to develop good practice guidelines found that one third of key personnel had no knowledge of the guidelines or the training that had been made available (Fallowfield & Jenkins, 2004). It is important that staff members are consulted and briefed to ensure that the rationale for introducing the guidelines is understood and valued.

> Initiating change and good practice demands that all of the key personnel involved believe it to be of value and can support their claim. (Cunningham, 1994, p.99)

There is significant evidence from Irish reports to show that difficulties occur in providing a seamless transition and continuity of care when parents need to access a range of services that come from different sources (e.g. hospital and community care) or when they require information about onward referral from one service to another (Western Health Board & Brothers of Charity Galway, 2003; South Western Area Health Board & Rush, 2003; Commission on the Status of People with Disabilities, 1996; Redmond, 2000). **It is therefore a central requirement of effective dissemination of best practice that all services involved in providing information and care to families in the initial stages of adapting to their child's disability consult and collaborate with each other in order to provide up to date information and appropriate liaison at the time of disclosure.**

Recommendations from the Literature

- Interagency collaboration should take place across hospital, community and disability service settings to ensure appropriate information is available to families when they are moving from one service to another, and liaison should take place between agencies to ensure continuity of care during onward referral.*
- Personal and professional development needs in this area should be acknowledged. Training, clinical supervision, continuous professional development and education should be available on an ongoing basis, especially due to high staff turnover.
- The guidelines should form part of hospital orientation or induction.
- Mentoring of junior staff members by senior staff colleagues in relation to disclosing a child's disability needs to be included.

There is broad agreement, therefore, on what constitutes best practice in how families are informed of their child's disability, across the wide range of themes which constitutes the full disclosure process. Several authors have summarised the specifics from these areas into two overarching themes; the 'cognitive' or information sphere of practice, and the 'affective' or emotive sphere (Cunningham et al 2002, Quine & Rutter 1994, Sloper & Turner 1993). The rationale for the prioritisation of the **information** that is provided to parents, and the **manner** in which it is presented is borne out by the research discussed.

2.6 Lack of Evaluation

One issue which is frequently highlighted in the literature and which is an area for concern, is that there is an almost complete lack of evaluation of training or practice in disclosing disability to families and in communication skills training in general (Cunningham et al, 2002; Fallowfield & Jenkins, 2004; Girgis & Sanson-Fisher, 1998).

> There has been little evaluation of such guidelines, for example whether they have been implemented, and whether they have an effect in increasing parents' satisfaction with the way they have been told. (Baird et al 2000, p475)

Of course it is difficult to match families and provide control groups for this kind of process. Guidelines have been evaluated by professionals (e.g. Hasnat & Graves, 2000; Dickson et al, 2002) and experience has been evaluated by parents (e.g. Sloper and Turner, 1993; Hatton et al, 2003) but very few studies emerge from the literature which match parental experience and outcomes with specific interventions or practice. In one of the few studies that bring the two perspectives together, Hedov (2002) examines professionals' clinical goals in Sweden and contrasts these with parental experience. His study finds gaps between the expressed clinical goals and the reality of the practice that families have experienced.

In a review of Early Services undertaken in 2003, the South Western Area Health Board concluded that the need for evaluation of practices implemented is of the utmost importance. It states that Early Intervention services should be designed and delivered from a solid foundation of research, which supports and informs evaluation activities. It also includes as part of this early intervention service aspects of the disclosure process identified in the 'Provision of Information and Support' category;

> After diagnosis families should receive an information pack which gives appropriate information on their child's condition, points to support groups, a description of the range of service options available, and guidance on how to access further support and information. (p.16)

The lack of evaluation described above means that existing guidelines have not uniformly been empirically tested for outcomes. It is a recommendation of the Informing Families Project that the implementation of guidelines in the future is accompanied by an evaluation process which provides data leading to evidence-based improvements and clarifications of best practice in this area.

2.7 Barriers to implementation

Throughout the literature various authors have identified barriers to the implementation of best practice in how families are informed of their child's disability. Cunningham (1994) suggests that is it necessary to overcome the myth that that there is no good way to give 'bad' news, before professionals will fully engage with changes leading to improved practice. In an Irish study Doyle (2004) demonstrates that there is no single policy or guidance in place currently to support professionals in good practice in this area. In relation to the services provided by the early services team, she recognises the strong role that early intervention will need to play in helping the family to adjust to the news that they have heard; *"The early intervention team should direct its attention initially to assisting the family to adjust to its new situation"* (Doyle, 2004, p.8). She goes on to indicate that existing difficulties in recruiting staff for early services teams can cause delays which mean that families are placed on waiting lists. Clearly, this will have a negative impact on achieving the objective of providing the support needed for the family to work through the adaptation process following diagnosis. As discussed above Fallowfield and Jenkins (2004) indicate the key importance of overcoming communication barriers within organisations in order to implement good practice in this area, and point to the difficulties experienced in one UK location where the *Right from the Start* (2003) guidelines were introduced but where evaluation showed that around one third of key professionals were unaware of their existence (Fallowfield & Jenkins, 2004). Abel et al discuss the difficulties that can arise in releasing staff for training; and within a hospital-based training workshop, in having staff members who are on-call during training (Abel et al, 2001). This report also recognises the importance of ensuring that senior staff members receive training, since many training initiatives concentrate on those members of staff still in training and this leaves a gap when more senior staff members who provide mentorship have not received training. All of the above will need to be taken into account when implementing best practice recommendations developed through the current consultation and research project.

2.8 National Legislative and Policy Perspective

The issue of how parents are informed of their child's disability is one that has received specific mention in successive Irish national policy and strategy documents over the past seventeen years. There are several key documents relevant to the development of national best practice guidelines in this area:

- Needs and Abilities (1990)
- A Strategy for Equality (1996)
- Towards an Independent Future (1996)
- Quality and Fairness (2001)
- Education for Persons with Special Education Needs Act (2004)
- Disability Act (2005)
- HSE Transformation Programme (2007-2010)

In mapping out the Irish policy context relating to disclosure of disability, it should be noted that this is an area for which responsibility crosses various Government departments including the Department of Health and Children, the Department of Justice, Equality and Law Reform, the Department of Education and Science, and the Department of Social and Family Affairs.

There are several key policy and strategy documents which reinforce the importance of good practice in this area from as far back as 1990. *Needs and Abilities*, compiled by the 'Review Group on Mental Handicap Services' in that year, is the most recently published Government strategy on policy for people with an intellectual disability in Ireland. As mentioned above, it sets out the importance of how the news is delivered:

> The manner in which the information is conveyed can have an important bearing on the attitude of parents throughout their child's life. (Review Group on Mental Handicap Services, 1990, p.21)

This report makes several recommendations that relate specifically to the communication of the diagnosis of a child's disability to parents. It states that relevant skills should be emphasised in training programs for professionals who are likely to communicate this news. It also details the need for close liaison between the maternity and general community health services for children and services for intellectually disabled persons.

On the topic of information provision, *Needs and Abilities* asserts that the needs of parents will be many and varied at this time. All are likely to require information, support, and practical advice, and the report recommends that:

> Personnel providing support to families should have available from their health board, for supply to parents, a dossier of printed material containing information on the disability; the name, address and telephone number of appropriate community care staff, and of the local service for intellectually disabled persons together with details of entitlements. (Review Group on Mental Handicap Services, 1990, p. 21)

The report of 'The Commission on the Status of People with Disabilities' published in 1996, entitled *A Strategy for Equality*, is a comprehensive equality strategy for people with disabilities in Ireland. It deals specifically with the process of disclosure of disability in several recommendations, amongst which is its assertion that *'the right to hear one's diagnosis in a sensitive and humane manner should be recognised'* (Recommendation 131). This report echoes the call of *Needs and Abilities* (1990) for information services to be provided for families, including at the ante-natal phase, and it identified significant gaps in co-ordination of services providing assessment and referral. It recommended the introduction of a hospital based key-worker to facilitate communication between hospital, staff and families. A progress report on the implementation of this strategy, entitled *Towards Equal Citizenship* (1999) found that many of the recommendations were under consideration, or had not been undertaken due to resource issues.

Towards an Independent Future (1996), followed closely after the publication of *A Strategy for Equality*, and built on the recommendations contained in that report as they affect health services for people with physical and sensory disability. In relation to the diagnosis of disability, its' recommendations included the establishment of regional child assessment teams, voluntary help lines, peer counselling and other family support services as an integral part of the community services available to people with disabilities.

The most recent health strategy published by the Department of Health and Children, entitled *Quality and Fairness* (2001), outlined equity, people-centeredness, quality, and accountability as being key principles of the health strategy. As with the previous strategy documents referenced, *Quality and Fairness* recognises the urgent need for the development of enhanced information provision;

> To meet the objectives of the Health Strategy and to deliver the quality of health services that people require, information is needed which is appropriate, comprehensive, high-quality, available, accessible and timely. Good information systems based on fast, efficient flows of shared information are, therefore, essential to the success of the Strategy. (p.131)

In order to uphold the principle of equity when informing families of their child's disability, access will be required where necessary to translation and sign-language services, and there should be provision of appropriate information for groups requiring additional support. These may include those with literacy or language needs, visual or hearing impairments, or parents who themselves may have intellectual disabilities (p.78).

In order to develop more person-centred services *Quality and Fairness* indicates that services must be organised, located and accessed in a way that emphasises the needs and preferences of those using the service, and that health and social systems must have the capacity to accommodate service-user preferences. The strategy emphasises the need for co-ordination between services for the benefit of the service user;

> The health system in Ireland encompasses both health and personal social services and these must be accessible and well co-ordinated. (p.16)

Under Action 51 of the strategy, in order to place the person at the centre of the delivery of care, there should be *'greater communication and liaison between individual clinicians within services and across services…'* and the appointment of key workers in the context of care planning. The strategy includes children with disabilities as one of the groups most urgently requiring the provision of key workers.

To achieve greater quality assurance, the report sets goals to develop standards, protocols, and guidelines/models of best practice and to disseminate these across the system, and states that there should be increased evaluation and accreditation of initiatives, with an evidence-based approach to decision making. Accountability will be enhanced, according to the strategy, by increasing the involvement of consumers of the service as partners in planning and evaluation.

As a quality initiative which is based on national and international evidence; which relies on an individualised approach; and is dependent on providing clear information on access to services and entitlements for families, the provision of best practice guidelines for informing families of their child's disability is fully in line with the principles expressed in *Quality and Fairness*.

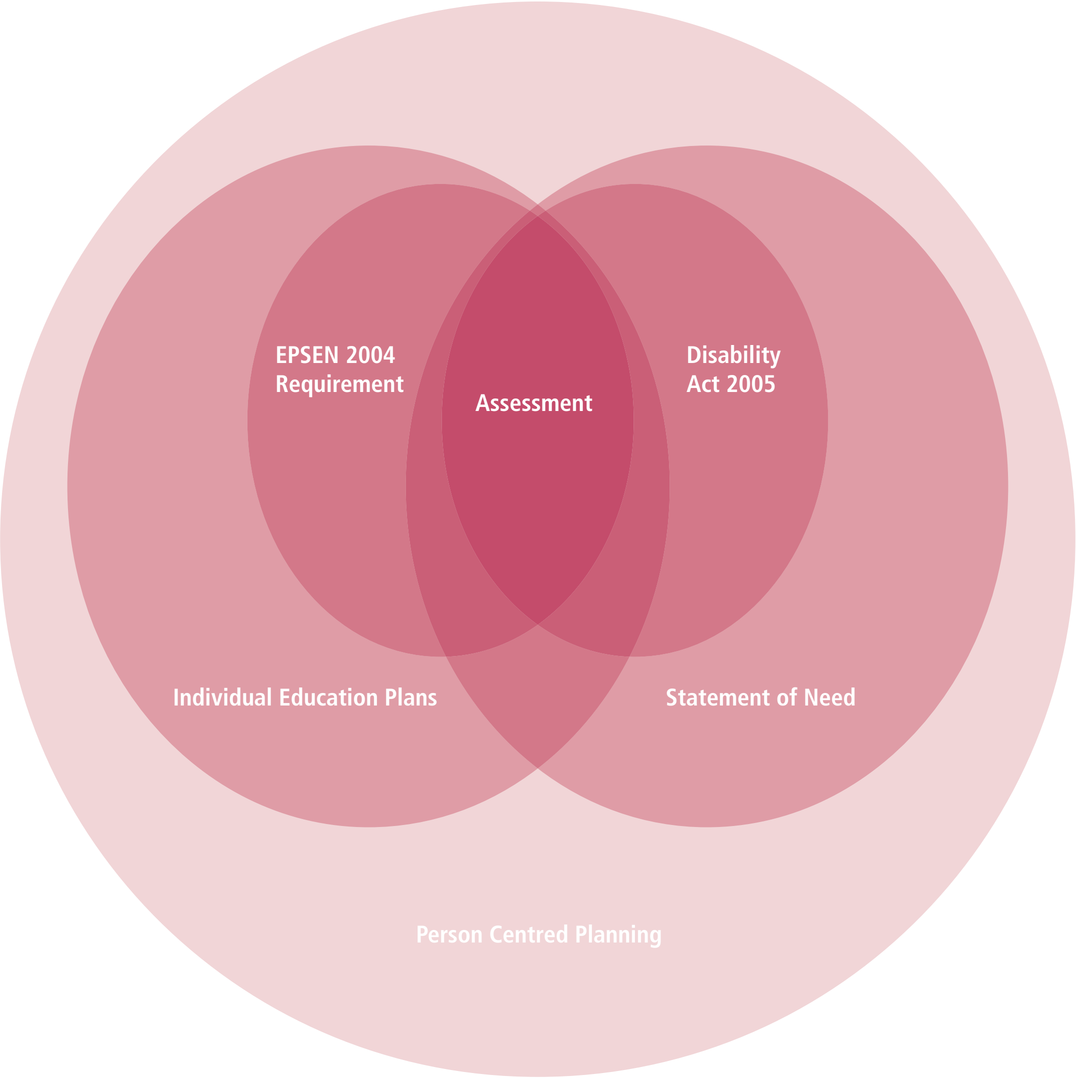
All of the above policies, and the present guidelines produced under the *Informing Families Project*, should be viewed in the context of the National Disability Strategy (2005-2009) and the current Health Service Executive Transformation Programme. An important aspect of this Strategy is the *Disability Act 2005*, and its provision for an independent assessment of need process for all persons with a disability. The practical application of the assessments will have an impact on where and when some families will first hear the news of a disability, or have a disability confirmed, and will need to be carefully examined when implementing guidelines for professionals giving the news. The statutory provision of an assessment of need process for children under the age of five took effect on 1 June 2007. The recruitment of Assessment Officers for this purpose had taken place at the time of going to print however it was too early to evaluate the workings of the new process on the ground. The Health Information Quality Authority has issued *Standards for the Assessment of Need* (HIQA, 2007). These standards set out requirements that the assessment must be person-centred and ensure that the person is appreciated and respected as an individual. In addition, the standards require that the person (or in this case the parent(s) of the child who is being assessed) is respected for their knowledge, and the experience that they bring to the process. This will be a particularly important standard for addressing the needs of parents whose children have an evolving diagnosis, as expressed in the literature above. The standards also address the need for co-ordination when they state in Standard 5.2:

> Where a number of people are involved in the Assessment of Need they work in a co-ordinated way to achieve a comprehensive Assessment of Need report (p.19).

In addition to the *Disability Act, 2005*, the National Disability Strategy provides a second legislative instrument for the assessment of a child's educational needs; the *Education for Persons with Special Educational Needs Act (EPSEN), 2004*. The Act ensures that persons with special educational needs can be educated where possible in an inclusive environment, that they have the same rights to education as persons who do not have special educational needs and that such persons are equipped by the education system with the skills they need to participate in society and live independent and fulfilled lives. The Act introduces an assessment and *Individual Education Plan for Children (IEP)* identified with special education needs.

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability, in its *Report to Oireachtas Committee on Education & Science* (Walls & Swinburne, 2006), strongly recommends that the assessments under both the *Disability Act, 2005* and the *EPSEN, 2004* are co-ordinated in the interest of the child. The development of a person-centred, holistic, whole-life, strengths and needs-driven joint integrated assessment and IEP process to meet the requirements of the EPSEN Act and Disability Acts for people with intellectual disability will require co-ordination between the Department of Health & Children, the Department of Education & Science and the Health Service Executive. The recommended model put forward by the National Federation of Voluntary Bodies is illustrated in Figure 2.1, below.

Figure 2.1. National Federation of Voluntary Bodies Integrated Assessment Interventions Model



A recurrent theme emerging from the strategy and policy documents above is the need for co-ordination and liaison across all organisations providing services to people with disabilities and their families, a principle which is echoed in the aims of the *HSE Transformation Programme* (2007-2010).

> Beginning now, and during the next five years or so, the goal of the Health Service Executive is to build a world class health service in Ireland. At the heart of this transformation will be programmes that make it easier for people to access quality services and easier for the HSE to deliver these quality services. (An introduction to the HSE, p.3. *www.hse.ie*)

Currently in the Republic of Ireland, there is an absence of a single national policy guiding good practice for sharing the news, and consequently there are variations between regions, and between agencies (South Western Area Health Board & Rush, 2003; Western Health Board & Brothers of Charity Galway, 2003). As might be expected, this lack of consistency is reflected by a continuum of experience reported by parents (Kealy, 2004). Whilst elements of best practice are in place informally and sporadically, there is no one strategy, no consistency, and no standard guidelines to guide practice (Doyle 2004). The potential negative effects of a lack of consistent policy have been described above, where parents have had adverse experiences and lack vital information about the services available to them (Cunningham, 1994, Redmond, 2000).

The provision of guidelines for informing families of their child's disability is endorsed by the recent United Nations Convention on the Rights of Persons with Disabilities, which strongly affirms the dignity and worth of children with disabilities in the opening preamble and inclusively in Article 1 on Purpose, Article 3 on General Principles, Article 8 on the Right to Life and specifically in Article 7 on Children with Disabilities. Further detail is available at: *http://www.un.org/esa/socdev/enable/rights/convtexte.htm*

Clearly then, the implementation of best practice in how families are informed of their child's disability is strongly supported by the recent UN Convention and a wide range of Government policies and strategies, and has remained so over the past two decades. These documents call for the introduction of specific measures to support best practice in the disclosure of a disability diagnosis but as yet remain unimplemented, with a lack of consistent or coherent protocols or policies in operation on the ground to guide staff members who support families at this time (Doyle, 2004; South Western Area Health Board & Rush, 2003), and a lack of available information to provide to family members in spite of clear recommendations (Redmond, 2000; Western Health Board & Brothers of Charity Galway, 2003).

Literature Review Summary

In summary, the literature review has shown that the area of how families are informed of their child's disability is one in which there is an existing lack of comprehensive Irish research and this has led to the current study undertaking further national investigation. The way in which the news of their child's disability is communicated is an important process, which has an impact on the amount of information parents absorb and understand, and can impact on their adaptation to having a child with a disability. The disclosure process has also been shown to impact on attachment between child and parent. Poor practice can increase the risk of litigation. The skills required for positive disclosure processes are an area in which professionals have identified current deficits. Dissatisfaction with disclosure is not inevitable, and the provision of good practice is a key determinant of parental satisfaction. There is broad agreement in the literature on what constitutes best practice, with recommendations covering a wide range of areas including the location, setting, people present, information provided, cultural and language, communication skills, planning and organisation and training provision. The development of guidelines for best practice in how families are informed of their child's disability is fully in line with Government strategy and policy documents over the past seventeen years, and will require a specific and comprehensive implementation strategy to ensure that the recommendations become widely adopted.

"It's the toughest part of the job really. When you have experience you will prioritise this, because it's a big priority, because it's something that parents remember."

Consultant Paediatrician, Informing Families focus groups

CHAPTER 3
CONSULTATION AND RESEARCH STRATEGY

A key requirement in the development of national best practice guidelines for how families are informed of their child's disability was to identify how disclosure currently takes place in the Irish context. In order to explore all aspects of existing practice a consultation and research strategy was developed, with the aim of balancing at each stage two perspectives; the views and experiences of families of children with disabilities, and the views and experiences of staff members in hospitals, community care and disability services.

The research sought to identify and maintain those aspects of good practice already in place and to consult all stakeholders on recommendations for best practice going forward, and in so doing to address the following research questions:

1. How are families in Ireland today informed of their child's disability?
2. What is currently working well in how families are informed in Ireland?
3. What areas of the current process do families feel need improvement?
4. What areas of the current process do professionals feel need improvement?
5. What do families and professionals recommend should be included in future best practice for disclosing disability?
6. What are the support and training needs of professionals involved in informing families?
7. Validation of existing best practice recommendations for the Irish context

The programme of work began with the following elements:

Start-up Phase

1. Initial Exploratory Research
2. Literature Review

Informed by the knowledge gathered in this initial phase, the following developments were agreed:

Consultation Phase:

3. Seven Focus Groups with parents of children with disabilities
4. Fifteen Focus Groups with professional disciplines who communicate the diagnosis to parents or support parents immediately thereafter

Research Phase:

5. National Questionnaire Survey disseminated to 584 parents of children with disabilities[8]
6. National Questionnaire Survey disseminated to 1588 professionals

The details of how this research strategy evolved are outlined in this chapter. The information gained through all of the strands was analysed, collated, and used to inform and develop guidelines which then were then endorsed by the National Steering Committee of the Informing Families Project.

Aims and Objectives

The objectives of the research and consultation programme undertaken were:

- to provide a sound evidence base for the Guidelines developed
- to gather data and recommendations from key stakeholders
- to ensure that the policies recommended are in line with international best practice and appropriate for implementation in an Irish context.

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[8] For details on how samples sizes were determined, please see Chapter 5, pages 78-85.

1. Initial exploratory research

During 2004, meetings were held with parents of children with disabilities and with professionals from disciplines in various service settings. These meetings were held in order to gain an overview of the broad picture in Ireland today, to ascertain which professional disciplines are involved in informing parents that their child has a disability; how the news is told; and any issues currently standing in the way of consistent implementation of best practice.

The broad picture emerging anecdotally from the initial meetings was a lack of consistency across the country in terms of practice and policy. It appeared that written guidelines were rarely in place, and that many staff members had not had specific training in communicating the diagnosis of a child's disability sensitively. Parents who had heard the news in a range of settings (from those who received a diagnosis at the maternity hospital, to those with evolving diagnoses, and those with no diagnosis as yet), reported varying experiences - some in which good practice was evident; others with distressing accounts of how concerns about their child were first communicated.

The initial interviews undertaken found a very wide range of professional disciplines involved in disclosing the news of disability to parents in Ireland. The interviews found that staff members responsible for communicating the diagnosis include members of various medical disciplines; most commonly Paediatricians. In the case of sensory disabilities it was suggested that the diagnosis may be made by an Ophthalmologist, ENT Consultant, or Audiologist. Midwife-led clinics in the ante-natal setting are often the first stage at which a concern is raised during pregnancy. Some Midwives may communicate the concern directly and refer on to the Obstetrician, while the Obstetrician will be the first point of contact for the family in other areas. In the community setting the Area Medical Officer or GP may pick up concerns and refer on to specialised services. Within community services and disability service-providers parents are often told by Psychologists and various professional therapists working on multi-disciplinary assessment teams such as Social Workers, Occupational Therapists, Physiotherapists, and Speech and Language Therapists. Support for the family who have been given the diagnosis is provided by a range of professionals, often including midwives, nurses, social workers and other members of the multi-disciplinary team. The above is just an example of the myriad of settings and professionals who may be involved in sharing the news, as identified by the initial research, and is by no means an exhaustive list.

Parents often first suspected the news of their child's disability from interactions with staff members other than those who might be responsible for providing a formal diagnosis. In one case reported during the initial interviews, a father who was waiting outside an operating theatre while his wife was having a Caesarean-section was told by a hospital porter that his baby had Down Syndrome. Some other parents had sensed that something was wrong at the time of birth from the body language of all staff members present. These examples underlined the importance of including in the research all staff members that may be involved in the process, regardless of whether their direct responsibility includes communicating the news.

Valuable information emerged from these initial meetings, identifying systemic issues (e.g. lack of appropriate physical environments in which to communicate the news, a shortage of Developmental Paediatricians, etc.) as well as practice issues, hindering good informing. It became clear from these interviews that the research of the Informing Families Project would need to examine systemic practice, education and training, resource and policy issues, to find mechanisms to support professionals in successful implementation and adoption of best practice.

2. Literature Review

Examining existing research from Irish and international sources was a vital strand of the development of recommendations for best practice in informing families. As already discussed, an important finding to emerge from the literature review was a lack of Irish research in this area. There had been several reports (e.g. Redmond, 2000; South Western Area Health Board & Rush, 2003) referring to the experiences of families receiving the news of their child's disability. However there had been just one significant piece of recent Irish research focussing specifically on the area of policy and practice in informing families of their child's disability. This study; *Report of the Maternity and Intellectual Disability Review Group on Integrated Patient Care* (Doyle, 2004), was conducted by the then Eastern Regional Health Authority (ERHA), and examined practice within the maternity hospitals and early intervention services in the former ERHA region. The report found a lack of written guidelines or standard policy across the maternity hospitals and services studied. It made 23 specific recommendations for the implementation of improvements in practice. During the period of initial project investigation it was found that this study had not been replicated around the country, and that there was no clear picture in existing research of practice on a national level.[9]

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[9] With the inception of the *Informing Families Project* the HSE took the decision to provide the research of the *Report of the Maternity and Intellectual Disability Review Group on Integrated Patient Care* directly to the *Informing Families Project*, so that a coherent strategy taking into account both projects could be formulated. Therefore the *Informing Families Project* builds on the research begun in the ERHA study.

Development of research strategy

Following the set-up phase of the Project Steering Committee, the initial interviews with parents and professionals and the literature review, the Steering Committee of the Informing Families project met in December of 2004 and discussed the research strategy for the project in the light of this initial work. Several strands from the exploratory research came together to lead to the definition of the project scope. In summary:

- As discussed above the literature review revealed only one existing piece of recent Irish research (Doyle, 2004) dealing specifically with the area of informing families of their child's disability. There was therefore a need to undertake research to examine and validate the local findings of the ERHA report on a national basis.
- As there was a paucity of existing Irish research, there was a consequent need to validate guidelines which had emerged in international research, for the Irish context.
- There was a need to give a stronger voice to the experiences of parents within the Irish research, as little had been reported thus far of how parents experienced diagnosis.
- The early project investigation had indicated anecdotally that parents were reporting a range of dissatisfactory experiences that demonstrated an urgent need for policy guidance and staff support across the range of locations in which the informing of families takes place.
- The broad scope of professionals that deliver the news in Ireland, identified in the initial exploratory research, meant that there was a need for consultation to be undertaken with a wide and complex range of disciplines in order to successfully capture current practice and to identify the supports and training required by professionals to facilitate implementation.
- Systemic issues emerged, and needed to be fully identified and addressed in order to ensure that the guidelines produced would be viable, to inform successful implementation.
- A review of existing Irish policy and strategy documents revealed that the Informing Families project was seeking to fulfil a policy remit that has been specifically expressed, and yet unmet since *Needs and Abilities* in 1990, and reiterated in subsequent documents such as *A Strategy for Equality* (The Report of the Commission on the Status of People with Disabilities, 1996), and *Towards an Independent Future* (The Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, 1996).

Having examined these points the Steering Committee recommended a comprehensive consultation and research programme to fully explore all of the relevant issues. The resulting strategy led to the setting up of focus groups with parents and professionals, and the undertaking of the National Questionnaire Survey of Parents and Professionals to gather quantative data about the existing context and to validate a suggested set of best practice recommendations emerging from the focus groups and literature review.

As described above, the full consultation and research programme therefore comprised:

- Initial Exploratory Research
- Literature Review
- Focus Groups with Parents
- Focus Groups with Professionals
- National Questionnaire Survey of Parents
- National Questionnaire Survey of Professionals
- Collaboration with other groups

Chapters 4 and 5 of this report provide details of the methodology and results from the Focus Groups and National Questionnaire Surveys.

Collaboration with other groups

The *Informing Families Project* aimed to link with other agencies wherever cooperation and partnership created added benefits. In addition to the connections made with a wide range of service providers, professional bodies and trade unions during the research and consultation phases, links were also forged with the Hospice Friendly Hospitals Project in Ireland; the Department of Psychology and the School of Applied Social Science in UCD, and the Right From the Start group in the UK.

The Hospice Friendly Hospitals Project, (supported by the HSNPF and run by the former HSE North Eastern Region in partnership with the Irish Hospice Foundation) was initiated by the Irish Hospice Foundation in order to address issues of dying, death and bereavement in acute hospitals. A number of common concerns apply to this process and the process of informing families of a child's disability. The *Informing Families Project* and the *Hospice Friendly Hospitals Project* worked on a number of collaborative initiatives to address these areas; looking in particular at the need for sustainable communications skills training provision for professionals involved in breaking difficult news, and the need for improvements in the physical environments in which staff members communicate with families. A successful joint submission from the two projects was made to the SKILL Project, which is currently being run by the HSE to provide training for support staff and supervisory staff working in the health service. With support provided by the SKILL Project a pilot training course for support staff was run in Our Lady of Lourdes Hospital, dealing with the communications skills required when encountering families, service users and patients who have been given distressing or life-altering news. The joint submission was undertaken with the support of management and trade unions in Our Lady of Lourdes Hospital. One key aim of the training programme; *"Communicating in life-changing and difficult circumstances"*, was to provide support and acknowledgement of the vital role played by support staff such as porters, catering staff and any member of the team who comes in contact with family members who may be going through a confusing, shocking or distressing time.

Further to the aim of an integrated approach to communications skills training, the Hospice Friendly Hospitals Project and the Informing Families Project organised a joint seminar which took place in April 2006. The aim of the seminar was to present the initial evidence gathered through research on both projects to an audience of key decision makers and service providers, in order to encourage the nationwide implementation of communications skill training for staff. Through sharing the knowledge and common aims of the two projects it is intended that the collaboration will leverage the work being undertaken on both projects to the maximum benefit possible, and ensure that the projects deliver outcomes effective on a national and integrated basis.

The Right From the Start group is a team set up in the UK in 1994 with the specific focus of improving practice when families are told of their child's additional needs. The group published a good practice template in 1996, updated in 2003, and have produced a range of resources to support practice development. Their work with the Department of Health in the UK on the implementation of improved practice has led to the development of an audit programme and training for trainers. Contact was made with this group in order to gain as much comparability in the research carried out here, with that done in the UK, to enhance the validity of the Irish research. At various stages in the research design the Right From the Start group were consulted regarding the methodology that had been used in the UK studies.

"…and its not just a sentence, every word is important because you are hanging on to everything they say and you will remember every word that they say, it sticks in your mind. They need to really plan their sentences and their words because this is going to stay with you for the rest of your life."

Parent, Informing Families Focus Groups

CHAPTER 4
CONSULTATIVE FOCUS GROUPS WITH PARENTS AND PROFESSIONALS

4.1 Methodology

The findings of the Literature Review undertaken for the Informing Families project showed that there was a lack of comprehensive national research into current practice in Ireland for informing families that their child has a disability. It was therefore agreed to undertake seven focus groups with parents around the country to address this information gap. These seven focus groups were undertaken with parents of children with physical, sensory, and intellectual disabilities and autism spectrum disorders. Initial research on the project had also found that the range of disciplines providing the news to families and supporting them immediately thereafter was complex, with various professionals at experienced and training levels involved. In order to capture the experiences and concerns of professionals fifteen focus groups were undertaken, bringing the total number of focus groups to twenty two, as illustrated in Table 4.1, below.

Table 4.1 - Background Statistics for Focus Groups

Number of Parent Focus Groups	7
Number of Professional Focus Groups	15
Total number of Focus Groups	**22**
Number of Parent Participants	38
Number of Professional Participants	93
Total number of participants	**131**
Mean number of participants per group	5.95

Aims

The intention when conducting the focus groups was twofold; firstly to address the information gap regarding current practice and secondly to initiate the process of consultation on best practice. The aims of the focus groups were:

- to gain a nationwide picture of current practice in how families in Ireland are told of their child's disability, from both the perspectives of parents and professionals
- to gather recommendations from parents and professionals for future best practice in how families are informed, including aspects that are currently working well, and areas that need improvement
- to explore options for the effective dissemination of best practice guidelines to the wide range of disciplines currently involved in disclosing the initial news to families or in supporting them immediately after the diagnosis has been given
- to gather qualitative data providing an insight into the impact of the disclosure process on parents and professionals

Selection of Participants – Parents

The Informing Families Project worked with six representative service providers in the physical, sensory and intellectual disability sectors to invite parents of children with disabilities between the ages of 3 and 6 to participate. In respect of six of the seven focus groups, staff members from Early Service Teams were contacted to liaise with parents who would be potential participants.

Staff members were asked to make contact with parents using the following criteria:

- Groups to be run in urban and rural areas across the country
- With parents of children between the ages of 3 and 6 years
- With both parents being invited to encourage input from the perspective of fathers and mothers
- The children represented to have a diversity of diagnoses, some with syndromes identifiable at or before birth; those who received an evolving diagnosis, and those still seeking diagnosis
- Groups ideally to contain between 8 and 10 participants

Four of the focus groups took place in conjunction with intellectual disability service providers, one with a physical disability service provider, and one jointly with two sensory disability service providers. The groups took place in rural and urban locations spread throughout the country.

For one additional focus group, parents of children who are currently older were invited to participate. The ages of the children whose parents participated in this group ranged from 11 to 33 years. These parents responded to an invitation to attend the focus group, which was issued to all members of a small parent-support group of which they were members. The rationale for including this group was that the evaluation of information from this group alongside the information from the parents of the younger children allows comparison between earlier practice and how the diagnosis has been communicated more recently. This gives an indication of some recommendations that were considered important by parents hearing the news up to thirty three years ago, and which parents hearing the news in the last six years still find important.

Ethical Considerations and Informed Consent

In working with each of the agencies, the ethical considerations of running the focus groups were given strong consideration, due to the sensitive nature of the material, and due to the event being quite recent for some parents. To this end each service provider was asked to choose a nominated contact person to co-facilitate the group together with the Project Co-ordinator. This contact person was available as a support to parents, should they feel in any way distressed after attending the group. In the case of the parents of the older children, the group was organised through a parent's support group, and was co-facilitated by a Social Worker who was available to the parents subsequently for any support needs.

For the six groups with recent diagnoses the lower age limit was placed at three years to minimise the number of participating parents for whom the disclosure event was particularly recent, and could therefore be more upsetting. It was also reiterated to parents in an introductory letter and verbally at the start of the groups that this can be an emotional topic to discuss, and that they should only provide information which they were comfortable sharing. The letter, distributed to each potential participant, indicated the purpose of the study, the voluntary nature of participation, intended use of the material and assured confidentiality. Signed consent was obtained from each focus group participant.

Selection of Participants - Professionals

In the case of professionals working in the area of disclosure of the news of disability to a family, the initial interviews indicated the involvement of a wide range of disciplines. It was clear therefore that there was a need to consult with a broad range of the key stakeholders. In order to achieve this, the fifteen groups listed in Table 4.2 were agreed through consultation with the Informing Families Steering Committee. For each of the disciplines listed a representative national organisation, professional body, trade union or agency was contacted to request participants. In the case of Ultrasonographers no such organisation currently exists at a national level, and these participants were therefore contacted by telephoning each of the maternity hospitals and units in the Republic of Ireland, to invite participants directly. Each of the professional focus groups was co-facilitated by two facilitators from the Health Services National Partnership Forum, with the Project Co-ordinator in attendance. All professional and parent focus groups were audio recorded with the consent of participants, and were subsequently transcribed for analysis.

Table 4.2 - Disciplines involved in Professional Focus Groups

Discipline	Organising Partner
Consultant Obstetricians/Gynaecologists	Irish Hospital Consultants Organisation
Trainee Obstetrician/Gynaecologists	Institute of Obstetrics and Gynaecology, RCPI
Consultant Paediatricians	Irish Hospital Consultants Organisation
Trainee Paediatricians	Faculty of Paediatrics, RCPI
Consultant Psychiatrists	Irish Faculty of Child Psychiatry
Neonatal Nurses	Irish Nurses Organisation
Midwives	Irish Nurses Organisation
Paediatric Nurses	An Bord Altranais
Ultrasonographers	Organised directly through maternity units and hospitals
GP's	Irish College of General Practitioners
Public Health Nurses	Organised through Directors of Public Health Nursing
Social Workers	The National Social Work Qualifications Board
Speech and Language Therapists	The Irish Association of Speech and Language Therapists
Psychologists	The Psychological Society of Ireland
Early Intervention	Irish College of General Practitioners
Early Intervention Multidisciplinary Group	Accessed through national organisations and early services teams. Included: Dieticians Home Teachers Occupational Therapists Physiotherapists Registered Nurses Intellectual Disability
Total Number of Groups	**15**

Ethical Considerations and Informed Consent – Professional Focus Groups

Informed consent for the professional focus groups was obtained through an information letter and consent form that was signed by each participant. The information letter set out the purpose of the focus group and the intended use of the material gathered, along with the voluntary nature of participation, and the confidentiality and anonymity policy agreed.

Questions

A semi-structured schedule was used to guide the discussion and maintain consistency across groups, but the structure also allowed for participants in groups to raise topics and issues. The following questions were put to parents:

1. What was your experience of being told that your child has a disability?
2. How would you recommend that families should be told about their child's disability in the future? (Incorporating prompts where necessary of: "What did you find most helpful about the way in which you were told?" and "What did you find least helpful about the way in which you were told?")

The following questions were put to the professional disciplines:

1. What is your involvement in the process of informing a family of their child's disability?[10]
2. What is working well in current practice in how families are informed?
3. What is not working well in current practice in how families are informed?
4. How do you feel when you inform a family that their child has a disability?

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[10] This question emerged as a requirement after the first three groups had been run on a pilot basis, and there are therefore three groups for whom this question did not form part of the focus group.

5. What are your recommendations for best practice in informing families of their child's disability?
6. What are the barriers and supports to implementing best practice, and how should the guidelines, training recommendations produced be disseminated?

Timeframe of data collection

Over the course of 2005 and early 2006, all seven focus groups with parents took place. The fifteen focus groups with professionals took place in late 2005 and throughout 2006. A key aspect of the focus group planning was to ensure that early contact was made with national organisations and training groups for each of the disciplines. For instance, the focus groups with Trainee Paediatricians and Trainee Obstetricians/Gynaecologists were organised through contact with the Specialist Registrar training groups of the Royal College of Physicians. In addition to providing consultation and links with the participants for the focus groups, the aim was to develop contacts that would be valuable in providing the maximum dispersion of the guidelines and training at the later stages of the project.

Focus Group Analysis

Each focus group was audio recorded and transcribed, and in addition flipchart notes were taken during the focus groups highlighting the key points and recommendations. Participants were invited to comment on the flipcharts and to satisfy themselves that the data collected was an accurate reflection of the discussion which had taken place during the focus group. The tape transcriptions and flipcharts from each focus group were then thematically analysed with points made grouped into categories and recommendations per focus group. Following the individual focus group analysis the recommendations and themes were then compared across all groups, to produce the amalgamated focus group findings. Finally a set of quotations from across all groups was chosen to provide a reflection of the key themes discussed, and these are presented in the following sections to illustrate the views of the participants.

4.2 Results

Communicating the Diagnosis – Location, Timing and Personnel

During the course of the focus groups, parents described the circumstances in which they had received their child's diagnosis and professionals detailed their involvement in providing this news to families and supporting them immediately thereafter. The following section details the service settings in which the participants described diagnosis taking place, and the personnel involved in the communication.

Parent's descriptions of when and where diagnosis was received

A wide range of services were involved in the disclosure consultations as described by the parents.

1. Antenatal Diagnosis

Some parents had been made aware of their child's disability as a result of ultrasound scans during pregnancy, and therefore had an opportunity to prepare and be informed about the diagnosis before the birth. In this case it was often the Ultrasonographer who indicated a concern and then consulted the Obstetrician for further confirmation.

2. Diagnosis at or near the time of birth

Many of the parents that attended the focus groups found out about their child's diagnosis at birth or close to that time. In these circumstances the maternity or neonatal unit was the setting for disclosure, with many parents finding out in the labour ward due to the concern becoming apparent in the moments immediately following birth, or in public wards due to the lack of private facilities. In these situations it was very often a Midwife or Obstetrician who had the first concerns and then contacted a member of the Paediatric team for further investigation. For those parents whose children required medical intervention shortly after birth, the diagnosis frequently came in the Special Care Baby Unit, sometimes with only the father present; particularly when the mother was recovering from the birth or a Caesarean Section and was therefore in a recovery room elsewhere in the hospital. These disclosures were often attended by a Paediatrician, perhaps with a support person present such as a nurse from the Special Care Baby Unit, or a Social Worker.

3. Evolving Diagnosis

For parents of children whose diagnosis emerged later, concerns were sometimes identified in the community setting by Public Health Nurses or Area Medical Officers when the child did not reach developmental milestones, or through parent concerns and GP referrals leading to consultations in paediatric settings – either in general hospitals or in specialist paediatric services. In these settings parents most often received the diagnosis from Consultant Paediatricians, or more junior staff on the Paediatric team. Others received the diagnosis from specialists to whom they had been referred. Among those mentioned by parents were

Neurologists, Consultant ENT, and Cardiologists. For parents living in areas outside the Dublin area initial information was sometimes provided in regional paediatric settings with follow-on referrals to paediatric hospitals in Dublin for specialist treatment, diagnostic services, or second opinions.

For some parents, confirmation of the diagnosis came in Early Intervention Services, through assessments, usually with a multidisciplinary, interdisciplinary or transdisciplinary team. Parents of children with suspected autistic spectrum disorders found their diagnosis to fall largely between Early Intervention Services and community or hospital psychiatric services, sometimes with a lack of clarity as to where this should take place. For parents whose children have a sensory disability, diagnosis involved Ophthalmologists and Audiologists and sometimes specialist services provided in tertiary centres in Dublin.

Roles played by professional disciplines in the disclosure process

During the focus groups staff members also described their involvement during the various stages at which diagnosis can take place, and the roles taken on by different disciplines in informing families of their child's disability, or supporting families who are receiving this news.

1. Ante-natal diagnosis

At the ante-natal stage, Midwives, Consultant Obstetrician/Gynaecologists and Trainee Obstetrician/Gynaecologists described a team approach whereby anomalies picked up on scans are very often initially communicated to parents by the Midwife-Ultrasonographer raising a concern which is then followed up and confirmed by the Obstetrician. Radiographers also perform obstetric ultrasonography in some locations. Staff members described how parents can be referred at this stage from regional services to tertiary centres in the three specialist hospitals in the Dublin area, if a scan shows a potential anomaly requiring specialist investigation, further testing and/or a second opinion. Trainee Obstetrician/Gynaecologists at the Specialist Registrar (SpR) level indicated that the demands of their work and the organisation of shifts mean that they are frequently alone when communicating the diagnosis of a disability.

2. Diagnosis at or near the time of birth

Midwives described the supporting and counselling role that they play in the maternity hospital when a baby is born with an unexpected disability at birth, particularly as they may be quite likely to be the first person to notice and therefore communicate the concern with the parents, and because they will have built up a relationship with the parents during labour. Some Midwives have a designated counselling role when babies are born with a disability.

Consultant Paediatricians described their role in communicating the diagnosis when the baby is born, either with a suspected anomaly indicated on a scan and later confirmed at birth, or with a disability that is unsuspected and only discovered at birth or in the following weeks and months. Trainee Paediatricians at SpR level indicated that they find themselves on the front line of providing the diagnosis to parents particularly between the hours of 5pm and 9am.

Neonatal and Paediatric Nurses described the strong relationship that they build with parents while caring for the child, and their key role in reinforcing, clarifying, and interpreting information given by doctors to parents. Many professionals described the practice of a second person attending the disclosure discussion alongside the professional communicating the news, to remain with parents and be available through the hours following the consultation as a support, should the family wish. This role is taken on by a number of different disciplines, including Midwives; Neonatal and Paediatric nurses; Social Workers and Pastoral Care staff. Medical Social Workers provide support to families in maternity and paediatric settings and information on services and supports available, as well as detailing entitlements and benefits and providing initial counselling, advocacy and advice. The paediatric multi-disciplinary team can include disciplines such as Physiotherapists, Dieticians, Occupational Therapists and Speech and Language Therapists.

Across the various stages, many of the professional focus groups from across the range of disciplines highlighted the very positive role played by Clinical Nurse Specialists who are present in a number of different specialist teams. This role can include co-ordinating between team members or indeed across several medical teams who may be providing care to the child, ensuring that the communication is consistent, interpreting and repeating information for parents, and advocating with the medical teams on behalf of the parents, particularly assisting the parents with questions that they may have.

3. Evolving Diagnosis

In the community setting, GP's described their role as being an advocate for the family; interpreting information that has been provided in the hospital setting and providing support particularly in the initial period following diagnosis. Public Health Nurses are involved either in specialist disability roles, where they have a particular responsibility for visiting families who have received a diagnosis, or through general roles, where they make routine visits to the child's home after the birth. Sometimes the Public Health Nurse may only become aware that a child has been given a diagnosis when they arrive at the home for a routine visit. Public Health Nurses are also involved in developmental checks either in the home or clinic setting, where concerns may be raised about a child's development, leading to onward referrals.

Consultant Paediatricians pointed out that a current lack of Developmental Paediatricians is causing an acute strain on resources and long waiting times for parents; which particularly affects families awaiting assessment and diagnosis in an evolving situation. Speech and Language Therapists provide first information to families in a variety of settings, including in the community setting, where they see children who have been referred by GP's, Area Medical Officers, or where there has been self-referral from families for suspected language delay. When the Speech and Language Therapist assesses this delay it may emerge that there is a more significant disability present, at which point the child is referred for further assessment, often with a Psychologist who may work as part of a team in Early Services or in the community setting. The Early Services team providing assessment may include members of a multi-disciplinary, interdisciplinary or trans-disciplinary team, such as Social Workers, Speech and Language Therapists, Physiotherapists, Occupational Therapists, Consultant Psychiatrists, Consultant Paediatricians, etc.

Consultant Psychiatrists described their involvement as being chiefly involved with children who have an evolving diagnosis, and having a particular role where there is dual diagnosis (of intellectual disability and a mental health diagnosis) and in the diagnosis of autistic spectrum disorders. Within the Early Services team the Social Worker provides direct support to the family and will commonly be the first person to introduce the team members to the family, and explain the services that will be provided.

What is currently working well, what needs to be improved, and recommendations for best practice.

The following section sets out the findings of the focus groups in relation to what parents and professionals felt was working well, what they considered to be in need of improvement, and the best practice recommendations arising from these discussions. The findings identified striking commonality between the recommendations made by parents and by professionals, pointing to a process that has clearly identified areas for best practice implementation. Within the focus groups the need was emphasised to pinpoint areas of current process that should be maintained as well as addressing areas that require improvement. The recommendations made fall broadly into the following categories:

1. Setting/Location and People Present at disclosure
2. Communication
3. Information and Support
4. Culture and Language
5. Organisational and Planning requirements
6. Training, Education, and Support for professionals
7. Dissemination of Guidelines and Best Practice

The following paragraphs summarise the themes in terms of good practice and current deficits as discussed in relation to each of these areas by both parents and professionals, illustrated by direct quotations from the focus groups and followed by the corresponding recommendations for each section. The quotations reflect a diversity of responses received with positive and negative experiences described. Some of the direct quotations describe distressing situations in which the families received their diagnosis and many show the empathy and commitment of staff members in providing the best service possible. The intention of this report is to provide an accurate portrayal of the experiences of staff and parents and to illuminate the issues that need to be addressed to promote best practice. The often emotive quotations used in this section of the report reflect the importance the participants in the parent and professional focus groups placed on the manner in which the diagnosis of a child's disability is communicated. Throughout the report any names, rare syndromes and other identifiable information mentioned has been changed to protect confidentiality.

4.2.1. Setting/Location and People Present at disclosure

Themes:

The experience of providing the news to parents that their child has a disability begins with the location that is chosen for this consultation, and the people who are present. During the focus groups professionals frequently expressed frustration with the existing lack of private facilities in which to give news to parents, while parents indicated that the lack of privacy was often a very distressing factor of their experience.

> *"You can be in a ward with twelve people, and you're telling them behind the curtain. The mother has had a Section so can't go elsewhere, you have to tell them on the ward, it's a horrible situation. We try to get them to rooms on their own but with crowding it's very difficult to get privacy. They do try but practically, it's not possible."* (Consultant Paediatrician)
>
> *"I always remember hiding under the sheets. I was in a four-bed ward, trying not to cry too loud. I felt I couldn't even scream or let my emotions out."* (Parent)
>
> *"I think, having worked in hospitals where there was a designated parent's area, and having worked in hospitals where that isn't present, you can really see the advantage of having it there. Just having a warm environment with simple things - a kettle and some tea make a huge difference. As well as that it gives you an area in which you are comfortable to deliver the news because you are used to that environment – it's somewhere that is familiar."* (Trainee Paediatrician)

As well as being private, the space in which the news is given should be comfortable, free from interruptions, and available for the family to spend time in following the disclosure. Parents advised that the number of staff members present while the news is being given should be limited and in particular that the disclosure consultation is not an appropriate time for training to take place.

> *"They brought us into a tiny room they use as a family room, there was a dirty yellow sofa, which was very low, and there was one other chair. We sat down and our knees were kind of pressed together with their knees, it was really a very awkward situation to be honest. So they all came in; the doctor came in, the social worker, the nurse, and the entourage of students…. There were six of them and two of us. I can understand one student, but three or four or five….?"* (Parent)

Many parents who received their diagnosis in the maternity setting spoke of having to stay in a public ward where other families were present after the news was given, and described the difficulties that this presented.

> *"It was only then the next day, the very first thing, you know when the clatter starts and everyone starts getting busy at half six in the morning? All three curtains of the other three ladies were all zipped around. Not a soul, not a sound, nobody saying a word, and they all with their babies. … So it was me who was doing the psychological thing in the morning, it was 'Good morning' to everyone… they didn't know what to say to me…. I had had a Caesarean, so four hours later I couldn't walk out the door, but I felt like doing it. … I felt like I was the one who was reassuring these other people."* (Parent)

Parents often described the importance of having time to bond with their child as a *baby*, before the focus is placed on the disability.

> *"There were about ten people in the delivery room plus ourselves, and when he was born the whole place went quiet. It was so eerie. That to me said that something was definitely wrong, and they took him over to examine him and I asked from the bed, 'Is the baby alright?' And nothing was said, and the doctor picked him up, brought him over and put him on my chest and said 'You can see for yourself'. He actually said that. So I just lost it – I said 'Has the baby got Down Syndrome?'"* (Parent)
>
> *"I kept asking him lots of questions when I saw him, and in fairness to the Professor he always gave us loads of time when he spoke to us. When I asked him, he said 'take him home, treat him as a baby. There are other things you wont have to worry about until he grows up like all the rest, and you still don't need to worry' I thought it was great what he said to us."* (Parent)

A particular difficulty emerged for parents who were given the news without their baby being present – many assumed that the 'bad news' they were being prepared for by staff members was the death of their child.

> *"What was unusual was, really there seemed to be some whispering going on in the room. You realise something secretive is happening and although the tension increased, it was about fifteen minutes before the Paediatrician returned. …His behaviour alarmed me. ..He said 'I'm afraid I have some very bad news for you'. The difficulty we had was that there was no child present, and no reassurance that we had a child."* (Parent)

> *"The baby taken away at birth [for several hours] I couldn't get any information. I just wanted to know was he alive or dead or safe or what."* (Parent)

Similarly, the importance of having both parents present when at all possible was stressed by both parents and professionals. Those parents who had been told alone spoke of the difficulty of having to inform the other parent themselves, while professionals indicated the need to find a trusted family member or friend to accompany a parent when both parents are not available.

Some professional groups described their role as being directly responsible for delivering a diagnosis, while a number of other professional groups identified their role as supporting parents when other disciplines have given the news. In the hospital setting the diagnosis is often given by the professional responsible for delivering the official diagnosis (such as a Consultant Paediatrician, or Consultant Obstetrician/Gynaecologist) together with a contact who is familiar to the family such as a Midwife, Paediatric Nurse or Neonatal Nurse.

> *"…especially working on a children's ward, they know you're looking after the baby all the time and that you're there and they get to know you and they're probably more inclined to ask you questions, as they see the consultant maybe once or twice a week …. but always say did he say this or did he say that, and reinforcing it."* (Paediatric Nurse)

Out of the hours of 9am to 5pm, it was indicated through the focus groups that it is often more junior doctors such as Trainee Paediatricians who provide the news to the family. Sometimes it is more difficult at night time to find a colleague to attend and support.

> *"At night time, you feel sometimes you're going wrong, and there's other patients to see right now, and its appalling but you've no choice. As opposed to during the day when you can give them the bombshell then the Clinical Nurse Specialist comes who has more time generally to come and sit down with them."* (Trainee Paediatrician)

In disability service settings there is often an interdisciplinary team who provide the news. It is important that sufficient staff members attend to allow support for both professionals and families while taking to care to ensure that there is not an imbalance of a large team of staff members informing a small family group. If parents wish, it may be appropriate for the team to come to the family home. The importance of giving adequate time to disclosure and sitting down with parents to give the news was recognised by many participants. Some professionals indicated that the pressure of caseloads and the needs of other service users and families creates a conflict of priorities, and adds to their distress as they feel that it is not possible to devote adequate time to supporting the parents.

> *"… you want to be there for one and a half hours, but you only have five minutes that day."*
> (Member of Multidisciplinary Group)

> *"It's a crisis driven service, and we're just involved when there's a really severe problem, as opposed to being part of the on-going."* (Consultant Psychiatrist)

A number of groups specifically mentioned 'picking up the pieces' after the news has been given as a central role that they play in the initial disclosure process, while others mentioned reinforcing and clarifying information that has already been presented by other disciplines.

> *"The consequences of poor diagnosis are that you feel other people have let you down… you are having to explain to parents at 5 years what the diagnosis means."* (Speech and Language Therapist)

All of the situations outlined above clearly point to the informing of families being a process rather than a single event, and for this process to work, a team based approach is required. It also suggests that the effectiveness of training provided would be increased by providing interdisciplinary training.

Throughout the groups, suggestions made to counteract time pressure included the need to actively manage the breaking of news; to schedule it for periods during the day that allow the most time, to provide a link person who can stay after the diagnosis is given and provide support, and to provide suitable environments for communicating the news that allow for privacy for the parents to stay and absorb the news even if staff members cannot stay.

Recommendations:

The following section contains concurring recommendations of parents and professionals about the people present and the location for disclosure. These are followed by recommendations made specifically in parents groups and professional groups respectively.

Recommendations made by both professional and parent groups:

- The diagnosis should be made verbally (not in writing) and in person (not over the phone)
- The diagnosis should be given in a private room that is:
  - Quiet
  - Free from interruptions
  - Comfortable and user-friendly
  - Available to the family to spend time in absorbing the news after the consultation
  - There should be a kettle, tissues, tea and coffee available
  - Within the hospital setting, private rooms need to be available in both in-patient and out-patient settings
  - Some professionals indicated that the consultation should not take place in a room that the family will be using again such as the labour ward or scanning room, as this will leave the parents with a negative association with this room for the future.
- The news should be given by a professional who is responsible for delivering and confirming the diagnosis, together with a staff member who is familiar to the family, and who can provide support to the family when the consultation is over.
- Both parents should be present during the consultation if at all possible
- If both parents are not available, a family member or friend should be present to support the parent being told
- If the parents are very young, it may be appropriate to invite extended family members such as grandparents as support for the parents.
- The parents should be given time to hold the baby before and if appropriate during the diagnosis consultation.
- The amount of professionals present should be limited and should not greatly outnumber family members.
- The appointment should not be rushed. Families and professionals agree that informing a family that their child has a disability should be seen as a priority, and consequently adequate time must be allocated.
- A follow up appointment must always be scheduled before the consultation is over so that the family leave with a plan, knowing when they will next have contact with those who provided the diagnosis. It is recommended that this appointment take place very quickly, no longer than a week to ten days after the diagnosis.
- Parents should be left in private to digest the news if they wish, but should be aware that there is support available to them should they wish staff members to remain, and that someone will make contact shortly to see how they are doing.
- Those giving the news should provide a contact number to the family, so that can make contact with questions if they wish.
- Several parents and professionals indicated that they felt it was inappropriate to have very junior or very young staff members present.

Recommendations made by parent groups in particular:

- It is important that the parents have seen the baby before the diagnosis is given, if the news is given close to the moment of birth. It is also very important that the parents can see the baby when they are being prepared for difficult news, as several parents indicated that they had been told that there was 'bad news' without the baby being present, and had assumed that the child had died.
- Staff members should sit down with the family, preferably beside the family, and not across a desk, when communicating the news. Parents indicated they would prefer a less formal approach.
- If a baby is in the intensive care unit, the parents should be facilitated to visit as soon as possible after the diagnosis is given, including facilitating a mother who herself may be recovering from surgery such as a Caesarean section.
- Care should be taken in the timing of the delivery of news, and the consultation should take place at the appropriate time; taking into account for instance that the mother may be recovering from the birth or surgery.

Recommendations made by professional focus groups in particular:

- Care should be taken to keep the father involved and supported at all times, as sometimes there is a tendency to concentrate exclusively on the needs of the mother.
- The number of staff members that the family have to interact with should be limited at this sensitive time. This can be facilitated by nominating one staff member as a key contact for the family.
- Staff mobile phones should be switched off during the disclosure discussion.
- In the hospital setting, due to frequent rotation of staff, at least one person should be present at the initial disclosure that will be available to meet with the family again to provide continuity of care and information.

Summary: It is recommended that a senior staff member should provide the news in a private, comfortable place, with both parents present, and a supporting member of staff should be available to remain/spend time with the family; the diagnosis should not be rushed, and parents should be given the opportunity to see and hold their baby before the news is given.

4.2.2. Communication

Themes:

The importance of the manner in which a child's disability is communicated was raised frequently during the parent focus groups in particular. Parents recalled very clearly the words that were used telling them the news, and the way in which they were spoken.

> *"…and its not just a sentence, every word is important because you are hanging on to everything they say and you will remember every word that they say, it sticks in your mind. They need to really plan their sentences and their words because this is going to stay with you for the rest of your life."* (Parent)

For those parents who expressed dissatisfaction with how they were told, it was very often in relation to communication that they felt was dismissive, blunt, disrespectful, or when the message was given in a very negative manner.

> *"The Cardiologist came in after a week, with a smile from ear to ear, and said 'Double whammy; Down Syndrome and hole in the heart, are you over it yet?' smiling from ear to ear."* (Parent)

> *"It was about twenty past one at night, we went up to the ward, and I was put in a room with five other people. And the nurse told [my husband] he had to go, and we were all to 'Shhh shhh' be quiet. I felt that was hard. He had to go home on his own, and I was in hospital on my own. I said [to the Paediatrician] 'Is it mild? He said to me 'No, there is no such thing, he is Down Syndrome and he will be for life'. I felt it was a bit harsh and his manner was abrupt."* (Parent)

The varied experience that the parents in the following quotation describe took place with two different professionals and shows clearly how the parents distinguished between the adverse news they had received, and the manner in which it was given.

> *"The Paediatrician came and we thought he was very good. He said 'I can't give you a definite…' and he looked at [the baby's] hand…and said 'I'm nearly sure he has Downs Syndrome but I couldn't say for definite. Its 75% but I will have to do some other tests'. The next morning my [Obstetric] Consultant breezed in, looked into the cot and said 'More than likely age-related type', and walked back out. And that was the first time that I felt guilt."* (Parent)

Parents and professionals alike recommended that the news should be given honestly and sensitively with empathy and humanity, in a non-judgemental fashion.

> *"The hospital and the nurses and the staff were absolutely wonderful… [The Paediatrician] sat down with us… he said one thing to me I will always remember. He said 'You take care of yourself and I will take care of his health, and between us we will get through this.'"* (Parent)

Parents indicated that respect could be shown for their child by simple measures such as using the child's name. Both parents and professionals stressed the need for hope to be delivered with the diagnosis.

> *"I think we can put a positive slant on it. Now that the problem has been identified, specific things can be put in place to help the child to reach its full potential… now that it's been identified as a problem we can look at the solutions."* (GP)

> *"[The Paediatrician] came in an hour later and spent time with us and that was very useful…the best part of getting the diagnosis was that [she] spent an awful lot of time with us trying to tell us that it wasn't the end of the world."* (Parent)

> *"I think hope is an ingredient that isn't quantifiable, but there's that balance between giving a positive message but yet not minimising the seriousness of a condition….and not minimising the future but leaving that space that they can hope."* (Psychologist)

Several families indicated that they felt that the birth of their child had not been celebrated as it should have been, and felt hurt that the disability became the sole focus at the time of diagnosis.

> *"I think what disappointed me as well was that not one person congratulated us. I find that sad because she's just a little girl."* (Parent)

Some professionals indicated that they thought it would be better to give the worst case scenario, and this contrasted with parents' views that realistic and positive messages are best.

> *"I said look, if you had an ordinary child, they don't give you a book saying, look, he's going to rob a car and he's going to get a girl pregnant or he's going to fail his exams. So you have to live life as it goes by. They don't tell you that with the ordinary child."* (Parent)

> *"I would say to them, if they are fine today, well look you are in good form today but you are going to have bad days and be honest with them. And tell them, down the road you are going to meet various stumbles and you are going to have to get over that. And its not always going to be rosy in the garden, you are going to have very bad days."* (Midwife)

> *"Give us the information we need to deal with over the next few weeks, few months, not all the awful things that could happen."* (Parent)

The importance of listening as an integral part of the communication process was highlighted by parents and professionals alike.

> *"If a parent says they are worried about a child's development you really have to take it seriously."* (GP)

> *"Be there to listen and support and maybe to make sure the child gets what can bring the child on and to get the early intervention – I would see that as being important."* (Public Health Nurse)

> *"We were very lucky to have Dr. 'P' because he was like a best friend for the two, two and a half years. Every so often he would bring me in books on syndromes. And he was very good to listen to me, he always asked my opinion on everything...He was just fantastic."* (Parent)

Parents indicated that there was a very particular need for sensitivity to be displayed when **confirming** a diagnosis, even if the parents have previously been made aware of the likely outcome. Several families discussed how any glimmer of hope is clung to until the final diagnosis is made, and therefore confirmation of a likely diagnosis needs to be handled with as much empathy and care as the initial communication of a concern. It should also be noted that the final confirmation may be provided by specialists who have only brief interaction with the parents or by professionals with whom the parents are familiar.

> *"He held up the CAT scan and said 'yep yep brain damage' and went to walk away. I told him 'I didn't like your manner, you were our 10% hope that we were clinging to.' He said 'I'm sorry, I thought you knew'. It wasn't nice the way he told us."* (Parent)

Parents and professionals felt that individual communication styles vary, with some displaying sensitivity and empathy while others provide less supportive communication.

> *"People who came here tonight* [to the focus group] *are people who are interested in the subject, so are probably doing it well but in the generality of paediatrics there may be a lot of people who are not doing a great job in a sense, and maybe don't realise that they are not doing a great job."* (Consultant Paediatrician)

> *"I think it varies as well, some people are better, and some people are sensitive and aware of breaking bad news, as well as to point out that it's not all doom and gloom that the child has some abilities as well. And some people are a bit uncomfortable, they don't know how to deal with it themselves I suppose, and I'm sure it can come across as being uncaring and a bit harsh and they think we're trying to get it done as quick as we can. It's very hurtful for parents."* (Paediatric Nurse)

Many groups, both parents and professionals, identified parents' shock as a significant factor of the initial consultation when a diagnosis is presented. Both parents and professionals indicated therefore, that only a very small percentage of the information presented is absorbed at the first disclosure. Short precise sentences in simple language were recommended to help make the information as clear as possible.

> *"He said 'There is no easy way to tell you this. Our tests indicate that your son has hearing loss and that it is significant. We need to do more tests.' They offered genetic testing.* [The mother was at this time pregnant with her second child]. *'I came home with two things in my head; that my son was deaf, and my baby might be. He was so good and professional, but that is all I heard."* (Parent)

All groups asserted the absolute necessity for a second, follow up appointment to take place within the first week, to go back over the information, and to clarify and to answer queries that the family may have. The importance of clearly explaining the meaning and significance of any medical terminology used was made clear. Some parent's stories showed how the significance of the diagnosis was not apparent to them for some time after the diagnosis was given, due to the use of medical jargon and or unclear terminology.

> *"She said 'You're carrying a very small baby' and you know how you think, 'Thank God' because all you think of is 'Push push, great news altogether'. I didn't realise how small."* (Parent)

Professionals spoke particularly of the need to make clear any statements about 'developmental delay'; and to clarify the implications as to whether they thought the child might 'catch up' and the possible outcomes if the child does not. There is a need to be clear about the implication of this gap for the future.

Professionals in several groups spoke of their feelings of needing to be strong for the families and to hold in their own emotions, which contrasted with views of some of the families, who felt comforted by the expression of empathetic emotions on the part of staff members.

> *"You have to hold a lot of the steady thoughts for them, you can't discuss it while breaking down and crying."* (Psychologist)

> [A mother was having a scan of twins at 30 weeks.] *"There was a nurse going on her break and she said 'I will stay with you'. I said I'd be fine but she said no, she'd stay with me, I was on my own.* [The scan could detect no heartbeat] *I just looked at her and she started crying. Neither of us, nobody expected this. I said 'Both of them? She said 'No, there's one but it's very weak'. When the babies were delivered no-one said if it was a boy or a girl. On the way out the door the nurse that was going down with* [the surviving baby] *turned back to me and said 'we're going to do our best for your beautiful daughter', and that was the first that I knew they were little girls."* (Parent)

Recommendations:

Recommendations made by both professional and parent groups:

- The news should be communicated with:
  - Empathy
  - Sensitivity
  - Honesty
  - Respect
  - Compassion
  - Understanding
- The language used to deliver the diagnosis should be:
  - Simple
  - Understandable
  - Straightforward
  - Appropriate
- Short, precise sentences should be used, particularly taking into account that many parents may be in shock when first hearing the diagnosis and may not take in a lot of information.
- Parents should be listened to. Listening to parents allows for the communication to be tailored to the individual needs of the family.
- Concerns that parents express should be taken seriously and followed up on.
- It is of vital importance that realistic yet positive messages are conveyed. Hope should be given along with the diagnosis. Positive messages can include describing support and assistance that will be available to the family and focussing on the individual child as a person, with the disability secondary.
- Staff members should clearly explain any medical terminology used, along with the implications and significance of any information given about the child's diagnosis. It is important to elicit the parents understanding of the information given and it should not be assumed that the parents have prior knowledge that would lead them to understand the diagnosis given without explanation.
- Parents should be encouraged to ask questions
- It is extremely important to keep communicating honestly with the parents at all times, including when there is uncertainty, so there is never a large gap between what parents know and what professionals know or are investigating.
- Professionals should seek to build trust with parents.
- The reactions of the parents should be acknowledged, and taken into account when communicating with the family. Parents will have different reactions and different coping mechanisms. Some may feel the need to 'walk away' for a period of time to come to terms with the news, others may be in shock and take in very little, still others may wish to have significant interaction, information and support from staff.
- Parents preferences should be sought and facilitated, including how much information they wish to receive, whether they would like to be alone or if they would like someone to remain with them, whether they would like to have visitors or if they would like to have support in limiting visitors while they come to terms with the news, whether they would like input from pastoral care teams, etc.

Recommendations made by parent groups in particular:

- Staff members should not use dismissive, impatient, aggressive or judgemental language when speaking to parents or children.
- Staff members should read the child's file before meeting with the family for the consultation, as it causes additional anxiety for parents to wait and watch while the file is read. Before starting the consultation professionals should be aware of the child's history, the reason for the consultation, and any tests/interventions that have been requested by a referring professional.
- The child's name should always be used, and the child should never be referred to by their diagnosis. For example, instead of saying 'this Down Syndrome baby' staff members should say 'Ben, who has Down Syndrome'.
- Staff members should be aware of body language and how this can be interpreted by parents, and should at all times avoid whispering in front of parents.

Recommendations made by professional focus groups in particular:

- It is important to ensure that the parents are not isolated after being given the diagnosis - if parents wish, a staff member should engage with the parents at this time to sit and spend time with them.
- It is important to focus on the aspects of the child that are just like any other. Professionals suggested asking parents questions such as 'Does the child look like any of your other children', and concentrating on everyday aspects such as breastfeeding etc. (It should be noted that families indicated that the question 'Does your child look like any of your other children' is inappropriate as it can be very upsetting for parents and can leave them with questions. Parents suggest that when trying to elicit how much already parent knows, it is more appropriate to ask 'Do you have any concerns about your child' or 'have any other members of the team expressed concerns about your child'.)
- Team members should reinforce the information already given by other disciplines so that families have several opportunities to absorb and clarify information provided.
- Some professionals indicated that it is very helpful to show parents visual images such as brain scans, in order to explain clearly a diagnosis rather than trying to describe it in words alone.

Summary: It is recommended that in giving the news of a diagnosis of disability, respect, sensitivity and empathy should to be shown to the family; using honest and straightforward communication and simple language. All medical terminology must be explained; the child should be referred to by name and not diagnosis; positive messages and hope to be given with the news, with the focus on the baby or child and not on the disability

4.2.3. Provision of Information and Support

Themes

Parents in the focus groups reported patchy provision of information, with staff members making every effort to supply information, but not always having appropriate sources available. Some parents reported receiving leaflets that were clearly out of date, while others only heard of support agencies through word of mouth, or their own investigation; often having waited for long periods of time before the information became available.

> *"There was nothing, there was one little leaflet that was as old as the hills, 1970s I saw on the copyright, now they were as helpful – they searched every cupboard in the place but…. It wasn't their fault"* (Parent)

> *"I literally took out the phone book and you know those green pages from the Department of Health in the middle? Anything that was from children's services, anything that had the word disability in it, I rang them. If I hadn't have done that I probably would have been waiting an awful long time."* (Parent)

Although professionals reported access to some relevant sources of information, there was a significant lack of information on catchment areas for Early Intervention Services, availability of support services (some that were thought to be available were no longer active), and information in languages other than English.

Parents and professionals in several groups specifically mentioned the benefit of providing parents with a booklet entitled *What do I do now?* which was written for parents of children with an intellectual disability by a group of parents called the Parents Future Planning Group and was published in 2000.

> *"She gave me this book, without this book I would have gone mad. This book is done by parents – Parents Future Planning Group, and it's a fantastic book. If I hadn't gotten this book I would have been lost. They're brilliant – even telling you what your rights are, what you are entitled to."* (Parent)

However many parents indicated that they had not received this information, or had received it very late.

The professionals in the focus groups identified a lack of clear **ownership** of information leading to some situations where families may not receive information that is available, as one professional assumes that another is responsible for this task. One example from the focus groups graphically highlighted this difficulty. Participants in the focus group with Social Workers were discussing the benefits of the *What do I do now?* booklet when a Medical Social Worker in the group mentioned that it was not available in the maternity unit in which she worked and that she would like to receive a copy of it. When the Project Co-ordinator contacted her later that week to post the booklet, the Social Worker had discovered that it was indeed available in her unit, but that she had not been aware of it and had therefore never been in a position to offer it to parents.

Frequent turnover of staff members means that even if information has been provided by support groups or services to those providing the diagnosis to families, the current lack of structure and ownership for this information means that new staff members coming on-stream are often unaware of it, and it therefore does not reach families.

> *"We are constantly sending our information leaflet* [to the hospital] *and the difficulty I find is that the registrar changes every 6 months – so there's no consistency there. We might get to the consultant but quite often they're too busy. People are often told there is nothing for you out there. We've had parents coming in to us who have been told there is nothing for you out there. It's very frustrating when you hear things like that, never mind the distress for them."*
> (Social Worker in Early Intervention Services)

Trainee Obstetricians described the difficulties encountered, particularly when trying to find information for families late at night, and when Internet access is not available. Even when access to the Internet is possible, the participants explained, in some locations the 'Net Nanny' software makes searches so restricted that it is not possible to access relevant articles. **This group recommended that there should be a national website created that would have leaflets available for download which would be suitable for distribution to parents and would provide information on particular diagnoses as well as the supports, entitlements and benefits available.**

The amount of information that parents wish to receive can vary, depending on their own coping style, and the circumstances of the diagnosis. Parents indicated that individual choice should be supported – some felt that providing too much information at once left parents feeling overwhelmed, in which case it would be better to provide the news in stages. Other parents found it difficult to get a full picture of all the information that they required and would have preferred to be given more detail. There was general agreement that it is therefore important to carefully gauge the level of information provided to suit the pace needed by parents.

> *"Sometimes people need to be drip fed – like titration, it goes in in small doses. You can't expect people to take it all in first time. They come to us for information to be clarified. It works well to give it little by little."* (Social Worker)

> *"There's a range of emotions and if you talk to people over ten or fifteen minutes you get a feel for where they are coming from quite quickly and then you can start. Because of the range of emotions, when you have experienced it for a while and you can see how different people react to it, you can use that data to see how you are going to handle the situation."* (Consultant Paediatrician)

> *"It works well to say 'What have you heard so far? – Get an understanding of where they are, what is their understanding and the level at which they operate. What does [the syndrome] mean to you? So tailor to their understanding."* (Consultant Paediatrician)

The importance of providing honest information to parents at all times was reiterated; the family should be told of any suspected diagnoses that are being investigated, and any gaps in knowledge or scope of practice should be acknowledged openly.

> "[The general Paediatrician] *hadn't a clue about albinism. He was asking stupid questions like; "Is her father fair?" so I felt annoyed about that. And he was checking her heart and I didn't know why he was doing that."* (Parent)

> *"If you're straightforward and honest to a patient, one thing that is very important, throughout the years I have found - if you don't know, you say you don't know. If you're honest like that with people they don't expect you to know everything."* (Consultant Obstetrician)

> *"…we change from topic to topic every 6 months to a year. It's very difficult to be, not that we're expected to be authorities, but to have sufficient knowledge. It comes back to having the most senior person there with the expertise. If you don't have the right answer you probably shouldn't be in that situation. It should be someone else."* (Trainee Paediatrician)

It was recommended in the focus groups that staff members should encourage parents' questions, and should not assume any **prior** knowledge about the disability.

> *"If you stop him and ask him he will explain – he was approachable. He came in and sat down beside us and relaxed. But I think sometimes you need to stop and ask questions because sometimes I think they are so used to speaking with medical people that they just forget, so for the common person coming in its hard for them to explain in our terms, so I think the fact that 'Peter' did stop and ask was good."* (Parent)

Families strongly made the recommendation that guidance should be provided by professionals on reputable and reliable sources of information on the Internet. Professionals found that the provision of such guidance was a significant support to their own work and decreased the anxiety which can be caused by reading inaccurate information that may not be relevant to the child in question.

When discussing the support options that are offered to parents at the time of diagnosis, it was again the theme of supporting individual choice that was recommended. A full range of options, such as contact with Early Services, meeting with other parents, contact with specialist groups for rare syndromes, and support groups were all highlighted as key supports to be provided to families, as long as individual preferences are respected and families are free to choose to take up these options at their own pace. One area that received a good degree of attention was the provision of counselling. Many professionals felt that being able to offer the option counselling in the period after the diagnosis is extremely important and many expressed their frustration at the lack of resources in this regard.

Recommendations:

Recommendations made by both professional and parent groups:

- Staff members should have available for supplying to parents, accurate, up to date, relevant written material on the diagnosis, on support groups, entitlements and benefits, and on Early Services, to be offered at the end of the initial consultation.
- Up to date information on the support services offered by agencies should be made available to staff members, taking account of staff turnover, as many families have outdated images of the services provided by some agencies, and therefore do not make use of valuable services available to them. A named person in each location should co-ordinate the updating of such information.
- Staff members should provide guidance to parents on reputable and reliable Internet sources of information. This can avoid unnecessary anxiety when parents read information that may not be relevant to their child's particular case, and is noted by professionals to be of assistance in facilitating parents' understanding of their child's diagnosis.
- The amount of information provided should be tailored to the individual parent's needs - avoiding information overload for parents who may feel overwhelmed, and meeting the information needs of parents who seek further detail.
- Parents should be kept up to date at all times. This includes acknowledging any uncertainty that exists about the diagnosis, and explaining any suspected diagnoses that are being investigated. There should never be a large gap between what professionals know about the diagnosis and what parents are made aware of.
- All tests and procedures should be carefully explained to parents.
- Parents should receive copies of all correspondence between professionals relating to their child's diagnosis.
- The option of counselling should be made available to families following the diagnosis if appropriate.

Recommendations made by parent groups in particular:

- Information on support groups for specific syndromes is particularly important to parents and should be provided when at all possible. Where support groups do not exist in Ireland, contact with UK groups should be investigated and facilitated.
- The option to be introduced to other parents should be offered, as this can provide significant support.
- Parents should be given a written summary of the consultation. (Many professionals also made this recommendation, and others felt that it was not realistic from a time perspective, or had anxieties about the implications for litigation of providing this information).
- Parents indicated that a litany of all possible negative implications of the diagnosis should not be given. It was felt that sometimes the worst case scenario can be presented, rather than the most accurate realistic picture. Parents felt that the tendency towards providing the worst case scenario may be augmented by a fear of litigation on the part of the professional.

- A sizeable proportion of the parents participating in the focus groups felt that they had been given too much information at the first consultation and that 'information overload' at an early stage needs to be avoided.
- Parents of children with intellectual disability recommended that the *What do I do Now?* booklet should be given to the family as soon as possible following the diagnosis.

Recommendations made by professional focus groups in particular:

- Directories of catchment areas should be developed in all regions, as there is currently a lot of confusion and wasted time while professionals try to ascertain the correct services catering for each child.
- Staff members requested a single source of information that collates the services available. Currently there are multiple pieces of information including flyers, websites, booklets etc. from various services provided and this does not allow for clear details to be presented to parents.
- It is very important that all professionals have access to up to date information on support groups – currently this is not always the case so that parents may be trying to make contact with support services that no longer exist.
- Information on disability services should made available through mainstream sources such as telephone books and parenting websites such as 'EUMOM.com' so that parents do not feel singled out when accessing this information.
- When possible it is very positive to provide information to parents about concerns before birth, as this allows parents time to prepare and come to terms with the information provided before their baby is born.
- Obstetricians and Gynaecologists, Ultrasonographers, and Midwives indicated the importance of explaining the purpose and scope of antenatal ultrasound scanning to parents ahead of the scan, so that there are not unrealistic expectations of what will be identified through the scan, and that if the scan is not an anomaly scan that parents will understand this. Currently staff members from these disciplines indicated that there is an expectation that the scan shows that the 'baby is ok', which may not necessarily be the case.

Summary: It is recommended that the family should be kept up to date at all times; there should be co-ordinated availability of accurate, up to date information for parents and professionals; with written material provided on benefits and entitlements, support groups, and early intervention services. Parents' individual needs regarding how much information should be provided and at what pace, should be taken into account when communicating.

4.2.4. Culture and language

Themes:

Professionals from Early Services teams and those working in community and hospital settings indicated that families who have come from other countries now constitute a large portion of their caseload. Some professionals indicated that 40 to 45% of their caseload may now be made up of families from countries other than Ireland, whilst others had not encountered quite so high levels of diversity. Professionals noted that many families are English-speaking (or have a member with a high level of English proficiency), and others are not. Written information in languages other than English does not appear to be widely available.

> *"Practically everything we have to hand out to patients is in the English language and we do not have access to translated versions…. I don't know how we deal with that."* (Consultant Obstetrician)

Several parent and professional groups pointed out that there are many professionals who are not native English speakers and that this can pose issues for families who may have difficulty in understanding what is being said. Some parents requested that in this case the family should be offered the option of having a support professional present to assist in explaining what has been said.

Different disciplines reported varying levels of satisfaction with interpretation services available. Some professionals only had access only to 'a disembodied voice' through telephone interpretation services, and stressed the inadequacy of this situation, while other professionals felt that there were adequate services available. From the information reported in the focus groups it would seem that there is a difference in availability of interpretive services depending on region; with interpretation services readily available in some areas, and to some disciplines, but difficult to access and only available over the phone in other areas.

The importance of using professional interpreters and not family members or friends came across clearly, although there were areas where family members took on the role of interpreter. A number of groups have alluded to cases where one member of the family (particularly the father in some cultures) speaks English and interprets for other members of the family who do not.

There have been several instances where, for cultural reasons, a family member or non-professional translator has not passed on full or accurate information to other non English-speaking family members.

> *"You need to be careful in terms of services because the information doesn't always pass over …. The male interpreter wasn't giving the information to the woman. What was a two minute sentence was turned into three words. I knew it couldn't possibly have been relayed."* (Trainee Paediatrician)

Professionals discussed the different understandings of disability present in various cultures and the challenges that exist for staff members to become aware of these meanings and to provide appropriate support. In discussing a family whose baby had been born with Down Syndrome:

> *"They were more isolated than anybody, because of the culture and the fact that the Dad – I couldn't say he was ashamed of this baby – but it was a sense of pride, that they had a baby with Down Syndrome. She was more isolated […] He didn't want anybody to talk to her. I don't know what you do there. The man is the leader of the family, and when it came to talking to the Paediatrician he didn't even want the wife there, didn't want her talking to him."* (Midwife)

The challenge of providing culturally competent care when disclosing a child's disability is one that was raised within the project at several different stages, and is an area requiring further research.

Recommendations made by professionals [11]

- There should be widespread access to written materials for supply to parents in languages other than English. It was noted that the information being explained to parents can be quite complex and is further complicated when there is a language barrier to be overcome.
- There should be equitable access to appropriate professional interpretation services, with interpreters available in person to attend the diagnosis consultation. It was suggested by some professionals that the interpreter should be made aware of what will be discussed prior to the consultation so that they are prepared when the news is given.
- Some disciplines indicated that it is not good practice to use family members as interpreters and that this practice should not take place, (as also indicated by international best practice guidelines (RFTS, 2003)). However some individuals indicated that this practice does take place in some locations.
- Professionals indicated that there is a need to build up capacity to deal with cultural, ethical and language issues.
- Some disciplines have highlighted a difficulty in verifying that families with limited English proficiency have understood information presented to them. A tendency of people to nod and say 'Yes', even when something has not been understood, has been identified. It was recommended that in this case the family should be invited back for a second consultation with interpreters present. It was acknowledged that this may seem offensive to families who have indicated that they feel that their English is adequate, but that without it, the needs of the child can be put at risk.
- Religious preferences of all families, regardless of nationality or culture, should be sought and respected when communicating with families. Some families felt that their religious preferences were not respected when religious comments were made or pastoral care services were provided when the family felt that this was inappropriate.
- Training should be provided to improve cultural awareness, and to take account of existing diversity. This training should include identifying the specific needs of groups such as the Traveller Community. Another aspect of cultural awareness noted was the need to have an understanding of how different cultures interpret disability, and that different cultures have different communication styles, all of which needs to be taken into account when communicating with families.

Summary: It is recommended that there should be widespread provision of appropriate interpretation and translation services; the availability of materials in the required languages, which are culturally appropriate; and diversity and disability awareness training which takes account of a new cultural era of diversity in Ireland.

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[11] Parents with limited English proficiency did not participate in the focus groups, as from a language point of view this would not be an appropriate forum in which to explore their experiences. Further research in this area is recommended.

4.2.5. Organisational and planning requirements

Themes:

Returning to the concept of the initial disclosure of the disability being a process which is undertaken by myriad of professionals, and which can take place in a great number of different circumstances, it is clear that effective practice in this area requires detailed organisation and planning. From the information provided in the focus groups with parents and professionals, it became clear that this planning needs to take place at two levels; at the system or organisation level; and at the team level.

System/Organisation Planning

The links between the individuals first telling the news and those supporting the family and clarifying the information immediately afterwards, can be within settings or across settings, from acute services to community and disability services. Professionals and parents were unanimous in their assertion that the links between settings are not sufficient and that there is currently a lack of a joined-up systems approach.

A GP describes her involvement after parents had been told of their child's possible diagnosis of Asperger's Syndrome:

> *"Their second child - their eldest son had possibly Asperger's Syndrome, he was told on a Friday evening, he arrived in to me at about 4 o'clock absolutely distraught, he'd been told by the Psychologist in the hospital and he was distraught. ..I thought it was so inappropriate, and it took at least 2 hours to calm down that man, and I thought 'God, if that was my child on a Friday evening, could they not have left it 'til Monday until there was someone there to support him?'. They could have said, well we're thinking over the report, I need to talk to someone else about it, come back on Monday and we'll discuss or whatever. And I had no knowledge of this, I was not aware that this assessment was taking place at that time. I knew something was taking place I had no time or venue or anything, so I was literally outside the whole circle but the minute the news goes down, I'm the first point of contact."* (GP)

> *"Families have to go knocking on doors and sometimes its just luck that they find the right door."* (Social Worker)

> *"One of the things that we were frustrated with was the lack of communication between all these services. As I went to whoever in each one for an appointment I was the one having to explain what 'Emma' has. And then I go to the health nurse for the regular check-up and she says 'She's not doing things that other children do' and I say 'excuse me but she is profoundly deaf'. And they don't know what to do, they don't know what kind of developmental things to do. I had to go and photocopy the results – every test that was done I asked for the results and then gave them to the Visiting Teacher. Except for one hospital who gave all the test results to the Visiting Teacher, the Speech and Language Therapist, and anyone who needed them."* (Parent)

Parents described the lack of continuity between services having an impact on them in many different ways. In terms of the actual delivery of the diagnosis, it was noted that poor communication between local or regional services and specialist centres to which families were referred for tests and/or a second opinion, meant that the diagnosis was sometimes given insensitively and without preparation, due to professionals assuming that the family had already been given information in another service and therefore communicating without adequate care information which was in fact new to the family.

Some parents described a lack of liaison between regional maternity units and specialist paediatric services leading to poor information provision to mothers who were still in-patients in the maternity hospital, while their child had been referred to a specialist centre.

> *"The communication between the [Regional Hospital] and [Paediatric Hospital] was just unreal. I had to ring, myself, every day. To get information was chaotic. If you would ring they would say 'oh the doctor is not here, they'll be around for their visits in the morning'. This went on. It was like it was a file you had sent up - it wasn't like a person. And when you did get through you felt like you were bothering them. I was on to different doctors every day… I had had a 'Section and had to get out of bed to make all of these phone calls."* (Parent)

Professionals indicated that the positive work being carried out by the National Neonatal Transport System, which manages referrals from regional units to tertiary centres and supports parents during the transition, should be extended from the current 9am-5pm basis on which it operates, to a 24- hour, 7 day service.

Some parents described the isolation that they experienced on discharge from hospital settings, or when waiting for referrals in the evolving diagnosis situation. Many felt that they had not received adequate information during this time and as a result were not aware of key support mechanisms that were available to them. Some parents felt that they had not been given sufficient support and training to meet their child's medical needs on discharge from high support neonatal facilities. Professionals echoed these feelings when they reported feeling distressed and anxious when discharging families, as they detailed difficulties in providing adequate linkage and support for the parents at this time.

> "[You need] *to have a named person that the parents get direct help, that they can leave a message on the answer machine and that would take away a lot of the stress but then you get the problem where they're ringing you back on a Sunday and I think we got something like 22 calls and we were dreadfully busy. There's no time allotted and there's no nurse allotted for that for education of parents we're not allowed any extra time, with tracheotomies and everything else, they take a huge amount of time and you're just not allowed, but you just don't get it, and it's difficult."* (Paediatric Nurse)

Team Planning

The second level of planning and organisation that is needed for effective management of the disclosure process relates to ensuring continuity and teamwork **within** organisations. When asked about the elements that are working well in the current process for disclosing a disability to a family, one of the aspects most often noted by professionals was the interdisciplinary team approach to giving the news. Staff members felt that mutual support is provided to team members when the disclosure is planned and provided through a team approach, and that the needs of the family could be best catered for in this way.

> *"It's usually planned in advance. It would be discussed on the daily ward rounds and if it is breaking bad news obviously the Consultants may all want to get together at a meeting with the multidisciplinary team. It might take a few days to decide how to approach it. Often the parents may have an inkling that all is not well and may be anticipating a problem. If the Consultant discussed it at the ward round in the morning we would try to give parents information to prepare during the day, for instance that there are tests being carried out."* (Neonatal Nurse)

The absence of this approach leaves staff members unsure of how to communicate, and can add to the stress experienced by parents.

> *"We need to develop communication between professionals in hospitals and in community and that's there it can fall down sometimes; or even between the consultants and nurses, because if you're not there when the news is being broken, you think, 'God what did they say', and 'What do the parents know?' and 'Can I go in and be completely honest with these parents now because it's all been laid out on the table, or have they just pussyfooted around the whole idea'? So that's a difficulty and very stressful because you don't know how far you can go with parents."* (Paediatric Nurse)

> *"We were dealing with so many different departments because they didn't know what they were dealing with. He was in for tests and you can't fault them, it has to be done. But the problem I had with all that was – before the consultant comes in the registrar would come, then the junior doctor, and each of them take your history. I felt like I was on trial. The way they question me, you'd just feel you had done something wrong."* (Parent)

Many of focus groups indicated the necessity for a follow up appointment to be planned and scheduled for within 24 to 48 hours of the initial diagnosis.

> *"At end of the session ask if they have any questions and make a plan - I'll ring you or you'll ring me, this is the phone contact, whatever. But do not let them walk out that door without giving them a contact number, knowing when you will next talk."* (Midwife)

Professionals described the pressure of competing priorities as one of the most stressful aspects of delivering the news of a child's disability. While recognising the necessity to spend time and avoid rushing the disclosure, staff members were also aware of the pressing needs of other families and often felt that it was impossible to give adequate time and support to the parents being told of their child's disability.

> *"And it's very difficult as a nurse to scrape yourself around and you do feel like you're running out on those parents who've just had the bottom taken off their world."* (Paediatric Nurse)

Within the team, scheduling and resourcing are of key importance to the adequacy of the response provided. As discussed above, where teams have been able to free up an individual to be available to provide support to the family, the continuity of care and co-ordination this brings is beneficial for the parents and for the team.

> *"We can be the continuity link between the consultant and parents… We can be a consistent link to answer questions or give information, its particularly important if there is staff changeover. If the parents have specific issues or questions I bring those to the consultant- to be an advocate for the parents."* (Neonatal Nurse)

> *"We found when we did eventually get our diagnosis they put us in touch with a genetic counsellor and the way that was done was extremely professional. Now I know we knew that she was going to be a special needs child… but when we went in to see him he had a counsellor present with him, so there were two people there, and she was very professional, very good. He explained everything in minute detail to us, what he was going to do, he was going to send off blood tests for 'Susan', there are a couple of thousand things it could be so he was going to send off blood tests for this particular one. There was something just comforting about having the other person present while he was talking to us- I understand that people are very busy and there is an awful lot going on and they have to see a lot of people so just having her there, having another person where we could actually talk to her afterwards if we wanted to; she gave us her number and her card and said anything you want to know or if you want to talk or to meet again just give a ring, and that was great. I think that's why actually getting her diagnosis in the end … we were ok."* (Parent)

For families with more than one child with a disability, parents reported issues with appointments being scheduled at varying times, leading to logistical difficulties and extra pressure on childcare arrangements. Parents living long distances from services also described the pressure that ill-timed appointments can put on the family, such as early morning consultations leading to the need for overnight stays.

The most commonly raised recommendation to address the fundamental issues described at the system and the team levels above, is the **provision of a link/liaison person** who would be assigned to the family from the time that the diagnosis is made or a concern is raised, until such time as the family is transitioned into appropriate services. This role is described by parents and professionals alike as providing direct support to families, linkage within and between teams and information for parents and professionals. It involves the parents having access to a single point of contact, a person to field queries and who will provide help with accessing services, entitlements and benefits. The team providing services to the family, particularly after discharge from the hospital setting and before transition into Early Services, may be dispersed through a number of locations and may have limited communication with one another. The role of the link person would be to co-ordinate services and communication between these professionals to ensure a family-centred and coherent approach. Where this service does exist, in a number of limited circumstances, the benefits reported in the focus groups were enormous.

At both the team and system level the focus group consultation process demonstrated the need for a family-centred approach to be adopted, with planning to ensure that the services are provided at the appropriate time and in the appropriate setting, by the appropriate team members.

Recommendations

Recommendations made by both professional and parent groups:

- A follow up appointment should be scheduled with the parents 24 to 48 hours after the initial diagnosis consultation.
- Providing a diagnosis of disability to a family is a priority task, and therefore calls for adequate time to be allocated, along with good planning.

- A liaison person should be assigned to the family to provide support and information from the time of diagnosis until such time as the family are transitioned into appropriate early intervention services. Some of the key aspects of the liaison person role include:
  - Providing a single point of contact for the family
  - Providing information to the family on entitlements and benefits, and services and supports available
  - Providing assistance with paperwork and applications for services, if appropriate
  - Ensuring that an 'Informing Families' checklist is completed and that all tasks relating to best practice in the disclosure process are carried out
  - Providing a central point of contact to support services and organisations for the supply of up to date information to the interdisciplinary team.
  - Providing a co-ordinating role within the interdisciplinary team, to ensure that information is shared and that coherent communication takes place with the family, including, if necessary, team conferences with the family.
  - The liaison person should have appropriate training to understand the needs of parents of children with disabilities
  - The liaison person was identified as potentially having a key role in disseminating best practice guidelines for informing families of their child's disability.
- Interdisciplinary team working and strong team communication are important. All team members who **may** come in contact with the family must have the same picture of what has already been told to the parents, so that families are not inadvertently told new information without adequate preparation. The team providing information to the parents should also liaise to ensure that no conflicting information is presented to the family.
- The initial period following discharge from neonatal care can be a difficult time for the family, and there is a particular need for continuity of care at this time. At a minimum, staff members from the discharging unit should stay in contact with the family by telephone during the first three to five days.
- Written information should be provided between professionals when referring on, detailing what parents have already been told, so that parents are not inadvertently given significant news without adequate preparation. Written information back to the referring party should also keep all parties up to date on the child's diagnosis; this needs to be sent to the parents, the GP (with parent's consent) and the referring party. Information should also be written on the child's chart in the hospital setting, to ensure all team members are kept up to date.
- Families should be offered the option of counselling following diagnosis where appropriate.
- A quality assurance and feedback mechanism should be put in place to evaluate practice in how families are informed.

Recommendations made by parent groups in particular:

- Families strongly indicated the need for family-centred services, which included the scheduling of appointments to minimise overnight stays for parents, the co-ordinated scheduling of appointments for families with more than one child receiving services, and the co-ordination of appointments with members of the interdisciplinary team to allow the minimum amount of separate visits possible.
- The child's history should be shared amongst all members of the team, to avoid parents having to repeatedly provide the same information to different professionals. It was also suggested that care should be taken at staff shift changeover times to alert staff members coming on to shifts that a family has been given the news of their child's disability.
- Families should be offered the option of private accommodation after being given the news in the maternity setting. Fathers should be facilitated to stay overnight in the maternity setting when the news of a diagnosis of disability has been given to the family.
- Parents should be offered the option of meeting other families whose children have similar diagnoses.

Recommendations made by professional focus groups in particular:

- There should be an increase in the amount of Developmental Paediatricians working in the system. Current resource deficits in this area can mean long waiting lists for parents and consequent delays in receiving diagnosis.
- The National Neonatal Transport System should be extended to provide cover on a 24-hour, 7-day basis.
- There should be an increase in the resources provided for psychological and educational assessments, particularly for children from the age of 4 upwards when diagnoses such as ADHD and educational deficits begin to emerge.
- Families should be referred to genetic counselling where appropriate.
- It is important to have a care-plan approach and to ensure that there is someone available on every shift that is capable of supporting parents who have a child diagnosed with a disability.
- Where specialist counselling services are made available, it is important that other staff members do not feel that they should no longer provide support and counselling, and that it is not all left to the specialist service. It is generally not possible to offer specialist services on a 24 hour basis and it is vital that all staff members recognise the importance of their own skills and input in counselling and supporting the family.

- Some professional groups identified the need to keep fathers involved and fully up to date in the communications loop, indicating that there can be a tendency to focus more on the needs of the mother. Instead a holistic, family approach should be taken, including taking into account the needs of siblings.

Summary: It is recommended that the diagnosis should be disclosed using an interdisciplinary team approach; continuity of care is vital – within and between settings, and very particularly in the initial period after discharge from hospital services; a liaison/link person should provide this continuity and co-ordinate the interdisciplinary team response as well as offering direct support to the family; a follow up appointment should be scheduled within 24-48 hours of the initial disclosure to clarify the information provided and answer questions.

4.2.6. Training, Education and Support for Professionals

Themes:

Focus groups with professionals revealed that the provision of training in communication skills generally, and training for the disclosure of disability in particular, is patchy and inconsistent, and for many disciplines is not present at all. Many of the more experienced professionals participating in the focus groups indicated that they had not received training in breaking difficult news or communications skills while going through formal training, and many had not received any since qualifying. For those participants still in training or more recently qualified there was an inconsistent level of training between and within disciplines, with some having received communications skills training, some having received 'breaking bad news' training in relation to palliative care, but very few having received training specific to the delivery of a diagnosis of disability.

> *"I don't remember getting a minute of training – I suspect the curriculum nowadays does cater for it but I don't actually know."* (Consultant Obstetrician)

> *"Teaching people how to break bad news needs to be mandatory... and it needs to come at the right time. ..Probably coming at the undergraduate level is not good because you don't do it every day. Even as an intern, in your first year qualified, you're not very good at anything for a while, and you probably are not in that situation. But certainly as you move up to your next couple of next levels it becomes more relevant. It's then that you should have a formalised approach on how to do this."* (Trainee Paediatricians)

For those who have been qualified for a long time, it may be assumed that this is an area in which they do not require training or updating of skills. In the absence of existing local or national guidelines, this can leave some professionals unsure of the elements that constitute good practice in disclosure:

> *"One of the reasons I came* [to this focus group]*, apart from sharing what little I have… its - how other people do it, because when you get to be a Consultant, you don't get to work with any other Consultants and you rarely get to work side by side."* (Consultant Obstetrician)

The benefits of implementing training in this area were illustrated by those who had received it:

> *"When I started my job that was the hardest part of my job, the Social Worker taught me that I can't take the pain away. I had to go away and learn how to do that...to learn to be support, when to say something, when not to say something and to perhaps to learn just to 'be there'."* (Midwife)

> *"I found that I have improved in delivery of news from parents' feedback. I think that is something that in some form I would like more of. You would be surprised by the things they say. Parents tell me they never forget the person who tells the news to them. If you come round in your cycle in jobs, two years later, they will immediately remember you as the person [who first told them]."* (Trainee Paediatrician)

Several groups recommended that feedback from parents was a key element of training required, as were counselling skills.

> *"Training should include counselling courses – we weren't 'born' to be a nurse or a midwife, we need to be trained. You have young girls who have never dealt with it, and without any support. It's not fair for people to be just landed in it. Like what do I do? What do I say?"* (Midwife)

In the absence of training professionals spoke of how they had learned by ‘trial and error’, with, of course, the attendant difficulties experienced by families who experienced the ‘errors’.

> *“And a problem is that if you are learning on the job you will make some mistakes before you get it right, as a learning skill, so the first people you told, it might not be as well managed as you do nowadays.”* (Consultant Paediatrician)

> *“I just felt with the junior team, the questions sometimes - they had a list of questions and wanted to get through it, they wanted to try out everything they had learned. For example, ‘Does anyone in your family have a big head; is anyone in your family a bit slow?’ When the consultant came around we were dealing with a whole different level of experience.”* (Parent)

> *“Our skills are developed through trail and error, instinct. One of our Social Workers did training on breaking news. We had an assessment for a child who was diagnosed with autism. The family broke down. The father left with the child. I felt as a Speech and Language Therapist I am not trained for this – I felt we had broken a marriage and ruined a life. Even the pointers the Social Worker gave us were very important.”* (Speech and Language Therapist)

All of the elements above point to a clear need for communications skills training for professionals, a recommendation which was supported across the board in the focus groups. The parents in particular strongly indicated that the training provided needs to be specifically related to the diagnosis of disability. This was further supported by the assertion of medical professionals that the communication skills required while working on a rotation such as oncology are very different from those required in diagnosing a disability.

> *“I used to assume that once you were good at telling news in one discipline it would follow on and you could do it in every discipline but it’s actually quite different from one to the other. There are different skills for each discipline so it’s an ongoing process that you have to learn. That has to be taken into account in any form of training for breaking news.”* (Trainee Paediatrician)

Parents expressed the view that there is a lack of disability awareness on the part of professionals in mainstream settings, and that better knowledge of what the disability means to the family and of the reality of disability in the wider sense would lead to the communication of more sensitive and more positive messages at disclosure.

It is important to acknowledge the emotional challenge and strain that can be felt by staff members who communicate the news or support families who have been told of their child’s disability. Without taking this impact into account it is likely that the implementation of best practice will be less effective, and that staff members will not receive adequate support.

Staff members giving the news of a child’s disability widely described the process as being challenging and emotionally difficult, with many indicating their own feelings of sadness and distress. Some of the professionals responsible for providing the diagnosis mentioned that it can be the toughest aspect of their job, while those supporting the family directly after the diagnosis indicated their feelings of empathy and their wish to show humanity and caring to the parents.

> “[You feel] *sad. You’re a mother yourself. You can be empathetic but you can’t understand. You can try, but I don’t have child with disability and you just can’t imagine know how they must be feeling. You just feel you can’t do anything for them. You do your best as a midwife and as a mother and as an individual. I feel that the only thing I can do is put my arms around her.”* (Midwife)

> *“It’s the toughest part of the job really. When you have experience you will prioritise this, because it’s a big priority, because it’s something that parents remember.”* (Consultant Paediatrician)

> *“I think the interviews I find can be very stressful because the parents are looking for hope – they are looking for some slight window of hope and they are trying to test you to see - to go over stuff with you, and it can be very difficult and you just have to try.”* (Speech and Language Therapist)

Particular sensitivity needs to be shown when professionals are themselves the parents of a child with a disability. Several participants in the focus groups who have children with disabilities spoke of feeling that extra responsibility for supporting families is placed on their shoulders, and others mentioned breaches of confidentiality when information regarding their children was made known within staff teams.

> *"I am a parent of a child with a disability and sometimes I am landed with it – sometimes I am asked to speak to parents as an expert but I am not…But I do find I'm not afraid to communicate with the family (sometimes) as a parent because I know what they will live with. Sometimes it's easier to concentrate on the fact that it's a child and not just a disability. Sometimes I mind and sometimes I don't. My friends are going in and feeling so awkward, and I feel sorry for them, but they always drag me in as if I'm Mrs know-it-all, and I'm not, I am just speaking from experience."* (Professional focus groups[12])

Staff members spoke of the impact that tiredness has on their ability to deal with the task of giving the news, and this was echoed by parents' experiences.

> *"It is more difficult when tired to put across the positive point of view."* (Trainee Obstetrician)

> *"When 'Tom' was transferred to the unit- when he was in the Special Care Baby Unit, this junior doctor came in, one morning early, and he had scrubs on and he had the stethoscope wound around his neck and he said 'I've been up all night' and I said 'Poor you'. So he put his back against the wall …and he slid down on his hunkers and he said 'You have a long road ahead of you' I didn't need to hear that… You need people to be positive around you."* (Parent)

For some staff members the pressures of potential litigation are a source of anxiety and stress, and can even have an impact on the diagnosis given.

> *"….and a fear of litigation is coming very much into it, all our practices for diagnosis; the way we word it, the way you say it, you know – just in case it doesn't work out the way you said it would at five years ago…at least that's in the voice at the back of my mind."* (Consultant Psychiatrist)

> *"The other side to that is the legal – If you get it wrong, and somebody has an autism treatment programme, and five years later it turns out the child is ok, they'll sue you for that, for putting them through that, that we broke up the marriage, maybe somebody committed suicide, you just don't know how people take it. . If you don't do the diagnosis of a child that turns out to have autism then they will sue you for that. I think psychologists are between a rock and a hard place. Everybody is, but it is putting pressure on people."* (Psychologist)

As well as training provision, professionals discussed other forms of support that should be provided to those communicating the news of a child's disability. Significant time was spent by during the professional focus groups discussing the topic of debriefing. The debate about the provision of debriefing, and the format that it should take is a complex one, with some disciplines indicating that further support in this area would be beneficial, due to the often emotional and stressful nature of providing a family with the news that their child has a disability, and supporting them directly afterwards. Suggestions such as a weekly visit to the unit from an independent Psychologist, which participants had experienced in other countries, and the use of reflective practice and team debriefing sessions to 'let off steam' after difficult periods, were welcomed by many groups. Conversely, other disciplines indicated their reluctance to use debriefing measures; some noting that it would seem 'soft' and that they were not encouraged to show emotions, while others doubted the efficacy of debriefing structures.

> *"Doctors aren't taken to be the touchy feely profession so we tend to not debrief and we're all very much like 'keep a stiff upper lip and you just told somebody something horrible but you're fine about it'. You don't go and talk to someone else about it, maybe your colleagues, a bit… or when you go home you might get upset and tell your friends about it but at the same time you're even thinking I shouldn't be doing this either; they don't understand or you don't want to burden them with it."* (Trainee Paediatrician)

> *"We have an extensive caseload and no supervision. I think if you are doing anything that involves counselling at any level then really you are obliged to have supervision. Even if you have a mentor to share what you have experienced and to know that you are doing the right thing. It's seen as 'you're not up for the job', if you go for support, so we need to change the culture. It's seen that you can't cope."* (Public Health Nurse)

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[12] Discipline withheld for reasons of confidentiality.

> *"For doctors it's just assumed 'ok, next baby' and it's just assumed that you are going to be ok about it, and I don't know why that is."* (Trainee Paediatrician)

All agreed that informal debriefing with colleagues is one effective avenue to relieve stress, and many noted the need for further exploration of this area.

Recommendations

Recommendations made by both professional and parent groups:

- Training provision in the skills needed to inform families of their child's disability should be increased and provided on a widespread basis.
- Training provided should include;
    - communication skills training,
    - counselling skills
    - cultural awareness and diversity training
    - input and feedback from parents
    - debriefing
    - reflective practice
- It was agreed that it is not appropriate for training to take place during the diagnosis consultation. The practical difficulties that this presents for training should be addressed, it was recommended, by role play training, and mentoring schemes where trainees receive a graduated introduction to the role on a team basis; beginning with involvement in the process through paper work and follow-up and moving on to the initial communication at a later stage when they have gained experience. Staff members who are not directly involved in providing care or support to the parents should not be brought into the diagnosis consultation.
- Parents should be informed and offered the choice of whether training takes place during the consultation.

Recommendations made by parent groups in particular:

- Disability awareness training in mainstream services should be increased, as many families indicated that they felt professionals would be better able to communicate in an empathetic and positive manner if they had more disability awareness training in general, and more understanding of what the diagnosis of disability means to families in particular.
- Parents focus groups indicated that key components of the training provided should include communications skills training and in particular the use of sensitive and appropriate language.
- It is important that professionals learn listening skills and how to respond appropriately to the various reactions that the news may cause, including shock.
- Parents indicated that they had experienced staff members communicating inappropriate displays of excitement on the identification of an unusual or rare diagnosis. It was recommended instead that when communicating with the family, care should be taken to focus on what the diagnosis will mean for the child and family; and that this should be emphasised in training courses.
- Parents in several groups indicated the need for professionals to understand the importance of support groups and services to the family, so that professionals will be aware of the necessity to provide information on these services to families.
- Where relevant, professionals should be provided with training in specific methods of communication skills such as sign language.
- Families indicated the need for broader disability awareness programmes for the general public.

Recommendations made by professional focus groups in particular:

- Professionals still currently receiving training indicated that the provision of communications skills training should take place at the appropriate time – the provision of this input should be concentrated when trainees begin working with service users, families and patients rather than during classroom-based education, to ensure its relevance and impact.
- Several participants in the professional focus groups raised the possibility that only those concerned with the issue of good communication would attend training, and that by default these may be the people who already have an awareness and concern for best practice in this area. It was suggested therefore that there should be a **mandatory** element to the training to ensure the guidelines reach those who have most need for improvement in their practice.

Summary: It is recommended that training and guidelines should be provided to support staff in the implementation of best practice including interdisciplinary training with role play, undergraduate and continuing professional education training in communication skills, mentoring schemes, and diversity and cultural awareness training.

4.2.7. Dissemination of the guidelines and best practice

Professionals were asked to make suggestions for effective strategies to ensure successful implementation of the guidelines within their own particular discipline, as well as how implementation should be co-ordinated in general. The key finding to emerge from this element of the focus groups is that one process of dissemination will not suit all groups, and that varying information needs and communication styles of different disciplines will need to be catered for in the implementation plan.

Suggestions for sustained and continuing implementation of agreed best practice included working through established communication networks in each of the professions; providing various information formats such as reports, checklists, laminated posters; along with ensuring that the guidelines form part of the induction process in each setting, and have clear ownership with members of staff responsible in each location. All of the above would not be sufficient for change to be effected, it was suggested, unless there was management endorsement for the implementation of the guidelines. Staff members indicated that without this support it would be very difficult for front line staff to encourage and adopt new practices.

Training at undergraduate level and for those already in practice is a central element of dissemination; professionals indicated that running information and training days would be a more effective way of ensuring practice is implemented then merely circulating the Guidelines.

Recommendations made by professional focus groups

- The Guidelines should be disseminated through training - aspects of which include communication skills, role playing, mentoring, debriefing, reflective practice etc, as mentioned above in section 6 of this chapter (Training, Education and Support for Professionals). Professionals in several groups recommended that the training should be mandatory, examinable, and should form part of Continuous Professional Development.
- It was suggested that the Guidelines should be provided to staff members working in general health care settings where disability may be diagnosed and not just specialists who work with disability on a daily basis.
- A network of staff members trained in the guidelines should be responsible for local dissemination and implementation of best practice. All key stakeholders should be involved in the planning for implementation within settings and across settings in each local area.
- An introduction to the guidelines should be included in induction programmes, to ensure sustainability through staff turnover.
- Checklists should be introduced, and along with this a nominated person should be appointed to ensure that all tasks have been completed by members of the multi-disciplinary team. The liaison person recommended in Section 5 (Organisational and Planning Requirements) of this chapter would ideally adopt this role.
- It was indicated that it is necessary for senior practitioners to 'buy in' to the implementation of the Guidelines before real changes will be seen on the ground. In addition it was recommended that the Guidelines should be 'fed down' via management to demonstrate organisational commitment to implementation.
- It is vital to provide an evidence base for any best practice to be implemented - without statistical evidence to support implementation; it will be very difficult to encourage change. Along with the evidence base it is important that the information disseminated includes direct quotations of parents' experience.
- The Guidelines should be disseminated through existing communication networks of professional bodies, training faculties and trade unions, and through email groupings of specialist professions. Medical students recommended that the Guidelines should be disseminated through the Medical Council.
- Adding an information session on the Guidelines to the agenda of existing information and training days will help to ensure that the maximum amount of relevant people are in attendance.
- Networking within and across disciplines and partnership working should be encouraged through the dissemination of the Guidelines.
- It was recommended that best practice in informing families of their child's disability should constitute part of hospital accreditation processes.
- Several disciplines within community and hospital settings recommended that the Guidelines should be produced on a laminated poster that could be displayed in the work setting, so that staff members have a quick reference guide and that having the information displayed in the environment will encourage familiarity. It was also mentioned that displaying the Guidelines would help support professionals who would like to point out shortcomings in practice to colleagues, since it would provide a clear indication of the expected standards of practice.

- Suggested formats for the production of the Guidelines included:
  - Flowchart
  - Poster
  - Leaflet
  - Booklet
  - Laminated sheet
  - 10-page report
  - Full evidence-based report
  - Induction pack
  - A binder which allows updates to be easily incorporated
  - Website
  - National TV and Media coverage

Summary: It is recommended that a multi-faceted, interdisciplinary approach to the implementation of best practice in informing families of their child's disability should be adopted. Implementation should take account of existing communication gaps and the differing information needs and communication styles of the various disciplines involved. The guidelines should be disseminated through training and mentoring; induction programmes; existing communication networks and through the use of tools such as checklists and laminated posters in the practice setting. Effective dissemination will require management support and buy-in from all key stakeholders.

The focus group with parents of children who are now older (between the ages of 11 and 33 at the time of participation) revealed that the fundamental concerns of parents at the time of disclosure; in particular for appropriate information and sensitive, empathetic communication; have remained unchanged over the past thirty years and were as pertinent three decades ago as they are today. The parents who participated in this group still vividly remembered being given their child's diagnosis, including the location, the people present and the manner of the disclosure. Some aspects of practice have changed significantly since that time; in particular there is a greater inclusion of fathers in the maternity setting; parents in this group who had received their child's diagnosis in the maternity hospital recalled that the father was not permitted to attend the birth, and was allowed to visit only briefly. Although fathers are now welcomed at the birth, parents today still express the often unmet need for partners to be allowed to stay overnight when adverse news has been given. The need for positive messages was also a theme common in discussing recent disclosures and those which took place some time ago. Service provision for children has developed in the past three decades, a point which the parents of older children noted as a positive message for parents receiving their diagnosis today; and they also indicated the importance of linking parents with other families of children with similar disabilities.

4.3 Summary

The focus group consultation process revealed a complex range of circumstances and a wide variety of personnel involved in communicating to families in Ireland the news of their child's disability. Diagnosis can be made at the ante-natal stage, at birth, or in an evolving situation that can take weeks, months or even several years; leading to a myriad of disciplines providing information and support across hospital, disability and community services.

Staff members and families alike indicated that while there is some good practice in place it is not consistent across individual practitioners or across settings. This is causing many parents to experience a less than satisfactory service, while the lack of resources and support for staff often leaves them without adequate physical environments, training and guidance in this sensitive task. Parents have spoken of aspects of current practice causing additional distress at what can already be a very difficult time, and professionals have clearly indicated that the process is an emotional and challenging one and that they have a requirement for support in this area.

The issues which both parent and professional groups most consistently identified as requiring the most urgent need for improvements were:

- Issues with the style and method of communication
- A lack of continuity of care
- Inconsistent provision of comprehensive, accurate and up to date information
- Inappropriate physical environments in which the news is delivered leading to a lack of privacy for parents, and to staff members having to do their best to communicate sensitively in clinical settings not designed or adapted for private or sensitive communication
- Insufficient training, support and guidance for professionals

The results detailed above provide clear recommendations for best practice in an Irish context, developed by parents living in Ireland and professionals working in an Irish context. The key points of recommended practice are summarised below.

- **Physical and Social Setting;** a senior staff member should provide the news in a private, comfortable place, with both parents present, and a supporting member of staff should remain/spend time with the family; the diagnosis should not be rushed, and in the maternity setting it is important to ensure that parents must have seen and if possible held their baby before the news is given.
- **Communication;** respect and empathy should be shown to the family; honest and straightforward communication and simple language should be used; all medical terminology should be explained; the child should be referred by name and not diagnosis; positive messages and hope should be given with the news. Positive messages can include focusing on the individual baby or child and not solely on the disability; and indicating the support and assistance that will be provided to the family.
- **Information Provision and Support:** the family should be kept up to date at all times; there should be co-ordinated availability of accurate, up to date information for parents and professionals; with written material provided on benefits and entitlements, support groups, and early intervention services; parent's individual needs regarding how much information should be presented and at what pace, should be taken into account when communicating.
- **Culture and Language:** there should be widespread provision of appropriate interpretation and translation services; the availability of materials in the required languages, which are culturally appropriate; and diversity and disability awareness training which takes account of a new cultural era of diversity in Ireland.
- **Organisation and Planning Requirements:** an interdisciplinary team approach is necessary; continuity of care is vital within and between settings, and very particularly in the initial period after discharge from hospital services; a liaison/link person should provide this continuity and co-ordinate the interdisciplinary team response as well as offering direct support to the family; a follow up appointment should be scheduled within 24-48 hours of the initial disclosure to clarify the information provided and answer questions.
- **Training, Education and Support for Professionals:** training and guidelines should be provided to support staff in the implementation of best practice including interdisciplinary training with role play, undergraduate and continuing professional education training in communication skills, mentoring schemes, and diversity and cultural awareness training.
- **Dissemination:** management buy-in will be required for implementation of the guidelines; various formats of information should be provided including leaflets, booklets, checklists and laminated sheets containing the guidelines; displayed in community and hospital service settings; training should be provided as detailed above; the Guidelines should be included in accreditation schemes; and there should be direct communication of Guidelines from professional bodies, trade unions and academic faculties.

"I think hope is an ingredient that isn't quantifiable, but there's that balance between giving a positive message but yet not minimising the seriousness of a condition… and not minimising the future but leaving that space that they can hope."

Psychologist, Informing Families focus groups

CHAPTER 5
NATIONAL QUESTIONNAIRE SURVEY OF PARENTS AND PROFESSIONALS

Evidence from focus groups undertaken with parents as part of the Informing Families Project suggested that practice was, in some cases, causing additional distress for parents during the already stressful experience of learning of their child's disability. Focus groups with professionals indicated that many staff members found the process of delivering a diagnosis of disability or supporting a family who had been given this news a challenging and emotional experience. Professionals stated that more training, education and support is required and that systemic issues such as resource availability and a lack of appropriate private environments are hindering the implementation of best practice. In order to effect changes in national practice, and given the lack of existing Irish research it was deemed necessary to conduct further research to explore these issues. In order to gather systematic statistical data it was decided to undertake a National Survey Questionnaire of parents and professionals further exploring the above qualitative evidence through quantitative research.

5.1 Questionnaire Survey Methodology

Aim:

The aim of the National Questionnaire Survey was to provide a sound statistical basis for the development of guidelines, training and education for informing families of their child's disability. In so doing the ultimate goal is to ensure improved outcomes for families through the implementation of best practice, and to provide improved support, guidance, education and training for professionals who inform and support families at the time of diagnosis.

Objectives:

The objectives of the National Questionnaire Survey were:

- To identify current practice in how families from around the country are told that their child has a disability and;
- To consider best practice recommendations which emerged from the international literature and from the findings of the focus groups

This was done through a postal questionnaire survey to parents of children with physical, sensory and intellectual disabilities and autistic spectrum disorders and to professionals involved in informing or supporting families receiving a diagnosis.

Research questions:

In order to provide quantitative data to support or refute the hypothesis that there is an absence of consistent best practice in place in Ireland and to explore the recommendations for improved practice in the future, the research questions informing the questionnaire design, in keeping with the research questions of the overall Informing Families study, were as follows:

- How are families in Ireland today informed of their child's disability?
- What is currently working well in how families are informed in Ireland?
- What areas of the current process do families feel need improvement?
- What areas of the current process do professionals feel need improvement?
- What do families and professionals recommend should be included in future best practice for disclosing disability?
- What are the support and training needs of professionals involved in informing families?
- Rating of suggested best practice recommendations from the literature and the focus group consultation.

Research Instrument used

As previously discussed, the Right From the Start group was a team set up in the UK in 1994 with the specific goal of improving practice when families are told of their child's additional needs. The survey questionnaire circulated to families through the *Informing Families Project* used as its starting point a questionnaire developed by the *Right from the Start* group to gather data on how families experience the disclosure of disability in the UK.[13] This was then adapted for the Irish context, and additional questions were added to allow comparison with data collected in a number of important studies from the literature review (eg. Quine & Rutter, 1994; Sloper & Turner, 1993).

The majority of the adapted questionnaire for parents contained closed questions, with 8 open questions, and a rating page which allowed participants to assess a list of 46 best practice recommendations collated from the international literature and the initial results of the *Informing Families* parent and professional focus groups. Participants were asked whether they agreed that each recommendation should be implemented, by choosing from a 5-point Likert scale that ranged from 'Strongly Agree' to 'Strongly Disagree'. The questionnaire contained sixteen pages, with an option at the end for participants to attach further pages if they wished to provide additional information.

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[13] Permission was obtained from the Right From the Start group.

The survey questionnaire for professionals mirrored the questions in the Parent Questionnaire in order to provide a comparison of experience. It contained additional questions to ascertain the support and training needs identified by professionals.

Parent Questionnaire - Ethical Approval

At each stage of the design of the questionnaire, the approval of the Informing Families Steering Committee was secured. Ethical approval for the Questionnaire Survey was secured from St. Michael's House Research Ethics Committee, and from the Provincial Ethics Committee of St. John of God Hospitaller Services.

Piloting

Four pilot studies of the Informing Families Questionnaire for Parents were carried out:

a) Intellectual Disability - Group feedback session on questionnaire with families in a Dublin-based service provider. (The families first completed the questionnaire on an individual basis).
b) Intellectual Disability – Postal pilot of questionnaire through ten families receiving services in a regional agency.
c) Physical Disability – Postal pilot of questionnaire through ten families receiving services with a physical disability service provider.
d) Sensory Disability – Postal pilot of questionnaire through ten families receiving services from a sensory disability service provider.

Based on feedback from these pilot studies, changes were made in the Announcement Letter (which preceded the questionnaire by one week), the Information Letter (which accompanied the questionnaire) and the Questionnaire itself.[14] Feedback related largely to the simplification, spacing, or clarification of question text. No families indicated that the questionnaire was inappropriate or that any of the questions caused offence. Many indicated that filling out the questionnaire was an emotional process but that it was worthwhile if change can be effected as a result. The questionnaire was typeset and professionally printed to ensure ease of reading.

One family made telephone contact with their nominated service provider to request a second questionnaire so that both the mother and father could capture their individual experiences. As a result a note was added to the Information Letter indicating that the questionnaire could be photocopied, additional pages added by the families, or that they could make contact directly with the Project Co-ordinator to request a second copy, should they wish.

Selection of Participants - Parent Questionnaire

The sampling frame for the Parent Questionnaire was broken into two separate populations; children with intellectual disabilities, and children with physical and sensory disabilities. It was necessary to use two separate means in order to access the most representative samples available nationally in both of these areas.

Parent Questionnaire - Intellectual Disability

The National Intellectual Disability Database (NIDD) is a set of information that outlines the specialised health services currently used or needed by people with intellectual disability in the Republic of Ireland. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. The NIDD was established in 1995 and has in excess of 25,000 registrations. The database is managed by the Health Research Board (HRB) on behalf of the Department of Health and Children. (HRB, 2007 - website www.hrb.ie)

The NIDD was used by the Informing Families Project as the sampling frame for the survey of parents of children with intellectual disabilities. The NIDD, whilst acknowledging that all children are not registered, is currently the most comprehensive source of data regarding population figures for people with intellectual disability in Ireland. With the approval of the Steering Committee of the NIDD, the HRB provided the researchers with a break-down of the number of children between the ages of three and six who were registered with each returning agency on the NIDD database in 2005. In the vast majority of cases, the returning agency to the NIDD is the main service provider for the child. Using a breakdown of the number of children with each returning agency on the database, therefore, it was possible to determine the correct national distribution of the questionnaire throughout intellectual disability service providers (including voluntary bodies and HSE services).

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[14] Final text of Announcement Letter and Information Letter can be seen in Appendix IV, page 167. For further details on the Questionnaire text contact the National Federation of Voluntary Bodies (www.fedvol.ie)

It was decided to survey 40% of children receiving services from each service provider in order to aim to gather data representative of the national population. This calculation was based on the return rates of the pilot questionnaire. No names or PIN numbers could be provided to the researchers for confidentiality reasons, so the break-down of the number of children registered by each agency was indicative of the number of children to be surveyed in each service; the names of which were then chosen using a random alphabetical system. It was agreed to survey only those agencies which provided services to more than 1% of children aged 3-6 nationally, for pragmatic reasons, since there were a large number of very small agencies providing less than 1% of service, and to include them would involve significant administrative support, without providing significant additional information.

The population figures were broken down as follows:
National Intellectual Disability Database 2005 Population Figures:
- Children aged 3-6 years = **1189 children** (excludes children receiving no service).
- Number of agencies providing services to >1% of 3-6 years population = **25 agencies.**
- Sum of 40% of the caseload of children (aged 3-6) of the above 25 agencies = **325 families.**[15]

A point to note is that the HRB indicated in correspondence to the Informing Families Project that the number of young children with intellectual disability is likely to be underestimated by NIDD registrations. In compiling the database, attempts are made to discover every child with intellectual disability at the earliest possible age but respect is also given to situations where parents are reluctant to allow information about their young child to be recorded on the NIDD.

Once the sample size for each agency was determined, an alphabetical list of children meeting the criteria to be included in the survey was compiled by each participating service provider. The following criteria were used to determine eligibility:
- The child was aged between three and six years at the time of dissemination (July 2006). Children were required to be aged three years of age by January 2006.
- The child's parent(s) or guardian(s) had received their child's diagnosis in the Republic of Ireland.
- The returns to the National Intellectual Disability Database for each child on the list were made by the agency disseminating the questionnaire (to avoid any double counting).
- The child was receiving services from the disseminating service provider for at least one year. (All children had to be with the service since at least 1 July 2005).
- Children who were no longer receiving any support/regular contact from Early Services (e.g. if they had moved on to mainstream school and no longer access support from the service provider) were removed to avoid contacting parents who did not have a clearly identified source of support.

Following the creation of the alphabetical list of children meeting the selection criteria, the final sample for each agency was determined using the steps below:
a. Each agency was made aware of the number of children required to be included from their service.
b. Using the final alphabetical list the contact person was asked to pick every third name, starting with the first on the list, and continuing with the fourth, the seventh, and so on until the end of the alphabetical list was reached.
c. When the end of the alphabetical list was reached the contact person returned to the remaining names from the top down to complete the required number for the sample.

Distribution

Ethical approval was secured to send the parents the questionnaire via a support worker (e.g. social worker, key worker) in the organisation providing services to their child, who would therefore be known to the parents. The support worker was contacted by the Informing Families Project Co-ordinator, to liaise on the distribution of the questionnaire. As with the UK survey, the questionnaire was disseminated by post.

The following procedure was followed by each agency:
- An announcement letter was sent to each of the families in the sample on 5th July 2006. The announcement letter indicated to parents that the questionnaire would be sent to them shortly. It detailed the origins of the project; its aims and objectives; and assured families that no personal information had been or would be passed on to any third party. It stressed that

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[15] The contact person in the smallest of the agencies which had agreed to participate (representing 4 families) was on annual leave at the time of distribution and this agency did not therefore participate.

participation was voluntary, anonymous and confidential and that the questionnaire would arrive in the following days. It indicated that those wishing to participate should return the questionnaire to the Informing Families Project Co-ordinator using the stamped addressed envelope supplied, and that those not wishing to participate should simply dispose of the questionnaire.

- One week later on 12 July 2006 the Information Letter and the Questionnaire were circulated to the same families, along with a stamped addressed envelope. The information letter reiterated the details from the announcement letter and advised families of the closing date of 28th July 2006. Both the announcement letter and the information letter provided details of the specific support/contact person who had been identified and was available to parents should they require it for any reason as a result of receiving the questionnaire. Both letters also invited the parents to make contact with the Informing Families Project Co-ordinator, should they have any questions or should they wish to access support from an alternative source. For ethical reasons it was decided that it would not be appropriate to issue a reminder letter.[16]

The questionnaire was returned directly to the Project Co-ordinator, rather than to the service provider so that no-one providing services to the family would be aware of whether the family responded or not, or any details of their response. To further safeguard the anonymity of the participants, and given that the respondents were fully informed of the purpose of the questionnaire, no consent form was used, so that no names were provided to the Project Co-ordinator. The front page of the questionnaire indicated that by returning the questionnaire, the respondent was consenting to participation. The only case in which the identity of families responding would be known to the service provider or Project Co-ordinator, was if the family chose to make use of the support contact offered – in order to access translation/interpretation/literacy support, or to receive support if filling out the questionnaire caused distress that the family wished to discuss.

Parent Questionnaire - Physical and Sensory Disability:

It was originally intended to use the database corresponding to the NIDD for physical and sensory disabilities in Ireland; the National Physical and Sensory Disability Database (NPSDD); as the sampling frame for the survey of parents of children with physical and sensory disabilities. However, the questionnaire was instead circulated to parents of children with physical and sensory disabilities directly by selected physical and sensory disability service providers, rather than using the returning agencies noted on the NPSDD as was originally planned. The reason for the difference from the NIDD approach is that whilst the returning agency for children listed on the NIDD is almost always the main service provider, the same case does not apply to children on the Physical and Sensory Disability Database. Within the NPSDD, there is limited involvement of service providers in the collection of data for this database. Hence the HSE Local Health Officers are primarily the agency returning the data, even though they may have a limited or no role in actual service provision to the child. The Health Research Board (HRB) has explained that people with physical or sensory disabilities tend to be involved with a myriad of service providers, (unlike intellectual disability services where people tend to receive all of their services through one provider) and identifying a primary service provider out of these would be a subjective judgement.

For ethical reasons, given the sensitivity of the topic, it was clear that it would be more appropriate for families to receive the questionnaire from a contact with whom they are familiar and to whom they could turn to for support if required, and it was on this basis that dissemination was carried out directly through the service providers. In addition, it was noted that the return rate to the 2005 NPSDD was just 59.4% of the estimated national target coverage for this database (Doyle et al, 2006) and the NPSDD was therefore not seen as sufficiently representative of the national population to be viable for the sampling frame in this instance. (The corresponding estimation of coverage of the NIDD for the same year was 95%).[17]

Four national service providers were chosen for the distribution of the questionnaire in the physical and sensory areas. Together, these sources provide the widest national populations of children in the age group of three to six years with physical and sensory disabilities, who have accessible and identifiable sources of support to satisfy the ethical considerations of the project.

- Enable Ireland (Physical Disability)
- Central Remedial Clinic (Physical Disability)
- National Council for the Blind of Ireland (Sensory Disability)
- Visiting Teachers for the Deaf, accessed via the Department of Education and Science (Sensory Disability)

Geographical areas were split between Enable Ireland and the Central Remedial Clinic, in order to ensure that no double counting took place. In order to determine the number of families that should be surveyed by each agency, the full population figures for each were requested from the service providers. As per the NIDD process, each national agency were then requested

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[16] Full text of Announcement and Information Letter available in Appendix IV, page 167

[17] Private correspondence from HRB

to survey 40% of their caseload within the age-group, again excluding local services around the country which provide less than 1% of national service to children with physical and sensory disabilities between the ages of three and six, as per the intellectual disability approach. The total number of families meeting these criteria was 263.

Once the sample sizes had been determined, the same process was followed as per the intellectual disability dissemination, using the same alphabetical system and documentation. The survey was posted in September 2006. The questionnaires were marked before being disseminated in order to allow the returns to be distinguished from the intellectual disability questionnaires for the final analysis. Taking the total sample size from the families of children with intellectual disabilities (321) plus the sample from the families of children with physical and sensory disabilities (263) the full sample size came to 584 families.

Summary of Ethical Considerations

The following safeguards were implemented into the research design of the questionnaire, to satisfy ethical concerns:

- It was decided to survey parents of children between the ages of three and six rather than nought and six, in order to minimise the chance of contacting parents for whom the disclosure event was very recent. (It is acknowledged that for parents of children with evolving diagnosis, diagnosis may still be recent or unconfirmed at age three).
- The service providers circulating the questionnaire were requested to only include parents of children who had been with their service for over one year. This was intended to further safeguard against contacting parents with very recent disclosure experiences. Any family whose child had moved on entirely from early services (e.g. into mainstream school) and therefore no longer accessed support from the agency were removed from the sample.
- Some open-ended questions used within the UK version of the 'Right from the Start' questionnaire were eliminated, as it was felt that these questions could be a very emotional trigger for parents, and that asking these questions in a questionnaire administered by post could cause ethical difficulties.
- The respondents to the parent questionnaire were made aware that support was available to them should they require it for any reason following completion of the questionnaire. A support contact known to the respondents was nominated in a covering letter provided with the questionnaire.
- Respondents were made aware that they had the opportunity to contact the organisation providing services (in the case of parents) or the Project Co-ordinator (in the case of the professionals) if they would like to provide additional information or explore any issues raised by the questionnaire in greater detail.
- The international literature was examined and precedence for a postal questionnaire to parents on this topic was established *(Abramsky, 2001, Brogan & Knussen, 2003).*
- All respondents to the questionnaire, both professional and parent, were assured that their participation was voluntary.
- All respondents to the questionnaire, both professional and parent, were assured that their responses remain confidential and that no personally identifiable information will be used.
- Children receiving no services were excluded from the study, as it was thought that their parents may have wished not to engage with service providers at this time, and in keeping with the 'no harm' ethical principle, it would not be appropriate to make contact with these families.

Questionnaire for Professionals:

A questionnaire corresponding to the parent survey was circulated in late 2006 and early 2007, to 1588 professionals in 27 disciplines who were identified through the Parent Questionnaire as disclosing the diagnosis of a child's disability, or supporting families immediately after the diagnosis is given.

Research Instrument used

The questions in the Professional Questionnaire mirrored those asked in the Parent Questionnaire, and asked professionals to reflect on the last occasion on which they had communicated a diagnosis of a child's disability to a family, or supported a family who had just received such a diagnosis. Additional questions were added to identify any existing guidelines and to explore the training and support needs of professionals when disclosing the news of a child's disability. Respondents were also asked to comment on how the Guidelines could be most effectively disseminated to the relevant professionals. The Professional Questionnaire was approved by the Informing Families Steering Committee and the St. Michael's House Research Ethics Committee.

Piloting

Four pilot studies of the Informing Families Questionnaire for Professionals were carried out:

a) Multidisciplinary Group – the individuals who took part in the multidisciplinary focus group during the qualitative phase of the project were invited to fill out the pilot questionnaire at the end of the session, as this provided access to a wide range of professional disciplines.

b) Hospital – Postal pilot of questionnaire to thirteen staff members, chosen from disciplines identified through the Parent Questionnaire as being involved in the disclosure process.

c) HSE Community Services – Pilot distributed by the HSE via email to members of 11 disciplines identified through the Parent Questionnaire as being involved in the disclosure process.

d) Disability Service Provider – Postal pilot of a rural based disability service provider; questionnaire circulated to each member of the Early Intervention Team.

In total 16 responses were received. It is not possible to determine the exact response rate as some of the distributing contacts did not wish to disclose the precise number of questionnaires sent out. The main issue raised in feedback from the pilot questionnaires was the length of the questionnaire, with some respondents feeling that it was too long. However, in order to remain fully comparable with the Parent Questionnaire it was decided to maintain the structure of mirroring the parent survey. The majority of respondents indicated that the questions asked were appropriate and relevant and did not recommend the removal of any specific questions. Adjustments were made to the language of a number of questions to ensure readability and to clarify meaning based on responses received. Respondents variously noted that the questionnaire took between 15 minutes and 1 hour to complete.

Selection of Professional Participants

In order to determine the sampling frame for distribution of the Professional Questionnaire, analysis was undertaken on the responses to the Parent Questionnaire. In the Parent Questionnaire the following question was asked:

> *"Who was involved in telling you about your child's disability?"*
> (Question 7, Informing Families Parent Questionnaire)

It was noted that the news often came over a few stages and parents were therefore invited to list those who had told them at various different times, if applicable (four blank spaces provided). The responses to all categories were added together and provided a list that included 85 separately named disciplines. There were clearly identifiable groups that could be categorised together within this listing (e.g. 'Gynaecologist', 'Obstetrician', 'Obstetrician/Gynaecologist' and 'Consultant Obstetrician/Gynaecologist' were all collapsed into 'Obstetrician/Gynaecologist'.) The list of 85 disciplines collapsed into 36 meaningful categories as indicated in Table 5.1. To the 36 groups identified by the parents one was added; Ultra-sonographers. It had emerged in the Focus Group consultation that those carrying out the ultrasound scan at the ante-natal stage are very often the individuals to first communicate a concern to parents in a prenatal setting. The reason that they may not have been named in the Parent Questionnaire may be due to the fact that many Ultra-sonographers are midwives or radiographers by discipline, and may be known to the parents in that way. Additionally, to mirror the focus group process, the category of 'trainee doctors', as identified 9 times by parents but not fully broken down into disciplines, was divided into Trainee Obstetrician/Gynaecologists (SpR level) and Trainee Paediatricians (SpR level). In a number of cases where disciplines were mentioned only once (e.g. Dermatologist, Oncologist) specialist medical advice was sought to see if it would be typical practice for this discipline to be involved in the diagnosis disability, and where this was not the case the disciplines were not surveyed.

Due to the large number of disciplines (and the large numbers present in certain disciplines such as GP's (at least 2,500)) it was not possible within the scope of the project to choose a statistically representative sample of each discipline. Two sample sizes were therefore chosen in order to reflect the relative involvement of the various disciplines, with those disciplines who were listed as being involved more often receiving a larger number of questionnaires. For all disciplines that received more than nine mentions in the Parent Questionnaires, 120 questionnaires were sent. Disciplines that received fewer mentions received 50 Questionnaires. For those whose disciplines contain less than 50 members, all members were surveyed. In the case of GP's due to the numbers present in the discipline 120 members were surveyed even though the discipline was mentioned only four times.

In each case serious consideration was given to the most representative manner in which to choose the sample. Table 3 illustrates the channels of distribution chosen. In the case of the disciplines listed under 'Irish Medical Directory', a sample was generated from all members listed in the 2006 Irish Medical Directory, as this was deemed the most complete available listing of members of those disciplines. An alphabetical system identical to that used in the Parent Questionnaire was employed in this case. For other disciplines it was possible to identify a sample through the membership of national organisations, professional bodies or trade unions. Many of these organisations do not have 100% coverage of all members of a discipline, but were chosen as the most complete and accessible national listing of the discipline. For Area Medical Officers, the Principal Area Medical Officers in the various regions provided the sample, whilst for Social Work and Ultrasonographers it was necessary to make individual phone calls to hospitals, disability organisations and community services in order to request participants, due to an absence of a national database for those disciplines.

Distribution

The Professional Questionnaire was accompanied by an 'Information Letter' and a reminder was sent three weeks after dissemination. Distribution of the Professional Questionnaire was a complex process due to the large number of disciplines and the need for differing processes to be followed with each. For a number of the participating organisations, the Questionnaire and reminder letters were posted directly by the contact person, as it was against organisation policy to release names and work addresses to researchers. For other organisations, a list of names and addresses was provided to the researcher, who then posted the Questionnaire. For those accessed through the Irish Medical Directory, the Questionnaire was posted by the researcher. As mentioned above, in the case of various disciplines, such as Social Work and Ultrasonographers, there is no existing national database of members, and therefore direct contacts were made in order to access names and addresses.

Consent

In order to ensure confidentiality and anonymity, it was agreed that it would not be appropriate to circulate a consent form requiring a signature. This approach was approved by the St. Michael's House Research Ethics Committee. Therefore as all respondents (parent and professional) needed to proactively send the questionnaire back to the Informing Families Project Co-ordinator in order to participate, it was deemed that free choice remained with the individual to choose to participate or not as they wished.

Treatment of data for parent and professional questionnaires:

- The survey questionnaire was administered by post, and returned to the National Federation of Voluntary Bodies Headquarters.
- The paper copies of the returned questionnaire are held in a secure locked cabinet.
- The data from the completed questionnaires was entered in a computer-held database.
- The software package Statistical Package for the Social Sciences (SPSS) was used in analysing the data.
- When the full Informing Families project work is completed the raw data will be destroyed. This will take place no later than 10 years from the date of publication, in line with the Data Protection Act.
- No personally identifiable information is stored on computer.

Table 5.1 - Distribution of Informing Families Questionnaire to Professionals

Discipline	n=Times listed in Parent Questionnaires	Sample Size	Distribution
Area Medical Officer	1	50	Via Principal AMO's
Audiologist	8	50	Audiological Society of Ireland
Cardiologist	3	50	Irish Medical Directory
Consultant (non-specific)	14	0	Not applicable
Community Nurse (RNID)	1	50	An Bord Altranais
Doctor (non-specific)	4	0	Not applicable
Dermatologist	1	0	Not applicable
Endocrinologist	1	33	Irish Medical Directory
ENT Consultant	2	50	Irish Medical Directory
Eye Specialist (Ophthalmologists & Optometrists)	6	50	Irish Medical Directory
Genetic Counsellor	7	7	Irish Medical Directory
Geneticist		4	Irish Medical Directory
GP	4	120	Irish College of General Practitioners
Liaison Person	3	0	(Not discipline-specific)
Midwife	9	120	Irish Nurses Organisation
Neonatologist	3	17	Irish Medical Directory
Neurologist	25	37	Irish Medical Directory
Nurse (Neonatal)	12	26	Irish Nurses Organisation
Nurse (Paediatric)		120	Irish Nurses Organisation
Obstetrician/Gynaecologist	11	120	Irish Medical Directory
Occupational Therapist	4	50	Association of Occupational Therapists of Ireland
Oncologist	1	0	Not applicable
Paediatrician	124	112	Irish Medical Directory
Parent	3	0	Not applicable
Physiotherapist	6	50	Irish Society of Chartered Physiotherapists
Psychiatrist	4	50	Irish Medical Directory
Psychologist	33	120	Psychological Society of Ireland
Public Health Nurse	4	50	An Bord Altranais
Radiologist	1	50	Irish Medical Directory
Social Worker	4	50	Individually contacted
Speech and Language Therapist	7	50	Irish Association of Speech and Language Therapists
Surgeon (non-specific)	3	0	Not applicable
Trainee Obstetrician/Gynaecologist	8	37	Royal College of Physicians Ireland
Trainee Paediatrician		48	Royal College of Physicians Ireland
Ultrasonographer	0	45	Individually contacted by telephoning all maternity units

5.2 Parent Questionnaire Survey Results

Response rate

584 questionnaires were sent to families of children with disabilities between the ages of three and six. 185 questionnaires (31.68%) were returned. As one respondent indicated that their child's diagnosis was received outside the Republic of Ireland the remaining 184 questionnaires were analysed, which gives a final response rate of 31.5%. It is not possible to comment on the demographics of non-respondents, as no specific information about the families who were sent the questionnaire was made available to the researchers due to ethical considerations.

Notes on data reporting

Throughout the following report (for both parent and professional questionnaires) identifiable information such as names, rare syndromes or recognisable locations have been changed or sorted into more general categories to protect anonymity. For the parent section of the report the percent rate reported for the answers to each of the questions is expressed as a percentage of all 184 cases rather than the percentage of only those who responded to the particular question, unless stated otherwise. For ease of reading the term 'parent' is used in this report to indicate all respondents including adoptive parents, foster parents, and grandparents. Tables are presented with totals at the end, except where multiple responses were possible, and the data within tables is presented in alphabetical order. Where the analysis of data in the report required it, specialist medical and/or statistical advice was secured.

5.2.1 - Child and Family Characteristics

Relationship of respondents to child

As can be seen in the table below, the majority of questionnaires were filled out by mothers. When taking into account foster mothers and adoptive mothers the percentage comes to 89.7%. As 20 mothers and fathers completed the questionnaire together and one grandmother and mother completed it together, there were more responses recorded to the question of 'relationship to child' than the total number of questionnaires received. Four families did not specify the relationship between the respondent and the child.

Table 5.2 - Relationship of respondent to child

Relationship to child	n=	Percentage
Mother	163	88.6%
Father	35	19.0%
Adoptive Mother	1	0.5%
Foster Mother	1	0.5%
Grandmother	1	0.5%
Missing	4	2.2%
Total	**205**	

Region

Parents were asked to indicate the province in which they had been living when they received their child's diagnosis (to take account of the fact that families may have moved since their diagnosis was received). The largest group of respondents (exactly half) came from the Leinster region, in keeping with the location of the largest population of the country, which is centred around Dublin. The smallest number of respondents came from Ulster.

Table 5.3 - Region in which respondent was living when diagnosis received

Region	n=	Percentage
Connaught	25	13.6%
Leinster	92	50.0%
Munster	49	26.6%
Ulster	6	3.3%
Missing	12	6.5%
Total	**184**	**100%**

Respondent’s first language.

The majority of questionnaires were filled out by respondents whose first language is English. A range of other languages was also reported, with the second most commonly reported language being Irish, as detailed in Table 5.4

Table 5.4 - First language of parents

Language	n=	Percentage
English	169	91.8%
French	1	0.5%
Irish	6	3.3%
Latvian	1	0.5%
Romanian	1	0.5%
Russian	1	0.5%
Ukrainian	1	0.5%
Missing	4	2.2%
Total	**184**	**100%**

Child’s Diagnosis

Parents in 167 cases (90.8%) had received a diagnosis for their child. Eight families (4.3%) indicated that they had not yet received a diagnosis. The responses of these families are included and analysed because a child may clearly have a disability, (and hence their parents were sent the questionnaire by the early services teams) but it may not yet have been possible to identify the specific diagnosis. In nine cases no response was given to the question of whether a diagnosis had been given.

Table 5.5 below indicates the types of disability that were present. Respondents in 43 cases specified that their child’s disability fell into more than one of the categories below, and therefore there are more than 184 responses to this question. Parents indicated that their children had diagnoses of disabilities from across the spectrum of physical, sensory, intellectual and multiple disabilities and autistic spectrum disorders. The most commonly reported disability type was ‘Learning or intellectual disability’, which was a feature of the diagnosis of half of the children.

Table 5.5 - Type of disability present

Type of disability present	n=	Percentage
Physical disability	72	39.1%
Sensory disability	38	20.7%
Learning or intellectual disability	92	50.0%
Multiple disabilities	22	12.0%
Autistic Spectrum	15	8.2%
Missing	14	7.6%

Severity of disability

Parents were asked if any terms indicating the likely severity of the child’s disability had been used at the time of diagnosis. Again, for some respondents more than one of the terms noted in Table 5.6 had been used and therefore the total count for this question exceeds the total number of respondents. The most frequently noted level of severity, which related to approximately one quarter of disabilities reported, was mild.

Table 5.6 - Severity of disability

Severity	n=	Percentage
Mild	47	25.5%
Moderate	36	19.6%
Severe	34	18.5%
Profound	14	7.6%
None of these	60	32.6%
Other	20	10.9%
Missing	13	7.1%

Syndrome or disability name

133 families indicated the specific syndrome name or disability with which their child had been diagnosed, and these are listed below in Table 5.7, which was categorised in conjunction with a Consultant Paediatrician and a Consultant Obstetrician/Gynaecologist. Fourteen respondents noted that they had not been given a name for their child's disability. As indicated earlier, there was a spread of disabilities reported from across physical, intellectual and sensory disabilities, and autistic spectrum disorders. The most commonly reported diagnoses were Down Syndrome (which was the diagnosis for just over a quarter of respondents), Cerebral Palsy, Chromosomal Disorders other than Down Syndrome, Musculo Skeletal, Spina Bifida, and Visual or Hearing Impairments.

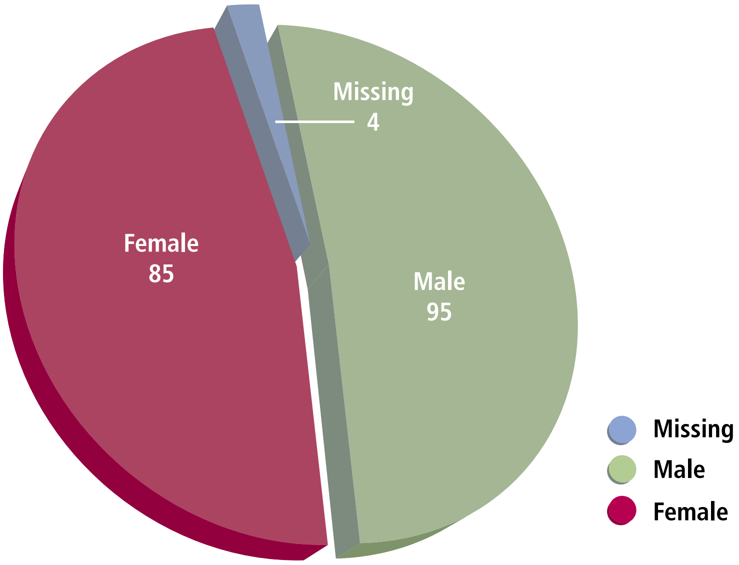
Table 5.7 - Disability or syndrome name

Name of syndrome	n=	Percentage
Albinism	3	1.6%
Autistic Spectrum Disorder	3	1.6%
Blindness/Vision impaired	3	1.6%
Cerebral Palsy	29	15.8%
Chromosomal	1	0.5%
Chromosomal (non Downs Syndrome)	12	6.5%
Cleft lip and/or palate	1	0.5%
Deafness/Hearing loss	2	1.1%
Down Syndrome	48	26.1%
Down Syndrome & Cleft lip and/or palate	1	0.5%
Epilepsy	1	0.5%
Genetic (non-chromosomal)	1	0.5%
Global Developmental Delay	1	0.5%
Learning/Intellectual disability	1	0.5%
Lissencephally	1	0.5%
Motor disability & learning disability	1	0.5%
Musculo Skeletal	7	3.8%
Neuro cutaneous syndrome	1	0.5%
Occular visual impairment	1	0.5%
Renal abnormality	1	0.5%
Specific language impairment	2	1.1%
Spina Bifida	7	3.8%
Tuberous Sclerosis	1	0.5%
Very rare syndrome	2	1.1%
Other	2	1.1%
Missing	51	27.7%
Total	**184**	**100%**

Child's Gender

51.6% of the children whose parents responded to the questionnaire were male and 46.2% were female. Four parents did not specify their child's gender.

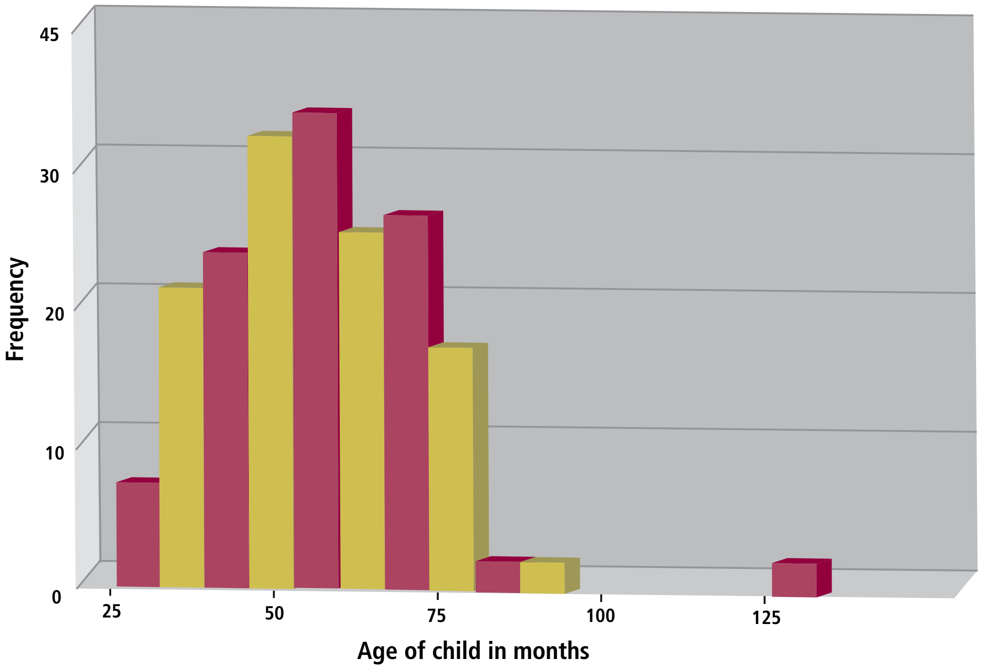
Figure 5.1 - Child's Gender



Child's age at time of response to Questionnaire

Parents were asked to indicate their child's age at the time of responding to the questionnaire. Of those who responded to this question, all except two children were over two and a half years (30 months) and had not yet reached their seventh birthday (84 months). Three parents (1.6%) did not indicate their child's age at the time of responding to the questionnaire. The age range captured indicates that although the researchers requested that the questionnaire be sent to the parents of children between the ages of three and six, some parents of younger children received the questionnaire. For one parent whose child was older than seven years there were two children in the family with a disability, and the questionnaire was answered in relation to the older child, who had received a diagnosis more recently than their younger sibling.

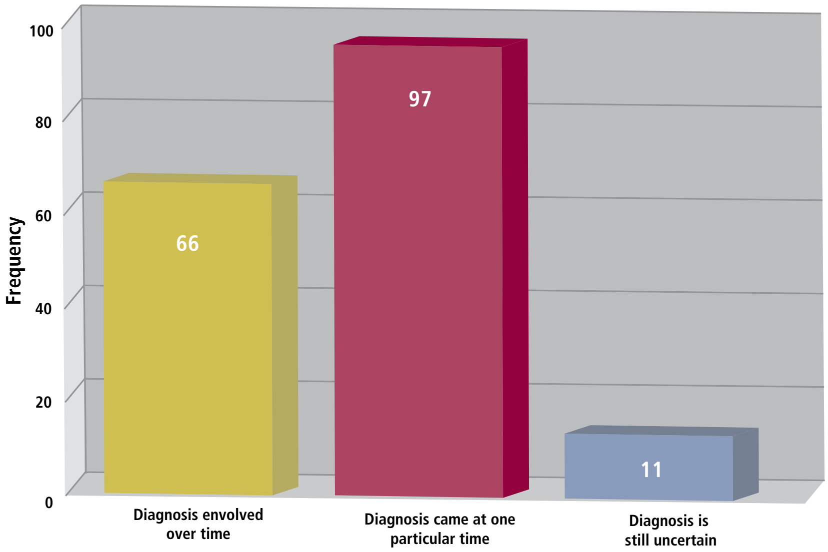
Figure 5.2 - Child's age at time of response



Diagnosis given at one time or evolved

For over half (52.7%) of the children the diagnosis came at one particular time whereas for 35.9% the diagnosis evolved over time. In responding to the question of how their child's diagnosis had evolved, 7.6% of families indicated that their child's diagnosis was still uncertain at the time of responding to the questionnaire. This figure is higher than the number of families (4.3%) who indicated earlier in response to the question of 'diagnosis/syndrome name' that they were not given a name for their child's diagnosis, and may indicate that there was a small number of families for whom a preliminary diagnosis had begun at the time of responding but the final diagnosis had not been made. Ten parents did not respond to this question.

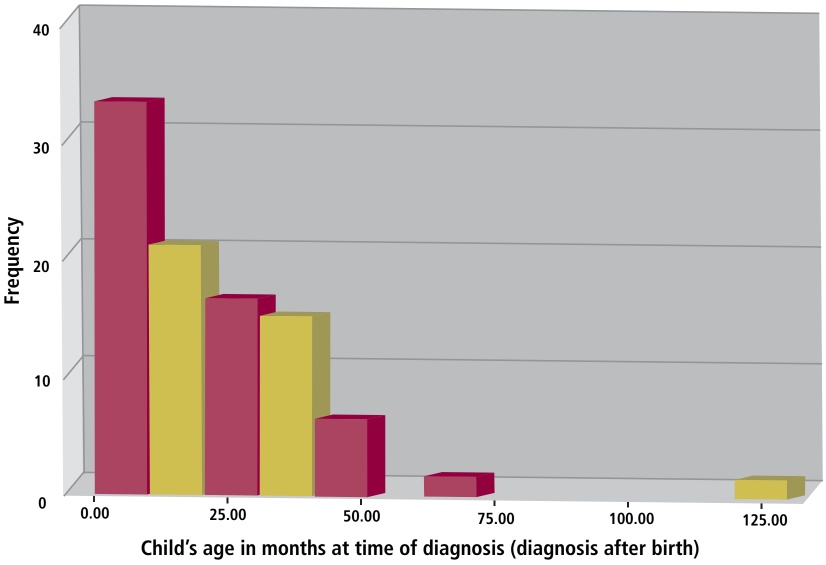
Figure 5.3 - Diagnosis came at one time or evolved over time



Child's Age at Diagnosis

Almost half (46.2%) of the parents received their child's diagnosis at the time of birth and a much smaller proportion (4.3%) received the news in pregnancy. One family received their child's diagnosis at the time of adopting their child. The following chart indicates the age of the child when the diagnosis was received (excluding those whose children received their diagnosis before or at birth).[18] There were 91 families who did not receive their child's diagnosis at or before birth. 45% of these families had received their child's diagnosis by the time that the child had reached one year. A further 49.5% of these families received the diagnosis when their child was between 1 and 4 years. A small number of respondents had received the diagnosis at a later age, with the eldest child receiving their diagnosis shortly before their eleventh birthday. There were seven non-respondents in this section.

Figure 5.4 - Age of child at time of diagnosis



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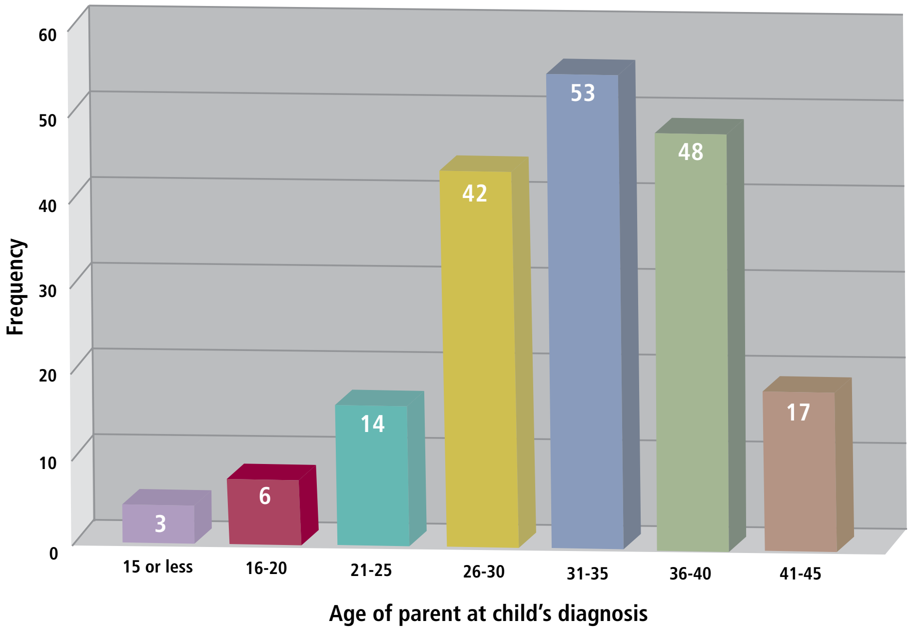
[18] For the purposes of this calculation any parents who indicated that the diagnosis was received within the first week were re-categorised as receiving the diagnosis 'At Birth'

Age of parents at time of diagnosis

The age range of parents when their child was diagnosed with a disability is widely spread, with parents younger than 15 years to parents of up to 45 years of age receiving the news. 189 responses were received from 184 questionnaires returned, since some mothers and fathers indicated their respective ages when filling out the questionnaire together, in which case both responses were analysed. 75.7% of parents received their diagnosis between the ages of 26 and 40.

Figure 5.5 - Age of parent at time of diagnosis



Siblings

For 37 families (20.1%) the child with a disability was an only child and 144 families (78.3%) had more than one child. Three families did not specify if they had other children. Fourteen families (7.6%) indicated that they had more than one child with a disability. In each of these 14 cases the families reported that they had two children with disabilities. Where families had more than one child with a disability, parents were asked to complete the remainder of the questionnaire in relation to their child who was most recently diagnosed.

5.2.2 Setting/Location and People Present

The following section of the report describes the setting in which the diagnosis was communicated to the family, and the people who were present. The vast majority (96.2%) of families first received their child's diagnosis in face to face meetings, with just 3 families (1.6%) receiving the news by telephone. One family were informed of their child's disability in writing.

Presence of family members

In almost three quarters of cases the parent being informed of their child's disability was accompanied by a partner, family member or friend. In approximately one quarter of cases the child was not present at the time of disclosure.

Table 5.8 - Presence of family members

People Present	n=	Yes	No	Missing
Partner, family member or friend present	181	72.8%	25.5%	3
Child present	179	71.2%	26.1%	5

People involved in communicating the diagnosis

Parents were asked to indicate the professional disciplines that had told them of their child's disability, and the service setting in which this had taken place. Four spaces were provided for each of these questions and parents were asked to list each of the disciplines, when the diagnosis had taken place over a series of meetings or when there was more than one professional present. Altogether 330 answers were noted in answer to the question of who had given the news.

In 60.9% (n=112) of cases there was a paediatrician involved in disclosure.

The range of disciplines reported by the parents as being involved was extremely wide with 85 individually mentioned specialties, which narrowed down into 36 broad categories. As detailed on page 85 of the methodology section of this chapter (Table 5.1), the most commonly reported professional discipline noted was 'Paediatrician'. This discipline was mentioned in 124 of a total of 330 instances (37.6%). The next most commonly mentioned disciplines were Psychologist in 33 instances (10%) followed by Neurologist in 25 instances (7.6%), Obstetrician/Gynaecologist in 11 instances (3.3%), Midwife in nine instances (2.7%) and Audiologist in eight instances (2.4%). The number recorded far exceeds the number of cases because for a large number of families the diagnosis was communicated by more than one individual, be that in one location or in various locations and/or at various stages. Ninety families were told by just one professional on one occasion. The disciplines reported by parents as being involved in the disclosure of their child's diagnosis work in the medical, nursing and social care sectors.

Presence of additional staff members

During the parent and professional focus groups it was indicated that the staff member responsible for informing the parents of their child's diagnosis is sometimes accompanied by second staff member to provide support to both the professional who is giving the news and to the family. Through the questionnaire survey parents were asked if additional staff members were present at the time of their child's diagnosis, and if so whether this was comfortable and/or helpful. Over half of the families (57.1%) indicated that additional staff members had been present at the diagnosis. Of the 105 families who reported the presence of additional staff members, clear agreement did not emerge as to whether this was helpful or not, as is shown in Table 5.9 below. Almost half found that it was comfortable and helpful, but many families did not. For the majority of respondents the additional staff member present was not previously known to them.

Table 5.9 - Presence of additional staff members

Was the presence of other staff members …	n=	Yes	No	Missing
Comfortable?	86	46.7%	35.2%	19
Helpful?	85	45.7%	35.2%	20
Were the additional staff members known to you?	102	33.3%	63.8%	3

Service setting for disclosure of the diagnosis

As discussed earlier, respondents were asked to indicate the service settings in which they had received their diagnosis and in so doing to list each setting if the diagnosis had taken place in a number of stages or across settings. Hence, the sum of the settings reported exceeds the total number of cases. As might be expected from the spread of physical, sensory, intellectual disabilities and autistic spectrum disorders reported, the service settings in which these diagnoses were given were varied and covered hospital, community and disability services. Approximately two fifths of the instances recorded related to the Maternity Hospital, but it is important to note that this does not infer 99 separate cases, as some parents received their diagnosis over a period of time within the Maternity Hospital, often from different disciplines at various times. Paediatric Hospitals and Early Services in various disability service providers were the next most common service settings reported. The settings reported are presented in Table 5.10.

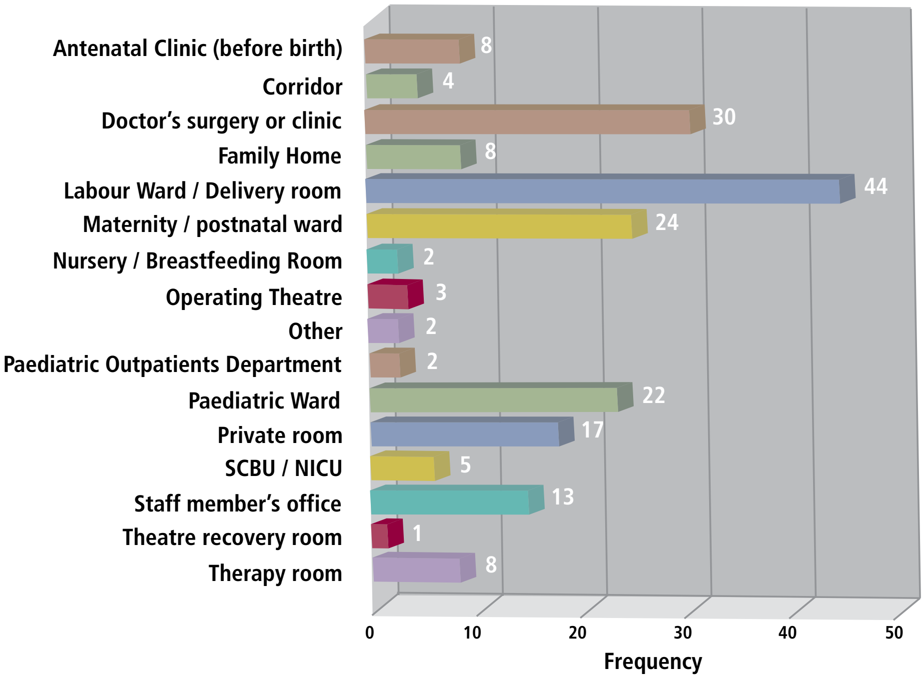
Table 5.10 - Service setting for disclosure

Service Setting	n=	Percentage
Child Guidance/Development Clinic	3	1.2%
Clinic	1	0.4%
Cochlear Implant Department	1	0.4%
Community Care Services	3	1.2%
Disability Service Provider	1	0.4%
Disability Support Group	1	0.4%
Early Services	**23**	**9.0%**
Eye Clinic	1	0.4%
Family Home	2	0.8%
General Hospital (& Local General Hospital)	5	2.0%
General Hospital (Maternity Ward)	2	0.8%
Health Board	3	1.2%
Hospital	11	4.3%
Intellectual Disability Service Provider	5	2.0%
Local Clinic	3	1.2%
Local Health Centre	1	0.4%
Maternity Hospital	**99**	**38.7%**
Outpatients Department/Clinic	2	0.8%
Paediatric Hospital	**47**	**18.4%**
Paediatric Ward General Hospital	1	0.4%
Physical Disability Service Provider	9	3.5%
Private Practice	5	2.0%
Psychological Assessment by post	1	0.4%
Regional Hospital	9	3.5%
Specialist Deaf Unit	1	0.4%
Other	16	6.3%
Total	**256**	

Location in which the diagnosis was given

Within the more general settings listed above, parents were asked to indicate the actual room, corridor, ward or other location in which the news had been communicated. A wide range of locations in which disclosure first took place was reported. As some families received the news in stages, there were respondents who listed more than one location in which the news was given. All answers in this section were collated together to provide an overall picture of the places in which the diagnosis is provided.

Figure 5.6 - Location for disclosure



Environment

As is reported in Table 5.11 below, the majority of respondents were given the diagnosis in a private environment and were not interrupted. However only one third of parents found the environment welcoming and only two fifths found it comfortable.

Table 5.11 - Environment for disclosure

Environment	n=	Yes	No	Missing
Private environment	168	71.2%	20.1%	16
Welcoming environment	124	33.7%	33.7%	60
Comfortable environment	135	41.8%	31.5%	49
Free from interruption	177	84.8%	11.4%	7

5.2.3 Communication

The following section explores aspects of the communication process in relation to how the diagnosis of the child's disability was first disclosed to parents.

Initiation of discussion

The process of disclosure of a child's disability may begin with the first communication of a concern or it may be possible to immediately provide a clear diagnosis. The data recorded in the focus groups undertaken with parents and professionals indicated that the first concern regarding a child's development or the presence of a suspected disability may be raised by parents or by professionals, or may come about as the result of routine screening. This concept was examined through the questionnaire survey, which found that in one fifth of cases the discussion in which the diagnosis was given was initiated by parents, and for almost a third it was staff members who introduced to parents the possibility that their child may have a disability.

Table 5.12 - Initiation of disclosure discussion

Initiation of discussion	n=	Percentage
Initiated by parent	38	20.7%
Initiated by staff member	52	28.3%
Both the staff and parent had concerns	28	15.2%
The concern was identified through routine screening	29	15.8%
Don't know	16	8.7%
Missing	21	11.4%

Communication of the diagnosis

Table 5.13 describes parents' assessment of the communication skills or styles used in disclosing the news of their child's disability. Over three quarters of parents felt that their child was referred to respectfully, and three fifths felt that they had been treated with empathy. Almost half of the respondents did not feel that they had been given the news with hope and positive messages, a number slightly exceeding those who felt that these elements were present. A large majority of parents felt that the person giving the news was direct. Approximately two thirds of respondents reported that the person giving the news was a good communicator, and had a good understanding of disability, but significantly fewer felt that the person giving the news understood what the diagnosis would mean for the family.

Table 5.13 - Communication of the diagnosis

Communication	n=	Yes	No	Missing
During the consultation did you feel that...				
You were treated with empathy	153	59.2%	23.9%	31
Your child was referred to respectfully	164	77.7%	11.4%	20
You were given the news with hope, and with positive messages	163	46.7%	41.8%	21
The person giving the news had a good understanding of disability	163	62.0%	26.6%	21
The person giving the news was approachable	162	58.7%	29.3%	22
The person giving the news was understanding	167	66.3%	24.5%	17
The person giving the news was direct	168	84.8%	6.5%	16
The person giving the news a good communicator	169	62.5%	29.3%	15
The person giving the news understood what it would mean for you and your family	159	46.7%	39.7%	25
Your reaction to the news was acknowledged/taken into account by the person who told you?	168	61.4%	29.9%	16

Comprehension of the diagnosis

The results in Table 5.14 below show that **following the initial diagnosis disclosure two fifths of parents did not feel that they had understood what they had been told about their child's disability**. More than three quarters of parents felt that they had an opportunity to ask questions.

Table 5.14 - Comprehension of the Diagnosis

Comprehension of the diagnosis	n=	Yes	No	Missing
Did you feel you had understood what you had been told about the diagnosis	179	56.5%	40.8%	5
Were you given an opportunity to ask questions	173	76.6%	17.4%	11

5.2.4 Provision of Information and Support

The following section of the report examines the type, volume and quality of information provided to parents when their child's diagnosis was disclosed, and the support options that were made available to the family at that time.

Amount/level of information received

Parents were asked to evaluate the level of information that they received at the first diagnosis disclosure. Although half of the parents felt that enough information was provided, almost two fifths of parents did not feel that they had received sufficient information when the diagnosis was first disclosed, and a small amount of families felt that they were provided with too much. The majority of parents (56%) were not asked if they would like to receive more information.

Table 5.15 - Amount/level of information received

Information received	n=	Percentage
Enough information	91	49.5%
Too much information	12	6.5%
Too little information	73	39.7%
Missing	8	4.3%
Total	**184**	**100%**

Quality of information

When asked about the information that they had received, approximately half of the families recorded that it had been easily understood, with slightly less than half indicating that it had been up to date and easy to remember. In 24 cases respondents reported that they received no information.

Table 5.16 - Quality of Information

Quality of information	n=	Yes	No	No Information Received	Missing
Was the information you received…					
Easily understood	165	54.9%	21.7%	13.0%	19
Easy to remember	144	44.0%	21.2%	13.0%	40
Up to date	130	45.1%	12.5%	13.0%	54
Too technical	136	19.0%	39.7%	13.0%	52

Timing of written information

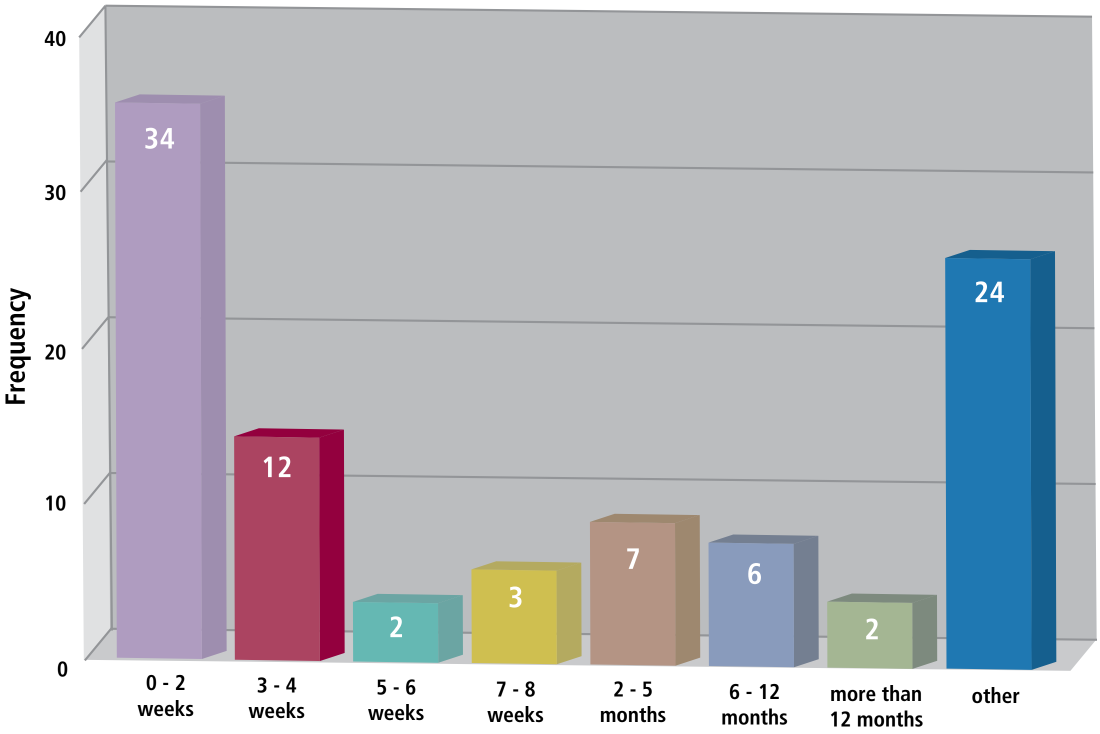
Almost two thirds of respondents did not receive written information at the initial disclosure discussion. As reported in Table 5.17 below, slightly fewer than half indicated that they had received written information at a later time.

Table 5.17 - Timing of Written Information

Timing of written information received	n=	Yes	No	Missing
Were you given written information…				
At the time of diagnosis	141	13.0%	63.6%	43
At a later date	146	46.2%	33.2%	38

Information from those who provided details of when they received written information is set out in Figure 5.7 below. Of those who indicated that they had received written information later than the time of diagnosis, some received it over a period of time or at various points following the diagnosis or during the process of an evolving diagnosis and some did not recall precisely when information had been provided. These answers are captured in the 'Other' column. There is a variance in the length of time represented by the bars in the chart since there was a concentration of information-giving activity up to the first 8 weeks, and following that the time-frame is considerable more spread out in the data.

Figure 5.7 – Timeframe of written information provision



Information about tests undertaken

For over three quarters of children tests were carried out or investigations undertaken subsequent to the disclosure of the disability or developmental concern, and these tests were explained to a large majority of the parents who responded, as can be seen in Table 5.18 below.

Table 5.18 - Information regarding tests

Information about tests undertaken	n=	Yes	No	Missing
After the news was given were any tests/investigations undertaken?	175	77.7%	16.8%	9
[Of those people who answered that tests were undertaken] 'Were they explained to you?	138	87.4%	9.1%	5

Provision of follow-up meetings/appointments and named contacts

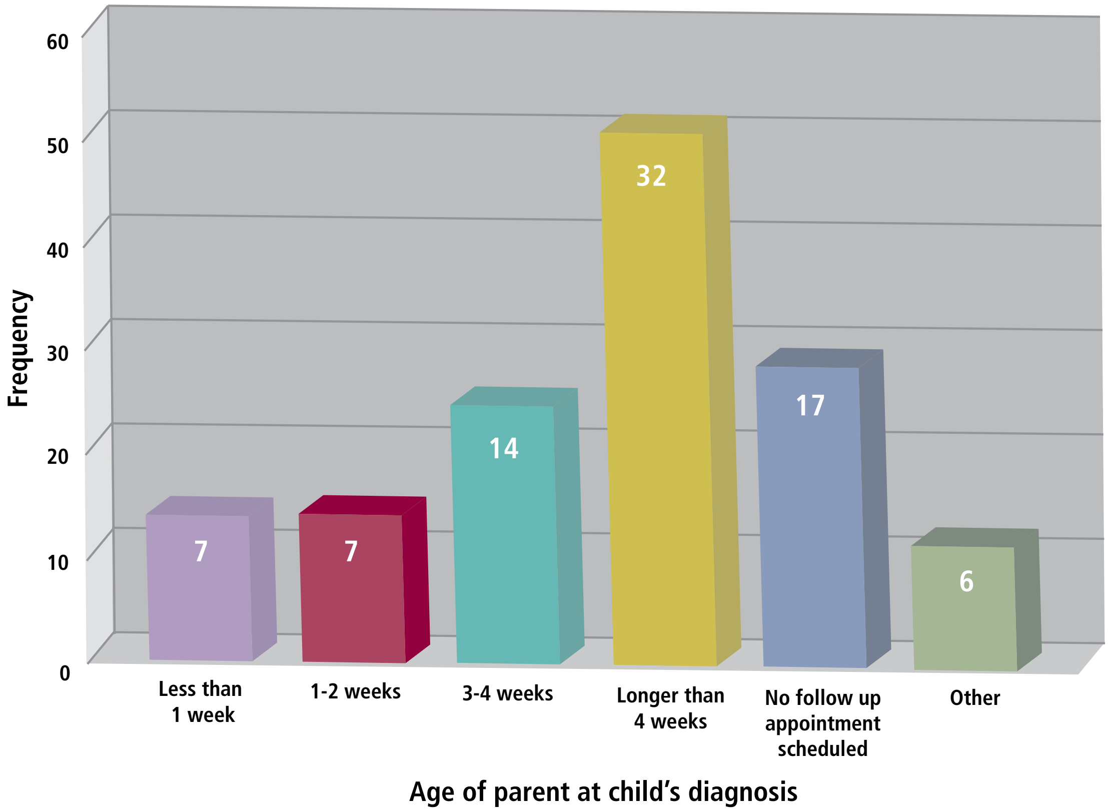
Approximately half of the families in this study left the initial disclosure meeting with a named contact person who they could meet or telephone for support or information but a significant proportion did not have this support available. Almost a third of parents were not provided with a follow up appointment to discuss the diagnosis or raise concerns.

Table 5.19 - Follow-up appointments and named contacts

Provision of follow-up	n=	Yes	No	Missing
Was a contact name provided after the first meeting?	178	51.6%	45.1%	6
Were you offered a follow-up appointment to discuss the diagnosis in more detail or clarify concerns?	175	65.2%	29.9%	9

Of the families that were offered a follow-up, six indicated that they had to wait six months for the appointment, and two stated that their follow-up appointment was scheduled for the following year.

Figure 5.8 – Length of time before follow-up appointment



Provision of support options

Parents were asked to comment on the provision of support options that had been mentioned in the parent and professional focus groups as being important, and to also indicate their preferences for these elements of support being offered. Tables 5.20 and 5.21 below, show that although approximately half of parents would like to be offered contact with other families of children with disabilities, in reality this was not available for almost three quarters of respondents. A similar trend is observed for the option of counselling. Just over half of parents would like to be put in contact with a social worker or liaison person, which corresponds closely with slightly less than half of parents who were offered this option. In a comments section which was provided with these questions, parents indicated that it is important to appropriately pace the provision of these support options as many parents may wish for contact with other families or the option of counselling at a later date but would find the introduction of these concepts inappropriate if provided too early, for instance at the initial disclosure.

Table 5.20 - Support options offered

Support option offered	n=	Yes	No	Missing
Contact with other parents of children with disabilities	167	16.8%	73.9%	17
Contact with a social worker/liaison person	176	48.9%	46.7%	8
The option of counselling	163	15.2%	73.4%	21

Table 5.21 - Parental preferences for support options

Parental preference for support options	n=	Yes	No	Missing
Contact with other parents of children with disabilities	156	46.2%	38.6%	28
Contact with a social worker/liaison person	156	56.5%	28.3%	28
Counselling	157	46.2%	39.1%	27

5.2.5 Culture and Language

Cultural and Linguistic Appropriateness of Information

As reported in Table 5.23, parents were asked to indicate whether they felt the information they had been provided with was appropriate to their culture (regardless of their first language). Two thirds found that the information was appropriate, for a small percentage it was not, and for almost a quarter of parents they either did not receive any information or ticked 'Don't Know' in relation to this question.

Table 5.22 - Cultural Appropriateness of Information

Culture	n=	Yes	No	No Information Received	Don't Know	Missing
Was the information you were given appropriate to your culture?	171	65.8%	4.3%	13.6%	9.2%	13

Within the small group of respondents whose first language was not English, less than 10% reported receiving written information in their first language, and less than 20% were provided with the option of an interpreter.

Table 5.23 - Language and Interpretation Services Provided

Language	n=	Yes	No	No Information Received	Missing
If your first language is not English were you provided with written information in your first language?	8	9.1%	54.5%	9.1%	3
If your first language is not English was the option of an interpreter provided?	8	18.2%	54.5%	-	3

5.2.6. Rating of Suggested Elements of Best Practice

Respondents to both the parent and professional questionnaires were informed that the Informing Families Project had carried out focus groups with families whose children had received a diagnosis of disability, and with professionals who are involved in communicating a diagnosis of disability to families. From these focus groups and from a review of the international literature, suggested recommendations were made for how the news should be given to families in Ireland in the future. Respondents were invited to rate these suggested elements of practice, with options ranging on a five-point scale from 'Strongly Agree' to 'Strongly Disagree'.

The tables from pages 99 to 102 below indicate the level of agreement with each of the 46 elements of practice, broken down into the categories used throughout this report to describe the various aspects of disclosure. A high level of agreement with the recommendations was recorded, with almost all of recommendations being rated as 'Strongly Agree' by the majority of parents. The exceptions which were not strongly agreed with by a majority include the suggestion that the child should be present at disclosure (Setting/Location and People Present) and the recommendations that parents are asked how much information they wish to receive and when they would like to receive it (Information & Support). When the 'Strongly Agree' and 'Agree' responses are combined for the recommendation regarding the presence of the child, the total comes to just 38.6%. However when the responses from 'Strongly Agree' and 'Agree' are combined for the latter two recommendations noted above, the combined levels of agreement were 82% and 80.5% respectively.

Table 5.24 - Recommendations for Setting/Location & People Present

Setting/Location & People Present	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
In future when parents are told of their child's disability…						
…the news is given in a private place with no interruptions	175	91.3%	2.2%	0.5%	0.5%	0.5%
Both parents are present when the diagnosis is given	179	82.1%	6.5%	7.1%	0.5%	1.1%
If only one of the parents is present, the choice of a family member or friend to be present is given	179	73.4%	17.4%	4.9%	0.5%	1.1%
During the consultation, the child is present	**176**	**28.3%**	**10.3%**	**35.3%**	**13.6%**	**8.2%**
The parents have seen the child before the diagnosis is given	176	64.1%	16.8%	13.6%	0.5%	0.5%
The parents have spent time with the child before the diagnosis is given	178	59.8%	17.9%	16.3%	1.6%	1.1%
The diagnosis is given by a senior staff member	179	76.1%	12.0%	6.5%	1.1%	1.6%
There is an extra staff member present as a support after the news is given	178	56.5%	21.7%	13.6%	2.7%	2.2%
No extra staff members are present for training purposes	175	56.0%	8.7%	19.0%	3.8%	7.6%

Table 5.25 - Recommendations for Communication

Communication	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The child is referred to respectfully; by name and not diagnosis	178	88.6%	6.5%	1.1%	–	0.5%
Parents concerns are acknowledged	179	87.5%	8.7%	0.5%	–	0.5%
Parents are listened to with respect, empathy and understanding	178	89.1%	7.1%	–	–	0.5%
Parents concerns are followed up	180	87.0%	8.7%	1.1%	0.5%	0.5%
Positive, realistic messages are given with the diagnosis	177	75.0%	16.8%	2.7%	1.1%	0.5%
Staff members giving the news use simple, understandable language	179	83.7%	12.0%	1.1%	–	0.5%
The reaction of parents is acknowledged and supported	180	81.0%	15.8%	0.5%	–	0.5%
The diagnosis is not rushed and parents are given time to ask questions	179	87.0%	8.2%	1.6%	–	0.5%
Parents are told what will happen next (e.g. tests)	179	83.7	12.0%	1.1%	–	0.5%
Staff members are aware of all aspects of their communication, including body language and possible interpretations	178	76.6%	16.3%	3.3%	–	0.5%
All medical terminology is explained	179	85.3%	10.9%	0.5%	–	0.5%

Table 5.26 - Recommendations for Training

Training	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Staff members are trained in communication skills	178	80.4%	15.2%	0.5%	–	0.5%
Staff members are trained in good practice for informing families of their child's disability	177	82.1%	13.0%	0.5%	–	0.5%
Staff members have a good understanding of disability	178	83.2%	12.5%	0.5%	–	0.5%

Table 5.27 - Recommendations for Referral

Referral	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Parents are referred to early services as soon as possible	172	84.8%	6.5%	1.1%	0.5%	0.5%
Parents are given information about the service they are referred to	171	81.0	10.9%	–	0.5%	0.5%

Table 5.28 - Recommendations for Information & Support

Information & Support	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Parents are asked how much information they wish to receive	**171**	**47.8%**	**34.2%**	**7.1%**	**1.6%**	**2.2%**
Parents are asked when they would like to receive information	**171**	**49.5%**	**31.0%**	**9.2%**	**2.2%**	**1.1%**
An interpreter is provided if English is not the first language of the parents	169	71.2%	17.4%	2.7%	–	0.5%
Staff members check that parents have understood what has been discussed	170	69.0%	20.1%	2.2%	0.5%	0.5%
Parents are given a written summary of the consultation	169	66.8%	14.7%	8.2%	1.6%	0.5%
Parents are not left alone for a long period without support	171	63.0%	16.3%	8.7%	3.8%	1.1%
Parents are given time alone together to absorb the news	170	69.0%	18.5%	3.8%	–	1.1%
Parents are given written information (leaflets, books etc.,) about their child's disability/diagnosis	170	70.7%	16.8%	3.8%	–	1.1%
The written information given to parents is in their first language	170	76.1%	13.0%	2.2%	0.5%	0.5%
Parents are given the option of information about support groups	172	64.7%	25.0%	2.7%	0.5%	0.5%
Parents are given the option of contact with other families	170	51.6%	28.3%	11.4%	0.5%	0.5%
Parents are offered the option of counselling	172	53.8%	31.0%	7.6%	0.5%	0.5%
Parents are offered contact with a social worker/liaison person	171	59.2%	26.1%	6.0%	0.5%	1.1%
Parents are kept up to date at all times, with honest information	171	75.5%	15.2%	1.6%	–	0.5%

Table 5.29 - Recommendations for Organisation and Planning

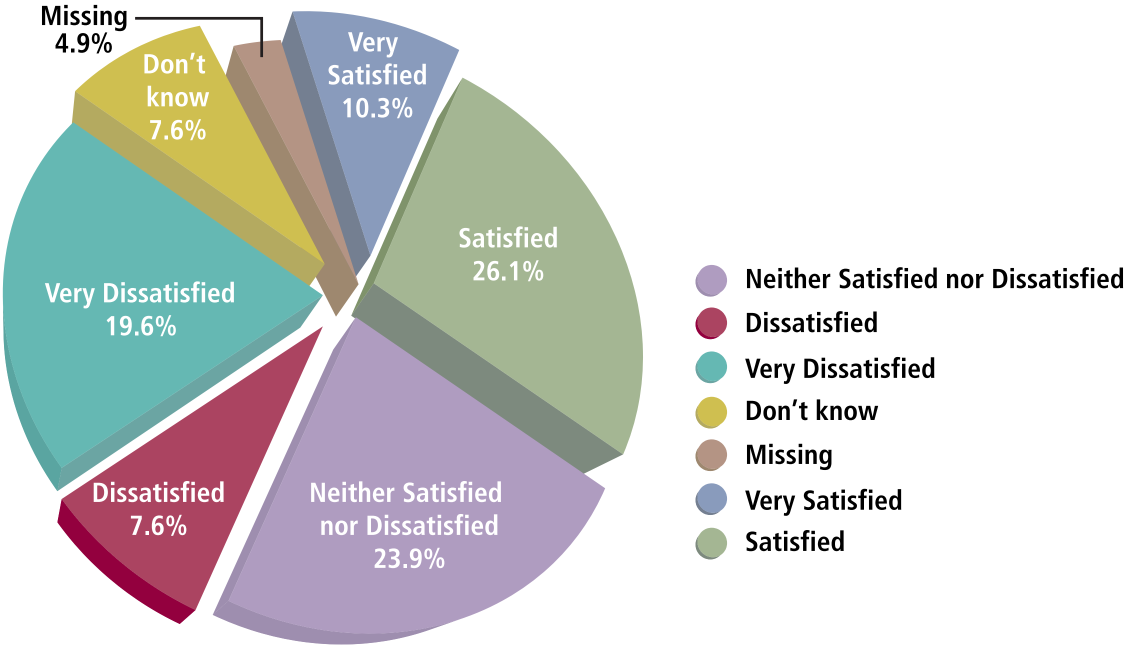
Organisation & Planning	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Staff members share information, so that parents do not have to give the same history or information to many different people	171	75.0%	13.0%	2.7%	1.1%	1.1%
Staff members coming on to new shifts are informed that parents have been given the news that their child has a disability	172	77.7%	12.5%	2.7%	–	0.5%
The GP is informed about the child's disability by those giving the news to the parents	171	72.8%	17.9%	1.6%	–	0.5%
The Public Health Nurse is informed about the child's disability by those giving the news to parents	172	69.0%	17.4%	4.3%	1.6%	1.1%
If the diagnosis has been given in the maternity hospital and the mother is staying overnight, a partner or a family member/friend is offered the choice to stay also	170	73.4%	14.1%	3.3%	0.5%	1.1%
The family are offered the choice of accommodation on their own, after the diagnosis	171	63.6%	16.8%	9.8%	1.6%	1.1%
Parents are offered a follow-up appointment within a maximum of two weeks to discuss the diagnosis.	172	78.8%	12.0%	2.2%	–	0.5%

5.2.7. Parental Satisfaction with Disclosure

Satisfaction with first disclosure of child's disability

Following the questions relating to aspects of how they had received their child's diagnosis, parents were asked to indicate how satisfied they were with how they were informed, the **first** occasion that they had been given information about a concern or diagnosis. The responses to this question are set out in Figure 5.9 below. Sixty-seven parents (36.4%) were either 'Satisfied' or 'Very Satisfied' with how they had been informed. Fifty parents (27.2%) were either 'Dissatisfied' or 'Very Dissatisfied'.

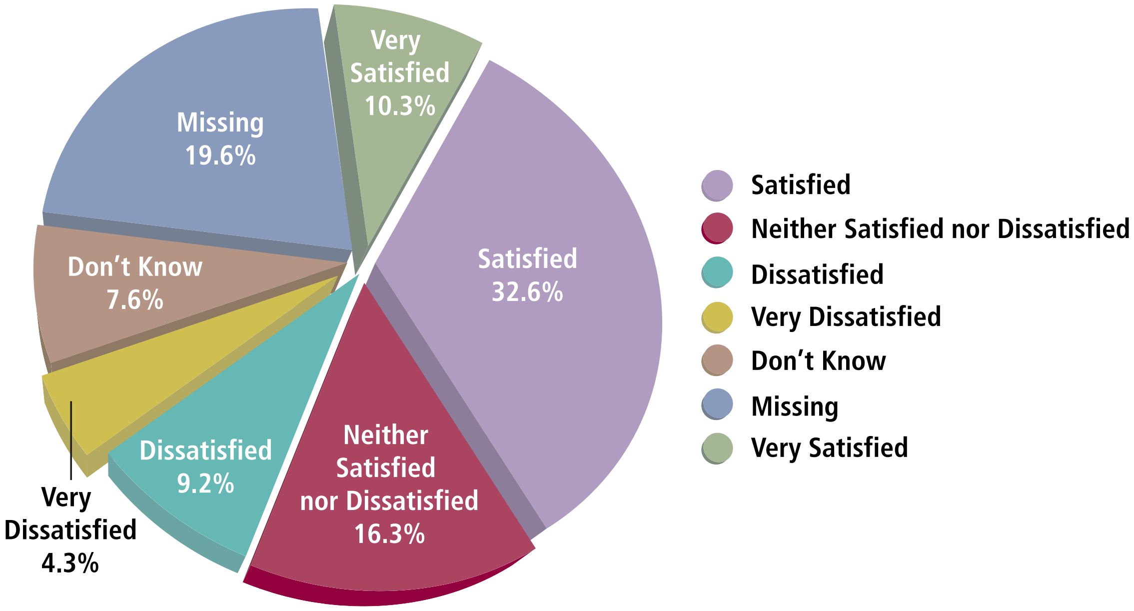
Figure 5.9 – Satisfaction of parents with how they were first informed



Overall satisfaction with disclosure, if parents told on more than one occasion

The findings of the literature review suggested that parents could readily distinguish between their satisfaction or dissatisfaction with how they had been told of their child's disability, and their feelings about the diagnosis itself. This concept was explored in the parent questionnaire through a second question on satisfaction levels, which asked parents how satisfied they had been with the disclosure of their child's disability if told on more than one occasion. Variance from the previous satisfaction question would suggest that parents were judging their levels of satisfaction based on the various disclosure experiences that they had rather than their feelings about the diagnosis itself. Levels of reported overall satisfaction were higher for those who responded that they had received the diagnosis on more than one occasion, with 42.9% of those who answered this question being either 'Satisfied' or 'Very Satisfied'. Levels of dissatisfaction were lower than those reported in the previous satisfaction question, with 13.5% of respondents indicating that they were either 'Dissatisfied' or 'Very Dissatisfied'. The higher levels of satisfaction reported in this section may also indicate that there was better practice in place when the diagnosis came over time, but it is not possible from this data set to extrapolate what the contributing factors to this might be.

Figure 5.10 – Overall satisfaction of parents if told on more than one occasion



5.3 Professional Questionnaire Survey Results

Response Rates

As detailed in the methodology section of this report, 1588 questionnaires were sent to professionals in 27 disciplines identified through the parent questionnaire as being involved in either communicating the diagnosis of a child's disability to the parents, or in supporting the family immediately after the diagnosis has been given. From the 1588 questionnaires sent to professionals 255 were returned. Although this represents a disappointing 16.1% response rate overall, the rate of response from each discipline varies, with those who are more usually involved in communicating the diagnosis or supporting families through this process answering more frequently. Paediatricians, which were the group most commonly mentioned by families as providing the news (reported at 37.6%) provided a 28.6% response rate to the professional questionnaire. Several other groups also demonstrated higher response rates, such as Social Workers (58%), Speech and Language Therapists (34%), Area Medical Officers (30%), Audiologists (26%), and Ultrasonographers (26%).

Conversely it would seem that those who provide the diagnosis only sporadically responded less often. For instance just three cardiologists responded to the survey. However they did not complete the questionnaire because they felt that this was not a common feature of their practice, and others from various disciplines indicated that they only worked with adults. Questionnaires were eliminated from analysis for this reason in 17 cases and the remaining 238 questionnaires were then analysed

Notes on data reporting

In the following section of the report, which details the responses of professionals, the percentage rate reported for the answers to each of the questions is expressed as a percentage of all 238 cases rather than the percentage of only those who responded to the particular question, unless stated otherwise. As with the parent questionnaire, tables are presented with a total figure except where it was possible for respondents to tick more than one option. Results in tables are presented alphabetically.

5.3.1. Characteristics of Professional Respondents

The first portion of the questionnaire sought information on the various disciplines; service settings; levels of experience and qualification; and employment types of those who responded to the professional questionnaire.

Current discipline of respondent

At the beginning of the Professional Questionnaire respondents were asked to indicate their current professional discipline. Table 5.30 below shows that of those who responded to the questionnaire, the most frequently noted disciplines were Consultant Paediatricians and Social Workers. As reported earlier, some categorisation took place on the parent responses as to who had given the news, and similarly the list of disciplines listed below has been categorised, for the sake of clearer analysis. For example, 'Obstetricians', 'OB/GYN' and 'Obstetrician/Gynaecologists' who responded were categorised as 'Obstetrician/Gynaecologist' and Midwives and/or Radiographers performing obstetric ultrasounds were categorised as 'Ultrasonographer'.

Table 5.30 – Current discipline of respondents

Current Discipline	n=	Percentage
Area Medical Officer	15	6.3%
Audiologist	12	5.0%
Community Nurse (RNID)	5	2.1%
Consultant ENT	1	0.4%
Consultant Geneticist	1	0.4%
Consultant Neurologist	1	0.4%
Consultant Obstetrician/Gynaecologist	10	4.2%
Consultant Paediatrician	30	12.6%
Consultant Paediatrician/Neurologist	1	0.4%
Consultant Psychiatrist	2	0.8%
Consultant Radiologist	1	0.4%
Eye Specialist (Ophthalmologist/Optometrist)	3	1.3%
GP	7	2.9%
Genetic Counsellor	1	0.4%
Midwife	15	6.3%
Neonatal Nurse	4	1.7%
Nurse	4	1.7%
Obstetrician/Gynaecologist	5	2.1%
Occupational Therapist	9	3.8%
Paediatric Nurse	16	6.7%
Physiotherapist	5	2.1%
Psychiatrist	2	0.8%
Psychologist	20	8.4%
Public Health Nurse	2	0.8%
Social Worker	30	12.6%
Speech and Language Therapist	17	7.1%
Trainee Doctor	1	0.4%
Trainee Obstetrician/Gynaecologist	3	1.3%
Trainee Paediatrician	5	2.1%
Ultrasonographer	9	3.8%
Visiting Teacher for the Deaf	1	0.4%
Total	**238**	**100%**

Region

The professional respondents were asked to indicate the regions of the country they were practicing in at the time of responding, and in line with the results of the parental study the most common region of practice was Leinster and the least common was Ulster. A number of respondents ticked more than one region, since it is possible to work across regions.

These responses were captured and lead to the count obtained being higher than the number of respondents, however the percentages are reported as a proportion of all 238 cases to reflect the percentage of responding professionals who work in each region.

Table 5.31 - Region professionals currently practice in

Region	n=	Percentage
Connaught	26	10.9%
Leinster	130	54.6%
Munster	68	28.6%
Ulster	13	5.5%
Missing	6	2.5%

Respondent's first language.

A large majority of questionnaires were filled out by professionals whose first language was English. A range of other languages were also reported. As with the parent questionnaire, the second most commonly reported language was Irish. Three respondents answered 'English/Irish', and these were captured by entering them as both 'Irish' and 'English'. As a result there are more responses to this question than the total number of questionnaires received.

Table 5.32 - First language of respondent

Language	n=	Percentage
Arabic	2	0.8%
Dutch	2	0.8%
English	224	94.1%
German	1	0.4%
Irish	7	2.9%
Tamil	1	0.4%
Telugu	1	0.4%
Missing	3	1.3%
Total	**241**	

Length of time qualified in stated discipline

Respondents were asked both how long they had been qualified in their particular discipline and also how long they had spent actively practicing in this discipline. Figures 5.11 and 5.12 below show a wide range of responses to both questions and indicate that the professionals answering the questionnaire had differing levels of experience, on a spectrum from those who had been qualified for less than a year to those who had been practicing in their particular discipline for over thirty years. The largest group of respondents were qualified for between 5 and 14 years (36.1%). A slightly higher percentage (42%) had been *practicing* in their stated discipline for between 5 and 14 years, taking account perhaps of those who had been practicing whilst in training in their specified discipline.

Figure 5.11 - Length of time qualified in stated discipline

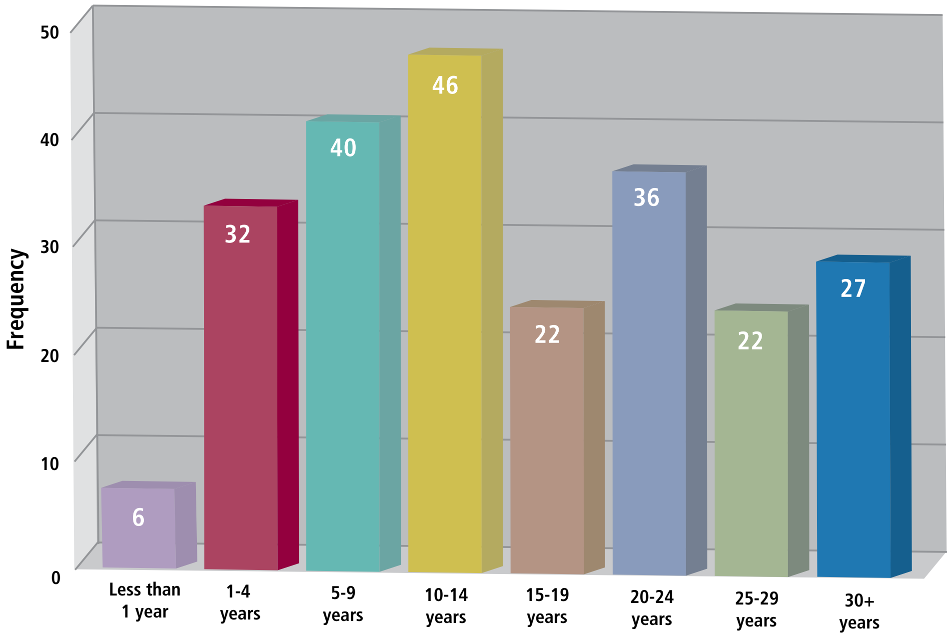
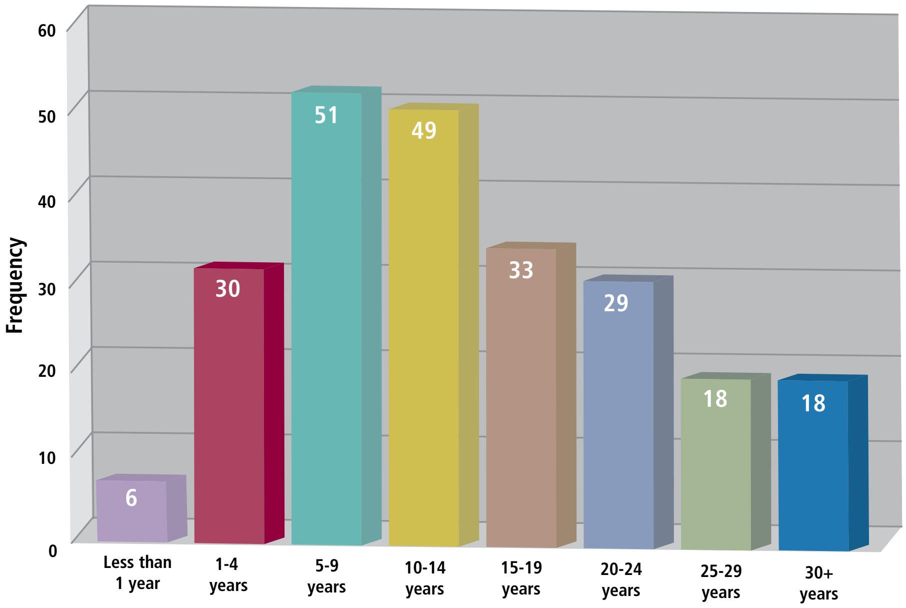


Figure 5.12 - Length of time practicing in stated discipline



Service settings

Professionals who responded to the questionnaire work in a wide variety of service settings. The most common area of current practice reported was 'Paediatric Unit in General Hospital'. In addition to the pre-defined areas available on the questionnaire for respondents to choose listed in the table below, additional areas of current practice were also noted, captured under the heading 'Other'. These included general practice, private practice and audiology services. In many cases respondents worked in more than one setting.

Table 5.33 - Current practice settings of professionals

Current practice settings	n=	Percentage
Hospital		
Maternity Hospital	39	16.4%
Maternity Unit in General Hospital	15	6.3%
Neonatal Unit/SCBU	26	10.9%
Neurology Unit	8	3.4%
Paediatric Hospital	34	14.3%
Paediatric Unit in General Hospital	43	18.1%
HSE Community Services		
Child and Adolescent Mental Health Services	7	2.9%
Child Development Clinic	16	6.7%
Child Health Clinic	13	5.5%
Early Intervention Services	16	6.7%
Occupational Therapy Services	3	1.3%
Physiotherapy Services	3	1.3%
Psychology Services	9	3.8%
Public Health Nurse Service	3	1.3%
Social Work Services	3	1.3%
Specialist Multi-Disciplinary Assessment Team	14	5.9%
Speech and Language Services	9	3.8%
Voluntary Disability Services – Early Intervention		
Autistic Spectrum Services	10	4.2%
Intellectual Disability Services	27	11.3%
Physical Disability Services	21	8.8%
Sensory Disability Services	7	2.9%
Other	44	18.5%

Employment type

A range of responses was reported in relation to respondents' employment types, showing a spectrum of professionals with differing terms of employment. The majority of respondents indicated that 'permanent contract' best described their current post. The next most common type of employment of the professionals in the report was 'self-employed'.

Table 5.34 - Employment type of professionals

Type of Post	n=	Percentage
Permanent Contract	196	82.4%
Self-Employed	15	6.3%
Training Post	10	4.2%
Temporary Contract	7	2.9%
Locum	4	1.7%
Other	3	1.3%
Missing	3	1.3%

Role of professional in disclosure process

Over half of the professionals (57.6%) involved in this study had responsibility for informing families of a child's diagnosis, or a concern about same. 71% of the respondents indicated that they were responsible for supporting families when they have been given the news that their child has a disability. There was cross-over present in the responses to this question, indicating that many professionals define their role in this process as both informing and subsequently supporting parents.

Frequency of involvement

Wide variance in the frequency of involvement in disclosure was reported from staff members who described their role as being responsible for initially disclosing the diagnosis; some of whom are involved in this process very regularly – over 35 times per year, while others only occasionally communicate this kind of news to families. Almost half (49.7%) note the frequency of informing families at between 1 and 9 times, and almost a fifth undertake this task more than 35 times per year, as can be seen in Table 5.35 below.

Table 5.35 - Frequency of involvement for staff responsible for informing

Number of times staff responsible for informing gave the news to families in the past year	n=	Percentage
Never in the last year	6	4.4%
1-4 times	36	26.3%
5-9 times	32	23.4%
10-14 times	19	13.9%
15-19 times	7	5.1%
20-24 times	4	2.9%
25-29 times	2	1.5%
30-34 times	2	1.5%
35+ times	25	18.2%
Other	3	2.2%
Missing	1	0.7%
Total	**137**	**100%**

Similarly, there was a spread of responses reported by staff members who noted their role as supporting families when they have been given their child's diagnosis, in relation to the frequency of their involvement in the disclosure process. Both tables also show that there are many professionals informing families of their child's disability who encounter this task only occasionally in their day to day work.

Table 5.36 - Frequency of involvement for staff members supporting families

Number of times staff members responsible for supporting families involved in disclosure in the past year	n=	Percentage
Never in the last year	7	4.0%
1-4 times	45	25.6%
5-9 times	37	21.0%
10-14 times	26	14.8%
15-19 times	10	5.7%
20-24 times	10	5.7%
25-29 times	1	0.6%
30-34 times	4	2.3%
35+ times	26	14.8%
Other	1	0.6%
Missing	9	5.1%
Total	**176**	**100%**

Just over one third of the professionals in this study (34.9%) manage staff members with responsibility for informing or supporting families at the time of diagnosis of a child's disability. There was a wide variety of service settings reported in which these those respondents who manage staff practice; across hospital, disability and community service settings.

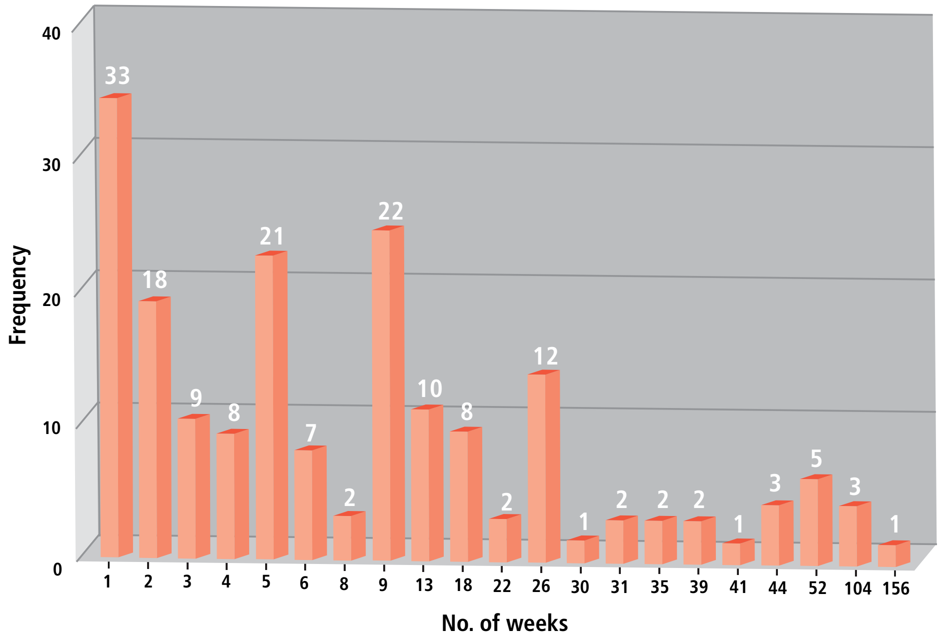
5.3.2. Child and Family Details

The following section sets out the child and family details of the cases described in the professional questionnaire responses. In order to mirror the parent questionnaire in its exploration of various aspects of disclosing a child's disability, professionals were asked to think of the last time they had been involved in either communicating the news or supporting families who were receiving the news. When analysing the results it was necessary to remove a number of answers of one respondent as this portion of the questionnaire was filled out in relation to the professional's practice in general and referred to the generality of cases seen instead of the last case in which they were involved. It is important to acknowledge that staff members who supported families who had received their child's diagnosis may often not have been present at the actual time of disclosure but perhaps became involved shortly afterwards, or were responsible for confirming and repeating information for family members after the event. This factor in how families are informed contributes to the fact that there are many 'missing' respondents in the following sections describing the actual disclosure event.

Most recent time professional informed a family

As was seen above when professionals estimated how often they are involved, there are varying levels of frequency with which staff members encounter the disclosure process in relation to a child's disability, and the following table supports this finding, in showing that the most recent time that professionals recalled communicating this news varied from within the past week to as much as 3 years previously. The largest group of respondents (13.9%) had informed a family within the previous week.

Figure 5.13 – Length of time since the professional last informed a family



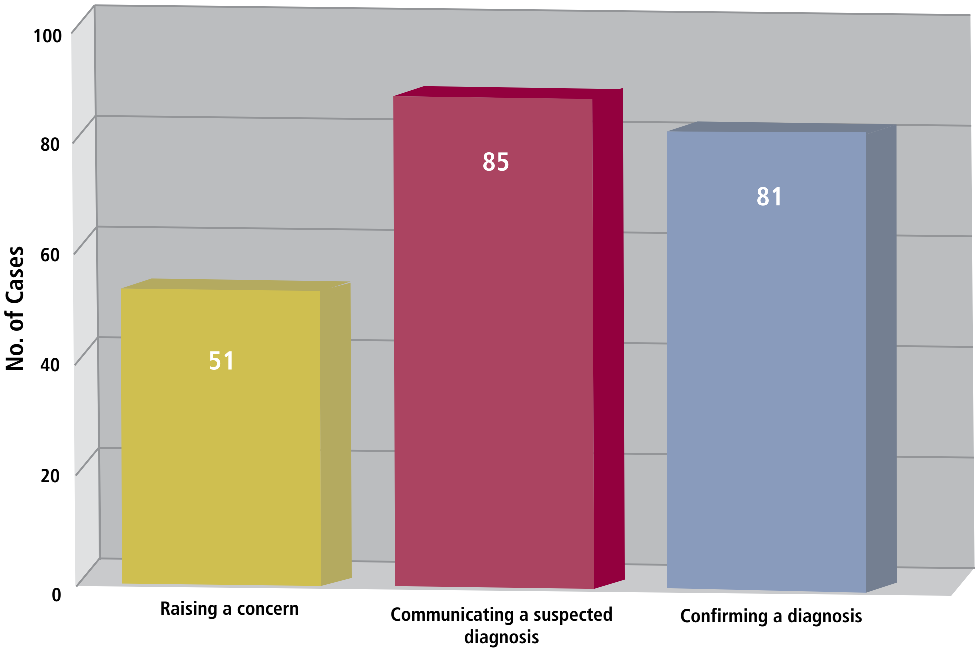
When referring to the last time that they had been involved in the disclosure of a disability to a child's family, over two fifths (43.3%) of the professional respondents described their role as being involved in supporting both the family and the professional delivering the news. Slightly fewer (39.1%) were responsible for giving the diagnosis in the particular case being described.

Child's Diagnosis

The professional respondents were asked what stage of diagnosis was being communicated the last time that they gave the news or supported a family receiving the news; raising a concern, communicating a suspected diagnosis, or confirming a diagnosis.

In Figure 5.14 below we can see that there was a relatively even spread of responses as to the stage of diagnosis the respondents were involved in, with the most common stage reported being that of 'communicating a suspected diagnosis'. Fifty-five respondents did not respond to this particular question.

Figure 5.14 – Stage of diagnosis the professional was involved in disclosing



It was possible for the professionals to give the family a clear diagnosis in just over two fifths of the cases (41.6%). Table 5.37 below indicates the types of disability that were present. As with the parent questionnaire, respondents indicated more than one category in many cases, and in keeping with the findings of the parent questionnaire, intellectual disability was again the most common type of disability present.

Table 5.37 - Types of Disability Present

Types of Disability Present	n=	Percentage
Physical disability	63	26.5%
Sensory disability	30	12.6%
Intellectual disability	82	34.5%
Multiple disability	49	20.6%
Autistic spectrum	27	11.3%
Missing	52	21.8%

Severity of disability

Professionals were asked if any terms indicating the likely severity of the child's disability had been used in relation to the child's diagnosis. Multiple categories were indicated by a number of professionals in answer to this question. Similar levels of moderate, severe and profound disabilities were present in the parent questionnaire however the percentage of professional respondents who indicated mild disability was less than half of those in the parent questionnaire.

Table 5.38 - Severity of Disability

Terms used in relation to child's disability:	n=	Percentage
Mild	26	10.9%
Moderate	45	18.9%
Severe	39	16.4%
Profound	13	5.5%
None of these	69	29.0%
Other	21	8.8%
Don't Know	5	2.1%
Missing	56	23.5%

Syndrome or Disability Name

Respondents were asked to specify where possible the name of the syndrome/condition diagnosed. As with the parent questionnaire results, there was a wide range of disabilities reported from across physical, intellectual and sensory disabilities, and autistic spectrum disorder, and these are set out in Table 5.39 opposite. This table was categorised in conjunction with a Consultant Paediatrician and a Consultant Obstetrician/Gynaecologist.

Table 5.39 - Disability or syndrome name

Name of syndrome	n=	Percentage
Acquired brain injury (ABI)	1	0.4%
Autistic Spectrum Disorder	13	5.5%
Cardiac	3	1.3%
Cerebral Palsy	5	2.1%
Chromosal (non Down Syndrome)	10	4.2%
Cleft lip and/or palate	1	0.4%
Congenital deafness	2	0.8%
Downs Syndrome	17	7.1%
F.A.P.	1	0.4%
Genetic (non chromosal)	4	1.7%
Hearing loss/deafness	3	1.3%
Hydrocephalus (non Down Syndrome)	2	0.8%
Learning/Intellectual disability	11	4.6%
Lissencephally	1	0.4%
Mito chondrial disorder	2	0.8%
Musculo skeletal	4	1.7%
Neurological	1	0.4%
Occular	1	0.4%
Renal	2	0.8%
Respitatory	1	0.4%
Specific language impairment	1	0.4%
Spina Bifida	1	0.4%
Very rare syndrome	3	1.3%
Other	3	1.3%
Missing	145	60.9%
Total	**238**	**100%**

Child's Age at diagnosis

In responding to the stage at which the diagnosis they were describing had been given to the family; during pregnancy, at birth, or at a later stage, a much smaller proportion of families (less than 15%) were reported in the Professional Questionnaire as having received the diagnosis at the time of birth compared with 46.2% of respondents to the Parent Questionnaire. Almost one quarter of professionals did not respond to this question.

Table 5.40 - Stage at which diagnosis given

Time of diagnosis	n=	Percentage
Before birth	25	10.5%
At birth	34	14.3%
At the time of adoption	5	2.1%
At a later time	119	50.0%
Missing	55	23.1%

Of the 50% of the families reported who did not receive their child's diagnosis at or before birth, there was a wide spread of ages as to when the diagnosis took place. Figures 5.15 and 5.16 below show these age ranges, broken down into those that occurred within the first year after the child's birth (31.9%), and those that took place after the child was one year of age (68.1%).

Figure 5.15 – Time of diagnosis – children aged less than 1 year

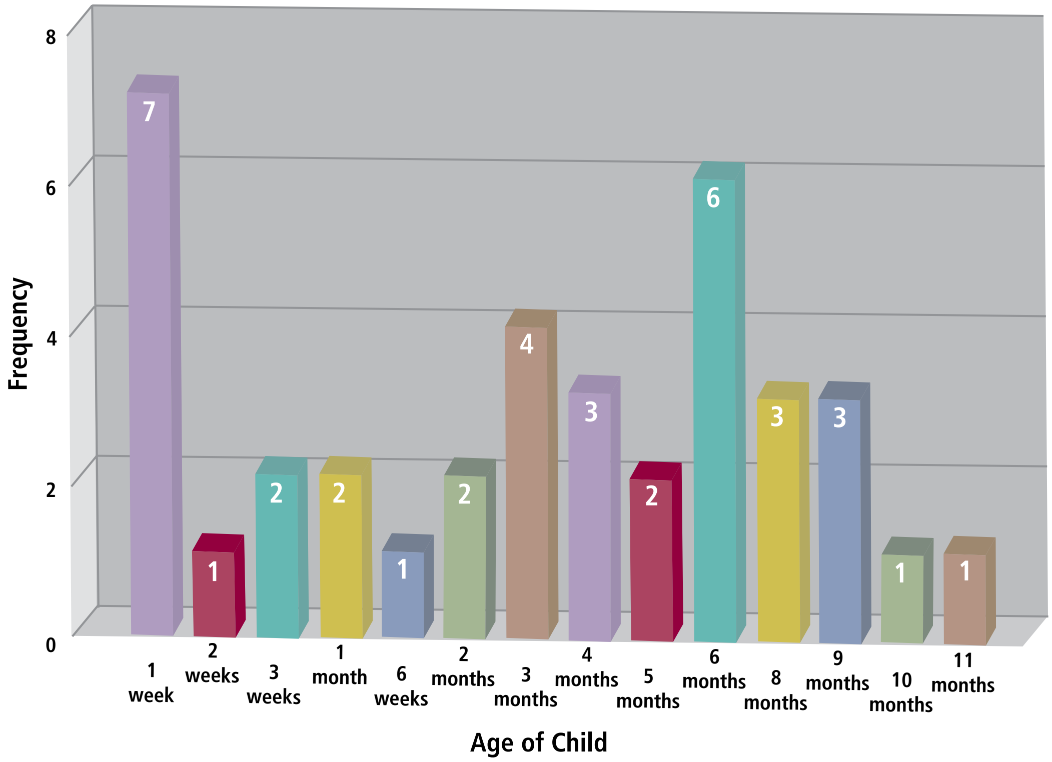
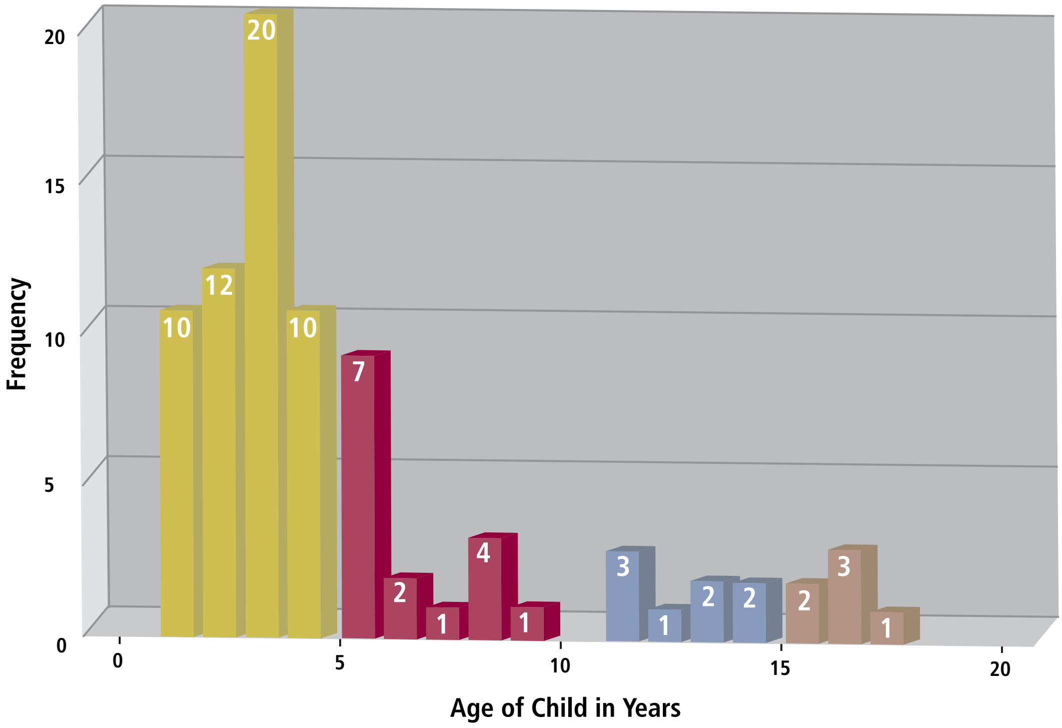


Figure 5.16 – Time of diagnosis – children aged 1 year or more



Parents age at diagnosis

In estimating the age of the parents of the child whose disability was diagnosed, the most common age range indicated by professionals for both mothers and fathers was the '30-39' bracket

Table 5.41 - Parents age at time of diagnosis

Age at time of diagnosis	Mother		Father	
	n=	Percentage	n=	Percentage
10-19 years	1	0.4%	-	-
20-29 years	26	10.9%	14	5.9%
30-39 years	108	45.4%	87	36.6%
40-49 years	33	13.9%	40	16.8%
50-59 years	-	-	3	1.3%
Missing	70	29.4%	94	39.5%
Total	**238**	**100%**	**238**	**100%**

There was an approximately even amount of cases where the child being diagnosed was the first child in the family, and where this was not the case

Table 5.42 - First Child in the Family

	n=	Yes	No	Don't Know	Missing
Was this child the first child of the parents?	183	36.6%	38.7%	1.7%	55

Diagnosis given at one time or evolved

In contrast to the parent questionnaire where for over half of the children (52.7%) the diagnosis came at one particular time, this was the case for just 19.7% of the children whose diagnosis was described by the professional respondents. A higher number of children had an evolving diagnosis (43.1%) in the professional survey versus 35.9% of cases in the parent survey.[19]

Table 5.43 - Diagnosis came at one time or evolved over time

Diagnosis given at one time or evolved	n=	Percentage
Did the diagnosis…		
Evolve over time	103	43.1%
Come at one particular time	47	19.7%
Diagnosis still uncertain	25	10.5%
Don't know	6	2.5%
Missing	58	24.3%
Total	**239**	

These findings show that for a large proportion of families the first news involves the communication of a concern or a suspected diagnosis but does not provide the final syndrome name or disability. **This is an important indicator that disclosing a disability to the family is a process rather than a one-off event.**

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[19] For this table the figures relate to 239 cases, as one respondent ticked two boxes and so both answers were captured.

5.3.3 - Setting/Location and People Present

The following section of the report describes the setting in which the news was given to the family, and the people who were present. In almost four fifths (77.7%) of cases reported by the professional respondents the news was given to the family in face to face meetings, with only one case reported in which the news had been given in writing and no cases in which parents had been informed over the telephone.

Professional that first informed the family

Professionals responding to the questionnaire were asked to indicate which member of the staff team had first given the news to parents that their child had a disability. As with the parent section of the report, the most commonly noted discipline that first gave the news was 'Paediatrician'. This was significantly higher than the next most frequently reported discipline which was 'Psychologist'. There were a high number of non-respondents to this question, possibly largely due to supporting staff members not having been present at the first disclosure.

Table 5.44 - Professional who first gave the news

	n=	Percentage
Which member of the team first gave the news?		
Audiologist	3	1.3%
Cardiologist	1	0.4%
Consultant	3	1.3%
Consultant Anaesthetist	1	0.4%
Consultant ENT	1	0.4%
Doctor	5	2.1%
Eye Specialist (Opthalmologist/Optometrist)	1	0.4%
Foetal Medicine Specialist	2	0.8%
GP	1	0.4%
Genetic Counsellor	1	0.4%
Midwife	6	2.5%
Neonatologist	2	0.8%
Neurologist	3	1.3%
Nurse	1	0.4%
Obstetrician/Gynaecologist	9	3.8%
Paediatric Nurse	1	0.4%
Paediatrician	**52**	**21.8%**
Physiotherapist	1	0.4%
Psychiatrist	4	1.7%
Psychologist	**12**	**5.0%**
Public Health Nurse	1	0.4%
Speech and Language Therapist	3	1.3%
Trainee Paediatrician	1	0.4%
Ultrasonographer	2	0.8%
Other	1	0.4%
Missing	120	50.4%

Presence of additional staff members

As with the parent questionnaire, professional respondents were asked to list the additional staff members present if more than one staff member attended the disclosure, and four spaces were provided in the questionnaire for the purpose of listing those present. 270 responses were given to this question and are categorised in Table 5.45 below. Paediatric nurses were mentioned in the highest number of instances as being additional staff members. Paediatricians, Psychologists, Midwives, and Trainee Doctors were the next highest instances in terms of additional staff members in attendance.

Table 5.45 - Presence of additional staff members

Disciplines Present	n=	Percentage
The disciplines present when the news was given were...		
Audiologist	6	2.2%
Cardiologist	1	0.4%
Clinical Nurse Specialist	1	0.4%
Consultant	13	4.8%
Consultant Anaesthetist	2	0.7%
Consultant ENT	3	1.1%
Dermatologist	1	0.4%
Doctor	2	0.7%
Family Members	1	0.4%
Foetal Medicine Specialist	1	0.4%
GP	2	0.7%
Genetic Counsellor	1	0.4%
Guidance Counsellor	1	0.4%
Interpreter	2	0.7%
Midwife	**23**	**8.5%**
Midwife Manager	4	1.5%
Neonatal Nurse	4	1.5%
Neonatologist	2	0.7%
Neurologist	2	0.7%
Neurology Nurse Specialist	1	0.4%
Nurse	17	6.3%
Obstetrician/Gynaecologist	7	2.6%
Occupational Therapist	7	2.6%
Paediatric Nurse	**29**	**10.7%**
Paediatrician	**26**	**9.6%**
Parent	3	1.1%
Physiotherapist	5	1.9%
Psychiatrist	4	1.5%
Psychologist	**25**	**9.3%**
Psychotherapist	1	0.4%
Public Health Nurse	5	1.9%
Social Worker	16	5.9%
Speech and Language Therapist	10	3.7%
Teacher	5	1.9%
Trainee Cardiologist	1	0.4%
Trainee Doctor	**18**	**6.7%**
Trainee Paediatrician	9	3.3%
Trainee Psychologist	1	0.4%
Trainee Social Worker	1	0.4%
Ultrasonographer	2	0.7%
Other	5	1.9%

Service Setting for Disclosure

Professional respondents were asked to indicate the service settings in which the diagnoses were given to the parents, and so doing were given a number of spaces in order to capture each setting if the diagnosis had taken place in a number of stages or across settings. As with the parent questionnaires there was a spread of service settings reported from hospital, community and disability services. In contrast with approximately two fifths of the instances recorded by parents taking place in the Maternity Hospital, this was the setting for less than 2% of the cases described by professionals. Paediatric Hospitals and Early Services were mentioned in many instances, in keeping with the parent cases reported, and a category not previously reported in the parent questionnaires; Child and Adolescent Mental Health Services, also featured frequently. 168 responses were given to this question in total.

Table 5.46 - Service setting for disclosure

Service Settings	n=	Percentage
Audiology Department	1	0.6 %
Autism Services	1	0.6 %
Child and Adolescent Mental Health Services	**15**	**8.9%**
Cardiology Unit	1	0.6 %
Career Guidance	1	0.6 %
Child Guidance/Development Clinic	2	1.2%
Clinic	1	0.6 %
Community Care Psychology Services	1	0.6 %
Community Care Services	2	1.2%
Community Paediatric Services	1	0.6 %
Dept. of Education & Science (NEPS)	1	0.6 %
Dept. of Education & Science Learning Support	1	0.6 %
Disability Service Provider	3	1.8%
Ear, Nose and Throat Services	1	0.6 %
Early Services	**14**	**8.3%**
Foetal Assessment Unit	6	3.6%
Hospital	4	2.4%
Intellectual Disability Service Provider	2	1.2%
Maternity Hospital/Unit	**3**	**1.8 %**
Neonatal Unit	5	3.0 %
Obstetric Unit	5	3.0%
Oncology Unit	1	0.6%
Outpatients Dept/Clinic	5	3.0%
Paediatric Hospital/Unit	**63**	**37.5%**
Paediatric ICU	4	2.4%
Paediatric Neurology Services	1	0.6%
Prenatal Diagnosis Services	4	2.4%
Prenatal Ultrasound	4	2.4%
Scan Unit	1	0.6%
SCBU/NICU	5	3.0%
School	2	1.2%
Speech and Language Services	1	0.6%
Others	6	3.6%

Number of staff members present at disclosure

The most common number of staff members present when the diagnosis was communicated, in the cases described in the professional questionnaire, was two (26.9%). In a smaller number of cases (15.5%) there was only one staff member present. Five respondents stated that there were more than four professionals present when the news was given. In 14.3% of disclosures the staff members present were not known to the family. The respondents were asked to reflect on whether the number of people present was comfortable and helpful to the family, and to the professional respondent themselves. The findings from the data recorded can be seen in Table 5.47 below.

Table 5.47 - Effect of number of staff members present

	n=	Yes	No	Missing
Do you think the number of people present was...				
Comfortable for the family?	132	52.9%	2.5%	106
Helpful to the family?	89	31.9%	5.5%	149
Comfortable for you?	88	33.2%	3.8%	150
Helpful to you?	84	29.4%	5.9%	154

Family members/friends present at disclosure

Professionals responding to the questionnaire indicated that in 17.6% of cases, the person receiving the news of their child's disability was alone. This compares with 25.5% of parent respondents who indicated that there was no family member or friend present. The news was most often given to the mothers, **with fathers present in just over half of cases**, as can be seen in Table 5.48 below.

Table 5.48 - Presence of family members/friends

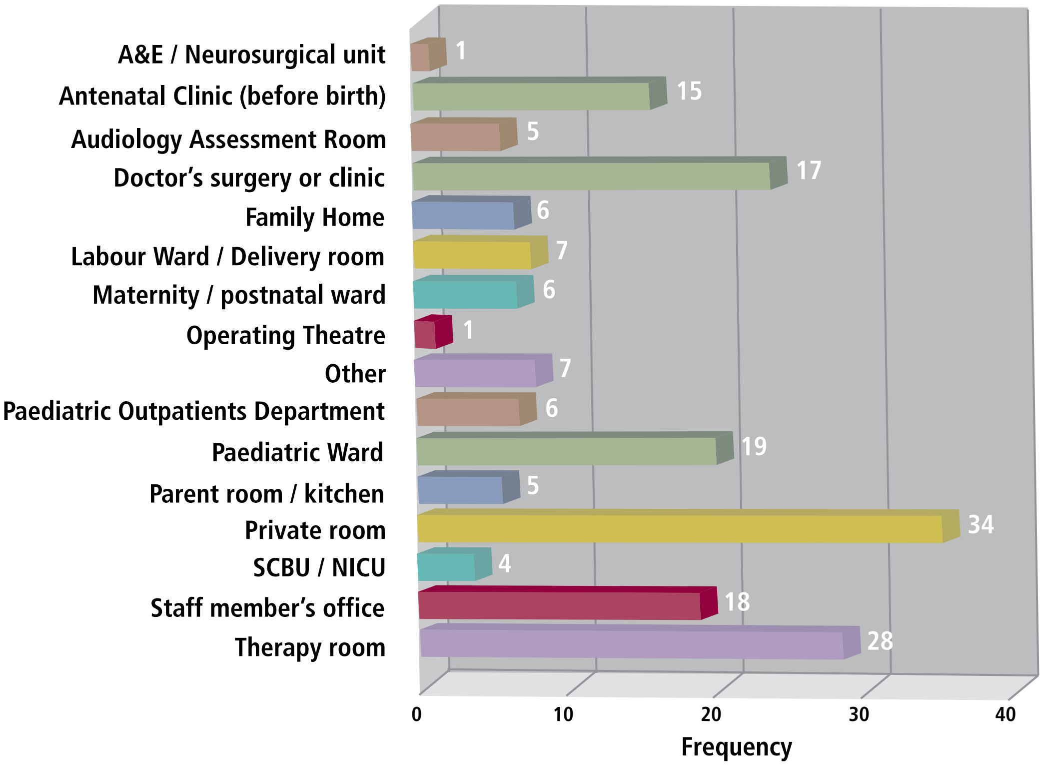
Family members/friends present at disclosure	n=	Percentage
Child (Older/Teenager)	1	0.4%
Family Friend	1	0.4%
Father	**129**	**54.2%**
Grandfather	1	0.4%
Grandmother	2	0.8%
Grandparents	2	0.8%
Maternal Aunt	1	0.4%
Mother	**169**	**71.0%**
Mother's Partner	1	0.4%
Siblings	1	0.4%
Uncle	2	0.8%
Missing	64	26.9%

38.2% of professionals indicated that the child was present at the disclosure, with this question not being applicable for the 8.8% of diagnoses which were given before birth.

Location in which the diagnosis was given

Within the wider service setting category professional respondents were asked to specify the actual room or location where the news was given. In keeping with the results of the parent questionnaire, there was a wide spread of responses indicating where disclosure took place. Respondents specifically noted 'Private Room' as the location in 14.3% instances, the most common location. However, it is important to note that a number of the other specified locations might be considered private rooms as well. The next most common location was the 'Therapy Room' (11.3%), followed by the 'Paediatric Ward' (7.7%), 'Staff Member's Office' (7.3%) and 'Doctor's Surgery or Clinic' (6.9%).

Figure 5.17 – Location for disclosure



Environment

Table 5.49 below indicates that, in the opinion of the professional respondents, the environment was private the majority of the time, and was comfortable in half of cases. However just two fifths of professionals found the environment welcoming. A very small number of respondents indicated that interruptions had occurred during the time in which parents were told of their child's disability.

Table 5.49 - Environment for disclosure

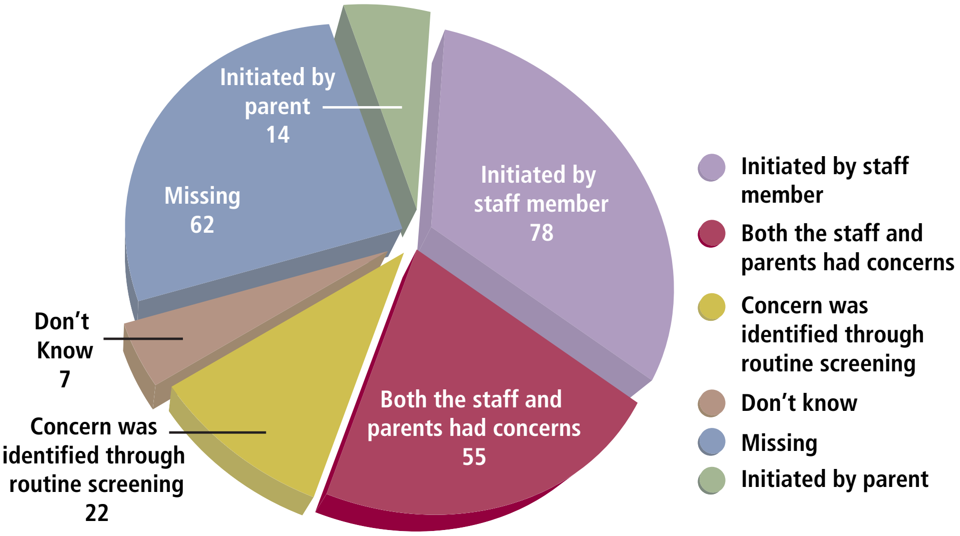
Environment	n=	Yes	No	Missing
Private environment	165	67.2%	2.1%	73
Welcoming environment	120	40.8%	9.7%	118
Comfortable environment	137	50.8%	6.7%	101
Were there interruptions?	122	5.0%	46.2%	116

5.3.4. Communication

The following section explores how the diagnosis of the child's disability was first communicated to parents, as detailed in the cases described by professionals who responded to the questionnaire survey.

From Figure 5.18 below we can see that the discussion of diagnosis was most commonly initiated by staff members (in 32.8% of cases), followed by the initiation through concerns of both staff and parents (23.1%). Initiation by parents alone occurred less frequently (5.9%).

Figure 5.18 – Initiation of disclosure discussion



The table below shows the assessment by the professional respondents of the communication skills used during the consultation. Over two thirds of respondents felt that the family was treated with empathy and that the child was referred to respectfully. These results largely reflect the results of the parent questionnaire. However there was a 20% higher estimation by parents that the professional giving the news was direct, while professionals were 15% more confident that the person giving the news understood what it would mean for the family. Less than 10% of professionals felt that the news was not given with hope and positive messages, in contrast with the 48.1% of parents who made this assessment. The 'Don't know' category was added in the professional questionnaire to take account of the fact that many professionals indicate that it is difficult to objectively critique one's own skills, and since others were not present at the initial disclosure as detailed above.

Table 5.50 - Communication of the diagnosis

Communication	n=	Yes	No	Don't Know	Missing
During the consultation did you feel that...					
The family were treated with empathy	172	68.1%	0.4%	3.8%	66
The child was referred to respectfully	169	66.8%	0.4%	3.8%	69
The news was given with hope, and positive messages	168	52.5%	8.8%	9.2%	70
The person giving the news had a good understanding of disability	167	63.0%	2.5%	4.6%	71
The person giving the news was approachable	170	65.1%	1.3%	5.0%	68
The person giving the news was understanding	169	66.4%	–	4.6%	69
The person giving the news was direct	169	64.3%	1.3%	5.5%	69
The person giving the news a good communicator	167	61.3%	1.3%	7.6%	71
The person giving the news understood what it would mean for the family	169	60.9%	1.3%	8.8%	69
The reactions of the family were acknowledged and taken into account	168	65.1%	–	5.5%	70

Comprehension of the diagnosis

The results in Table 5.51 below, report that nearly two thirds of professional respondents felt that the parents understood what they had been told during the diagnosis, which is slightly higher than the 56.5% of parent respondents who indicated that they had understood. In two thirds of cases professionals report that a member of the staff team checked to ensure parental comprehension, which contrasts with the 45.1% of parents who felt this had happened. A significant majority of both parents and professionals indicated that parents had an opportunity to ask questions.

Table 5.51 - Parental comprehension of the diagnosis

Parental comprehension of the diagnosis	n=	Yes	No	Don't Know	Missing
Did you feel that the parents understood what they had been told about the diagnosis?	167	62.6%	7.6%	n/a	71
Did you or another member of the staff team check if the parents had understood what they had been told?	175	62.2%	7.1%	4.2%	63
Did the parents have an opportunity to ask questions?	177	71.0%	–	3.4%	61

The results in Table 5.52 below also indicate that the majority of professional respondents felt they themselves had a good understanding of disability and a clear idea of the consequences for the family.

Table 5.52 - Professional comprehension of the diagnosis

Professional Comprehension of the diagnosis	n=	Yes	No	Missing
Do you feel that you have a good understanding of disability?	174	68.1%	5.0%	64
Did you feel you had a clear concept of the consequences of the diagnosis for the family?	176	66.8%	7.1%	62

5.3.5. Provision of Information and Support

As has been seen from the focus groups and the results of the parent questionnaire, communicating the news to a family that their child has a disability can be seen as a process rather than a one off event. In order to assess the quality and level of information provided to families in the following section, the professional questionnaire asked first respondents if this was the first time that the parents in the cases described had received information that their child has/may have a disability, and the results are tabulated below.

Table 5.53 - First information received by parents of possible disability

Disclosure of Diagnosis	n=	Yes	No	Don't Know	Missing
Was this the first time that the parents had received information that their child has/may have a disability?	179	37.4%	31.5%	6.3%	59

Amount/level of information provided

In evaluating the level of information that was given to parents on the last occasion that professionals informed a family, the majority of respondents felt that the parents received enough information in contrast with 49.5% of parents who made this response. A very small proportion of professionals indicated that too little information was given, in contrast with 39.7% of parents. Over half (55%) of respondents indicated that they asked the parents if they wanted more information.

Table 5.54 - Amount/level of information received

Information provided	n =	Percentage
Enough information	152	63.9%
Too much information	15	6.3%
Too little information	13	5.5%
Missing	58	24.4%
Total	238	100%

Quality of information

The majority of professional respondents noted that the information provided to the family was both easily understood and up to date. A smaller proportion indicated that the information provided was easy to remember. No information was received by parents in three of the cases described. As can be seen from the table below very few professionals felt that the information provided was too technical. Parents indicated less often that the information they received was up to date (45.1%) and in two fifths of cases felt that it was too technical.

Table 5.55 - Quality of information received

Quality of information	n=	Yes	No	Don't Know	No Information received	Missing
Was the information provided to the family...						
Easily understood?	180	61.3%	5.5%	7.6%	1.3%	58
Easy to remember?	165	43.7%	9.2%	15.1%	1.3%	73
Up to date?	164	60.1%	0.8%	6.7%	1.3%	74
Too technical?	154	6.7%	44.5%	12.2%	1.3%	84

Timing of written information

Almost half the respondents indicated that no written information was provided to parents at the time of diagnosis. Responses from those who indicated that parents received information 'at a later date' were spread widely and ranged from 24 hours to 6 months later.

Table 5.56 - Timing of written information

Written information received	n=	Yes	No	Don't Know	Missing
Was written information provided...					
At the time of diagnosis?	152	15.1%	44.5%	4.2%	86
At a later date?	153	34.5%	22.3%	7.6%	85

Information about tests undertaken

Following diagnosis professionals indicated that tests or investigations were carried out in over two fifths of cases, (contrasting with over three quarters of parent respondents). In both parent and professional questionnaires the vast majority of respondents indicated that any tests undertaken were explained to the family. Of the professionals who indicated that tests/investigations had been undertaken, just over half (57.5%) explained the tests to the parents themselves.

Table 5.57 - Tests/investigations undertaken

Test / Investigations Undertaken	n=	Yes	No	Don't Know	Missing
Was written information provided…					
After the news was given were any tests/investigations undertaken?	174	44.5%	22.3%	6.3%	64
If yes, were they explained to the family?	104	95.3%	–	2.8%	2

Follow-up

Professionals indicated that in over two thirds of cases the family were provided with a contact name and were offered a follow-up meeting. The small number of families who did not receive a contact name or follow up meeting as indicated in Table 5.58 below, contrasts with 41.5% of respondents to the parent questionnaire who reported that they were not provided with a contact name, and 29.9% of parent respondents who did not receive a follow up appointment.

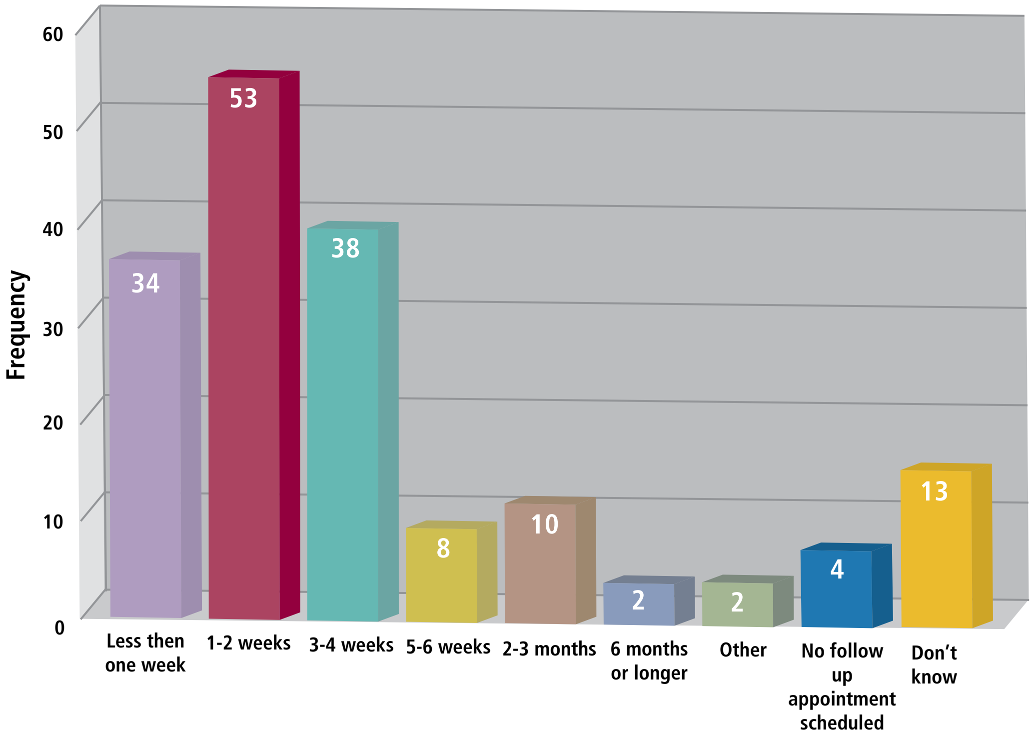
Table 5.58 - Follow-up appointments and named contacts

	n=	Yes	No	Don't Know	Missing
Was the family provided with a contact name after the first meeting?	182	65.5%	5.5%	5.5%	56
Were the family offered a follow-up appointment?	178	64.3%	5.5%	5.0%	60

Follow-up Appointment

From Figure 5.19 below it can be seen that the majority of follow-up appointments were scheduled within a month of the first meeting.

Figure 5.19 - Length of time before follow-up appointment



As can be seen in Table 5.59 below, in over two fifths of cases there was continuity between the staff members who had attended the first disclosure and those who were present at the follow-up appointment.

Table 5.59 - Continuity of staff members at follow-up appointment

Staff member continuity	n=	Yes	No	Don't Know	No follow-up appointment	Missing
Did the staff members that gave the first information attend the follow-up appointment?	172	43.3%	18.5%	8.4%	2.1%	66

Support Options

The proportion of families who were offered contact with a social worker and contact with parents of other children with disabilities matches closely with the figures reported in the parent questionnaire. The option of counselling was provided in almost a third of the cases reported by professionals but to a smaller proportion of parent respondents.

Table 5.60 - Support options offered

Support offered	n=	Yes	No	Don't Know	Missing
Contact with other parents of children with disabilities	173	14.3%	50.0%	8.4%	65
Contact with a social worker/liaison person	182	48.7%	23.1%	4.6%	56
The option of counselling	174	27.7%	36.1%	9.2%	64

5.3.6. Culture and Language

Parents' first language

For the majority of cases discussed in the professional questionnaire responses, the first language of the parents was English, as was the case in the parent questionnaire. A range of other languages was also reported for both the mother's and the father's first language. This data is presented in Table 5.61.

Table 5.61 - First language of parents

Language	Mother		Father	
	n=	Percentage	n=	Percentage
Arabic	1	0.4%	1	0.4%
Eastern European (Language not specified)	1	0.4%	–	–
English	158	66.4%	146	61.3%
English, French & Spanish	1	0.4%	1	0.4%
French	2	0.8%	1	0.4%
Irish	7	2.9%	8	3.4%
Latvian	2	0.8%	1	0.4%
Nigerian Dialect	3	1.3%	3	1.3%
Portuguese	1	0.4%	1	0.4%
Romanian	1	0.4%	1	0.4%
Romanian & Spanish	1	0.4%	–	–
Spanish	1	0.4%	–	–
Urdu	1	0.4%	1	0.4%
Don't Know	2	0.8%	4	1.7%
Missing	56	23.6%	70	29.4%
Total	**238**	**100%**	**238**	**100%**

Interpretation services

Of the 25 families for which professional respondents had indicated that one or both parents did not have English as their first language, seven families were provided with interpretation services and eight were not. In two cases interpretation services were offered but declined by the family.

Table 5.62 - Provision of interpreter

Language	n=	Yes	No	Not applicable	Missing
If the first language of the parent is not English, was an interpreter made available?	20	28.0%	32.0%	5.0%	5

In all seven cases for which an interpreter was provided, they attended in person rather than interpreting over a phone line. Table 5.63 below shows that in the majority of cases where an interpreter was provided it was a professional interpreter that was used, however there were also other cases where interpreting was carried out by staff members who spoke the parents first language and in one case a family member. An additional respondent indicated the presence of an interpreter for the deaf in a case where English was the first language of both parents.

Table 5.63 - Type of interpreter

Interpreter Details	n=	Percentage
A professional interpreter	4	57.1%
A family member	1	14.3%
A member of staff who speaks the parent’s first language	2	28.6%

It was found that only three of the 25 families with a parent whose first language was not English received written information in their first language.

Culture appropriateness of information provided

Professional respondents were asked to indicate whether the information provided to the family, written or otherwise, was checked to ensure that it was sensitive and appropriate to the family’s culture. This question specified that religious and cultural beliefs and practices, as well as language should be considered. It was indicated in under a third of cases that this had taken place.

Table 5.64 - Cultural appropriateness of information provided

Sensitivity to culture	n=	Yes	No	Don’t know	Missing
Was information provided to the family checked to ensure it was sensitive and appropriate to the family’s culture?	140	27.7%	15.1%	16.0%	98

5.3.7. Information Sharing and Liaison

Given the importance of the team approach when disclosing the news of a child's disability, as indicated in the focus group findings, the following questions were added to the professional questionnaire to explore information sharing and liaison between professionals involved in the communicating with the family. In two thirds of cases (66%) the respondent or another staff member recorded details of the consultation with the family. These were recorded in a variety of formats, the most common being file notes (15.0%) and on the child's chart (9.7%).

The respondents were then asked whether written details were sent to the family's G.P., Public Health Nurse and/or the family. While the GP was sent details of the child's diagnosis in almost half of the cases, it was less common for the Public Health Nurse to receive this information. This may be attributable to the Public Health Nurse being more involved with those children who are diagnosed before or shortly after birth. Written confirmation of the diagnosis was sent to families in less than one third of cases.

Table 5.65 - Written information-sharing between professionals

Information Sharing	n=	Yes	No	Don't know	Missing
Were written details of the diagnosis sent to the…					
Family's G.P.	179	47.1%	13.9%	14.3%	59
Public Health Nurse	178	29.8%	31.9%	13.0%	60
Family	182	27.7%	34.0%	14.7%	56

It is important to note that five respondents to this question indicated that they were the family's G.P. and one noted that they were a Public Health Nurse.

Other disciplines involved

The diagnosis of a disability can sometimes be given to parents in stages or evolve over time. For this reason the professional respondents were asked to indicate if they were aware of other professionals involved in telling the parents about the child's disability on previous occasions and on occasions after the consultation being described through the questionnaire. In almost a third of cases (31.1%) the respondents were aware of other professionals involved in telling the news on occasions prior to the consultation. Over a third of professional respondents (35.3%) indicated that they were aware of professionals involved in disclosing aspects of the news on occasions after the consultation being described. Table 5.66 below shows that where respondents were aware of other professionals there were over 10% of cases where liaison had not taken place.

Table 5.66 - Liaison between professionals

	n=	Yes	No	Not Aware of other Professionals being involved	Not applicable	Missing
If you were aware of other professionals involved in telling the parents, did liaison take place between the parties to ensure consistent communication?	129	30.3%	11.3%	5.0%	7.6%	109

Professional respondents listed the disciplines involved on previous occasions and on occasions subsequent to the consultation described in the questionnaire. They also listed the relevant service types. These findings are presented in Tables 5.67 to 5.70 below. The value of this information is that it shows the patterns of professional disciplines that may be involved at the early stages and at later stages of diagnoses.

Table 5.67 - Disciplines involved on previous occasions

Other Disciplines Involved	n=	Percentage
Area Medical Officer	3	4.0%
Audiologist	5	6.8%
Cardiologist	2	2.7%
Child & Adolescent Mental Health Services	1	1.4%
Community Nurse	1	1.4%
Consultant	2	2.7%
Consultant ENT	3	4.0%
Consultant Gastroenterologist	1	1.4%
Dermatologist	1	1.4%
Dietitian	1	1.4%
GP	6	8.1%
Genetic Specialist	1	1.4%
Midwife	4	5.4%
Neonatologist	1	1.4%
Neurologist	5	6.8%
Neurosurgeon	1	1.4%
Nurse	2	2.7%
Obstetrician/Gynaecologist	8	10.8%
Occupational Therapist	6	8.1%
Paediatric Link Worker	1	1.4%
Paediatric Nurse	2	2.7%
Paediatrician	36	48.6%
Physiotherapist	7	9.5%
Psychiatrist	6	8.1%
Psychologist	10	13.5%
Public Health Nurse	6	8.1%
School Principal	1	0.4%
Social Worker	4	5.4%
Specialist Nurse	1	0.4%
Speech and Language Therapist	6	8.1%
Trainee Doctor	4	5.4%
Trainee Paediatrician	1	0.4%
Ultrasonographer	1	0.4%

Table 5.68 - Service type of disciplines previously involved

Service Type	n=	Percentage
Child Guidance/Development Clinic	4	3.5%
Child's Home	3	2.6%
Clinic	8	7.0%
Community Care Services	10	8.8%
Community Paediatric Services	1	0.9%
Disability Service Provider	8	7.0%
Ear, Nose and Throat Services	1	0.9%
General Practice	2	1.8%
Genetic Centre	1	0.9%
Hospital	19	16.7%
Hospital/Community	2	1.8%
Local Clinic	2	1.8%
Local Health Centre	1	0.9%
Maternity Hospital/Unit	30	26.3%
Neonatal Unit	1	0.9%
Outpatients Dept/Clinic	1	0.9%
Paediatric Hospital/Unit	13	11.4%
Prenatal Ultrasound	1	0.9%
Private Practice	2	1.8%
School	2	1.8%
Others	2	1.8%

Table 5.69 - Disciplines involved on subsequent occasions

Other Disciplines Involved	n=	Percentage
Anaesthetist	1	0.6%
Audiologist	1	0.6%
Cardiologist	2	1.2%
Chaplain	1	0.6%
Community Nurse	2	1.2%
Consultant	2	1.2%
Consultant ENT	5	2.9%
Counsellor for Special Needs	1	0.6%
Dietitian	2	1.2%
Doctor	2	1.2%
GP	9	5.2%
Genetic Counsellor	1	0.6%
Geneticist	1	0.6%
Liaison Nurse	4	2.3%
Metabolic Consultant	1	0.6%
Midwife	4	2.3%
Neonatologist	2	1.2%
Neurologist	2	1.2%
Neurology Nurse Specialist	1	0.6%
Nurse	7	4.1%
Nurse Specialist	2	1.2%
Occupational Therapist	6	3.5%
Orthopaedic Surgeon	1	0.6%
Paediatric Nurse	2	1.2%
Paediatrician	19	11.0%
Pastoral Care	1	0.6%
Physiotherapist	12	7.0%
Psychiatrist	3	1.7%
Psychologist	12	7.0%
Public Health Nurse	14	8.1%
Respirologist	1	0.6%
Social Worker	15	8.7%
Speech and Language Therapist	13	7.6%
Surgeon	4	2.3%
Teacher	2	1.2%
Therapist	1	0.6%
Trainee Doctor	2	1.2%
Visiting Teacher for the Deaf	5	2.9%
Other	6	3.5%

Table 5.70 - Service type of disciplines subsequently involved

Service Type	n=	Percentage
Cardiology Unit	1	0.8%
Child Guidance/Development Clinic	1	0.8%
Child's Home	4	3.1%
Cochlear Implant Department	1	0.8%
College of Speech and Language Therapists	1	0.8%
Community Care Services	28	22.0%
Dept of Education and Science	2	1.6%
Disability Service Provider	16	12.6%
Early Services	1	0.8%
General Practice	2	1.6%
Genetics Centre	1	0.8%
Hospital	21	16.5%
Hospital/Community	4	3.1%
Intellectual Disability Service Provider	1	0.8%
Learning Disability Service Provider	1	0.8%
Maternity Hospital/Unit	12	9.4%
Outpatients Dept/Clinic	1	0.8%
Paediatric Hospital/Unit	15	11.8%
Paediatric ICU	1	0.8%
Physical Disability Service Provider	1	0.8%
Rehab Clinic	1	0.8%
SCBU/NICU	3	2.4%
Special Education	2	1.6%
Other	6	4.7%

5.3.8. Staff Support

A further key element in relation to the disclosure process which was raised during the focus group consultation was the need to provide staff members with adequate support and debriefing opportunities. The results in Table 5.71 below show that roughly equal numbers of staff members did and did not debrief, with almost two fifths of professionals reviewing or debriefing with a colleague or team member after the news was given to parents.

Table 5.71 - Reviewing with colleagues

	n=	Yes	No	Missing
Did you review/debrief following with a colleague or team member after the news was given to the parents?	177	39.5%	34.9%	61

In relation to those who were in training at the time that the disclosure being described took place, 20 individuals indicated that they had obtained advice from senior colleague.

Table 5.72 - Advice from senior colleague

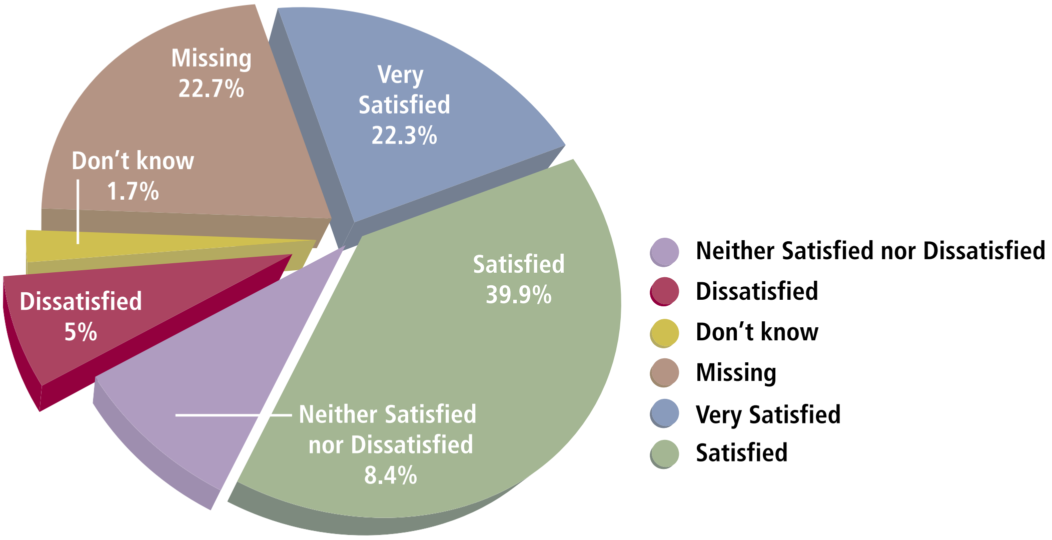
Information Sharing	n=	Yes	No	Not applicable	Missing
If you were alone and in training, was there a senior colleague from whom you obtained advice?	144	8.4%	2.9%	49.2%	94

5.3.9. Professionals Satisfaction with Disclosure

Professionals' satisfaction with disclosure

In relation to the specific disclosure that the professionals had described as being their last experience, respondents indicated their own levels of satisfaction with how the family had been informed. The responses to this question are presented in Figure 5.20 below. Two thirds (62.2%) of professionals were either 'Satisfied' or 'Very Satisfied' with the way in which the family was informed of their child's disability. This contrasts with 36.4% of parents who indicated these responses. A small minority of professionals (5.0%) indicated that they were 'Dissatisfied' with how the diagnosis was disclosed, and no respondents were 'Very Dissatisfied'.

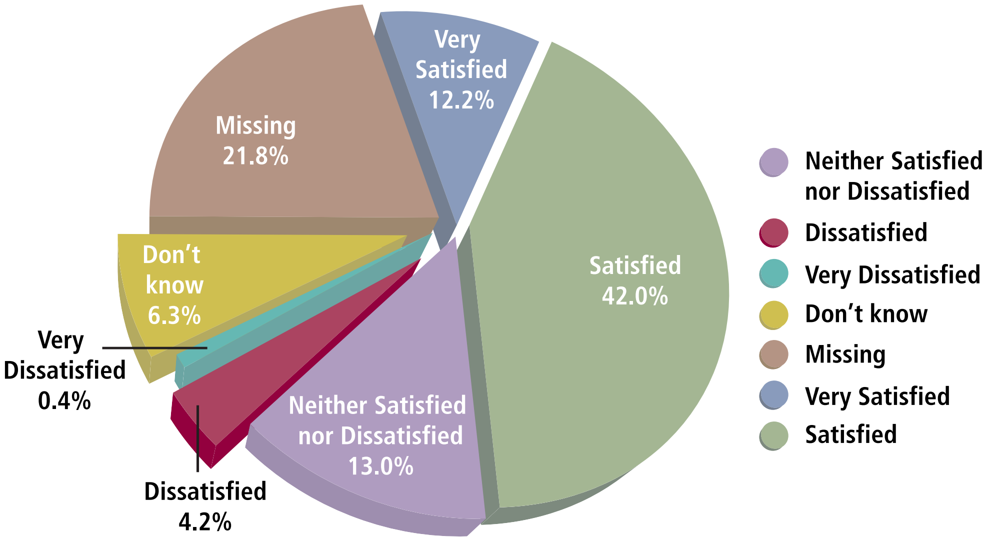
Figure 5.20 - Professional's satisfaction with disclosure



Professionals' assessment of parent satisfaction with disclosure

Having reported their own levels of satisfaction with how the disclosure was handled, professionals then expressed their assessment of how satisfied the family was with how they had been given the news of their child's disability. The majority of professional respondents (54.2%) indicated that they felt parents were 'Satisfied' or 'Very Satisfied' with how they had been informed of their child's disability. Eleven respondents (4.6%) were of the opinion that the parents were 'Dissatisfied' or 'Very Dissatisfied' with how their child's diagnosis had been disclosed.

Figure 5.21 - Professional's view of parents' satisfaction with disclosure



5.3.10. Rating of Suggested Elements of Best Practice

As with the parent questionnaire, professionals were presented with the suggested list of recommendations which emerged from the focus group consultation of the Informing Families Project, and the national and international literature. Professionals were given identical rating tables to those presented in the parent questionnaires, and as with the parent questionnaire there were high levels of agreement with the suggested recommendations. The results for each category are set out in Tables 5.73 to 5.78 below.

In keeping with the parent rating results, the presence of the child during the consultation was not 'Agreed' or 'Strongly Agreed' with by the majority of professional respondents. The only other element which did not receive a majority of agreement from professional respondents when the 'Agree' and 'Strongly Agree' categories were combined was the recommendation that 'No extra staff are present for training purposes'.

Table 5.73 - Recommendations for Setting/Location & People Present

Setting/Location & People Present	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
In future when parents are told of their child's disability…						
…the news is given in a private place with no interruptions	227	92.9%	2.5%	–	–	–
Both parents are present when the diagnosis is given	226	76.1%	14.3%	4.6%	–	–
If only one of the parents is present, the choice of a family member or friend to be present is given	226	69.3%	23.1%	2.5%	–	–
During the consultation, the child is present	**217**	**13%**	**15.5%**	**37%**	**17.2%**	**8.4%**
The parents have seen the child before the diagnosis is given	210	55%	19.7%	13.4%	–	–
The parents have spent time with the child before the diagnosis is given	212	55.5%	20.2%	13.0%	0.4%	–
The diagnosis is given by a senior staff member	223	69.7%	15.1%	7.6%	1.3%	–
There is an extra staff member present as a support after the news is given	223	61.3%	22.7%	8.8%	0.8%	–
No extra staff are present for training purposes	**220**	**23.1%**	**14.3%**	**22.3%**	**26.9%**	**5.9%**

Table 5.74 - Recommendations for Communication

Communication	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The child is referred to respectfully; by name and not diagnosis	228	92.0%	3.8%	–	–	–
Parents concerns are acknowledged	229	91.6%	4.6%	–	–	–
Parents are listened to with respect, empathy and understanding	228	92.4%	3.4%	–	–	–
Parents concerns are followed up	228	88.7%	7.1%	–	–	–
Positive, realistic messages are given with the diagnosis	227	81.1%	13.0%	1.3%	–	–
Staff members giving the news use simple, understandable language	227	86.6%	8.8%	–	–	–
The reaction of parents is acknowledged and supported	228	86.1%	9.7%	–	–	–
The diagnosis is not rushed and parents are given time to ask questions	226	86.6%	8.4%	–	–	–
Parents are told what will happen next (e.g. tests)	227	81.5%	13.9%	–	–	–
Staff members are aware of all aspects of their communication, including body language and possible interpretations	226	78.6%	15.1%	1.3%	–	–
All medical terminology is explained	226	84.9%	9.7%	0.4%	–	–

Table 5.75 - Recommendations for Training

Training	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Staff members are trained in communication skills	228	77.3%	17.2%	0.8%	–	0.4%
Staff members are trained in good practice for informing families of their child's disability	228	78.2%	16.4%	0.8%	0.4%	–
Staff members have a good understanding of disability	227	75.2%	19.7%	0.4%	–	–

Table 5.76 – Recommendations for Information & Support

Information & Support	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Parents are asked how much information they wish to receive	225	36.1%	38.7%	11.3%	8.0%	0.4%
Parents are asked when they would like to receive information	225	39.9%	38.7%	11.8%	3.8%	0.4%
An interpreter is provided if English is not the first language of the parents	227	81.9%	12.2%	1.3%	–	–
Staff members check that parents have understood what has been discussed	228	79.4%	15.5%	0.8%	–	–
Parents are given a written summary of the consultation	226	45.4%	23.5%	21.0%	4.6%	0.4%
Parents are not left alone for a long period without support	226	51.7%	36.1%	5.5%	0.8%	0.8%
Parents are given time alone together to absorb the news	225	60.1%	28.6%	5.9%	–	–
Parents are given written information (leaflets, books etc.,) about their child's disability/diagnosis	224	58.8%	29.8%	5.5%	–	–
The written information given to parents is in their first language	225	66.4%	24.4%	3.8%	–	–
Parents are given the option of information about support groups	226	62.6%	30.7%	1.7%	–	–
Parents are given the option of contact with other families	221	52.1%	29.8%	11.8%	0.4%	0.4%
Parents are offered the option of counselling	225	55.9%	28.2%	9.7%	0.4%	0.4%
Parents are offered contact with a social worker/liaison person	227	61.3%	26.9%	7.1%	–	–
Parents are kept up to date at all times, with honest information	227	75.6%	19.3%	0.4%	–	–

Table 5.77 - Recommendations for Referral

Referral	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Parents are referred to early services as soon as possible	228	79.0%	16.0%	0.8%	–	–
Parents are given information about the service they are referred to	228	77.7%	17.6%	0.4%	–	–

Table 5.78 - Recommendations for Organisation and Planning

Organisation	n=	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Staff members share information, so that parents do not have to give the same history or information to many different people	228	70.2%	23.5%	1.3%	0.4%	0.4%
Staff members coming on to new shifts are informed that parents have been given the news that their child has a disability	224	76.5%	17.6%	–	–	–
The GP is informed about the child's disability by those giving the news to the parents	227	72.3%	18.5%	4.6%	–	–
The Public Health Nurse is informed about the child's disability by those giving the news to parents	226	62.6%	20.2%	10.5%	1.7%	–
If the diagnosis has been given in the maternity hospital and the mother is staying overnight, a partner or a family member/friend is offered the choice to stay also	221	61.8%	19.3%	11.8%	–	–
The family are offered the choice of accommodation on their own, after the diagnosis	220	46.6%	24.8%	21.0%	–	–
Parents are offered a follow-up appointment within a maximum of two weeks to discuss the diagnosis.	225	57.1%	30.7%	5.5%	1.3%	–

5.3.11. Policies and Training

The sections examined thus far from the professional questionnaire explored the breadth of disciplines who inform families and the service settings in which they work, along with the particular details of the last time that they were involved in disclosing a child's disability. This final section of data from the professional questionnaire examines the support and training needs of professionals as they relate to informing families of their child's disability, examining this area in a more general sense, rather than focusing on one disclosure event.

Existing Guidelines for Informing Families of their Child's Disability

A sizeable majority of respondents to the professional questionnaire indicated that they were unaware of any guidelines already in place dealing with the practice of informing families of their child's disability. Of those who were aware of guidelines already in place, all who responded indicated that they worked within the recommendations of these guidelines.

Table 5.79 - Awareness and practice of existing guidelines

Guidelines for informing families	n=	Yes	No	Missing
Are you aware of any guidelines within your current agency or organization?	219	12.2%	79.8%	19
…If yes, do you work within these guidelines?	26	89.7%	–	3

Formal Training Received

Professionals were asked to indicate the areas related to disclosure of a child's disability in which they had received training, at both the undergraduate/postgraduate levels, and in work based training. The most prevalent formal training received by the respondents was in communication skills, with over half the respondents receiving communication skills training at undergraduate/postgraduate level and almost a third receiving work-based training. In both the undergraduate/postgraduate and work based settings approximately one quarter of respondents had received training specifically in relation to informing families of their child's disability.

Table 5.80 - Professionals' undergraduate/postgraduate training in specific areas

Undergraduate/Postgraduate training	n=	Percentage
Communication skills	133	55.9%
Breaking difficult news	84	35.3%
Informing families of their child's disability	61	25.6%
Disability awareness	94	39.5%
Adaptive/bereavement training	83	34.9%

Table 5.81 - Professionals' work-based training in specific areas

Work-based training	n=	Percentage
Communication skills	78	32.8%
Breaking difficult news	72	30.3%
Informing families of their child's disability	62	26.1%
Disability awareness	70	29.4%
Adaptive/bereavement training	67	28.2%

Relevance of training

When professionals were asked about the relevance of various aspects of training in relation to informing families of their child's disability, the response rate achieved was particularly high relative to the response rate for many other questions across the survey, with a sizeable majority indicating that each of the items noted; communication skills, breaking difficult news, informing families of their child's disability, disability awareness, and adaptive/bereavement training were all relevant to their posts.

Table 5.82 - Relevance of training in specific areas

Relevance of training	n=	Relevant	Not Relevant	Don't know
How relevant to your post do you consider training in the following areas to be?				
Communication skills	224	93.3%	–	0.8%
Breaking difficult news	221	85.7%	3.8%	3.4%
Informing families of their child's disability	220	80.7%	7.1%	4.6%
Disability awareness	218	84.9%	3.8%	2.9%
Adaptive/bereavement training	220	82.1%	6.3%	3.8%

Training needs

Over half of the professionals responded that there are training needs for themselves as individuals, for their team or department and for their main employer in relation to the process of informing families of a child's disability. The highest level of agreement corresponded with the need for training for the respondent's team/department.

Table 5.83 - Training needs for informing families

Training needs	n=	Yes	No	Missing
Do you feel there are training needs related to informing families of a child's disability…				
For yourself?	212	65.1%	23.9%	26
For your team/department?	195	69.3%	12.6%	43
For your main employer?	164	60.5%	8.4%	74

Debriefing structures

The majority of professionals involved who responded to the questionnaire (73.5%) indicated that there were no formal structures in place for staff to debrief after giving a family the news that their child has a disability, or supporting a family who have been given this news. Of this majority, almost three quarters (72.6%) would like to see such a facility provided. For those who noted that there already were formal structures in place, 70.3% reported using these facilities.

Format for guidelines

The final question of the professional questionnaire related to the respondents preferred formats for the best practice guidelines. The professionals were asked to specify their preferences from a list of potential formats that the guidelines could be presented in. There was a relatively low response rate to this question; however of those who specified, the formats most frequently chosen were 'Training Course with Peers', which over half the respondents chose, and 'Interdisciplinary Training Course', which just under half the respondents recommended. The focus on training here is in keeping with the findings of the 'Training Needs' section above, in which respondents indicated the highest level of indication for training needs as being within their team/department.

Table 5.84 - Format of Guideline policies and training

Policies and Training	n=	Percentage
Report	40	16.8%
Training course with peers	138	58.0%
Checklist	68	28.6%
Training CD-ROM	59	24.8%
Protocols	87	36.6%
Poster/laminated sheet of information	34	14.3%
Online training course	42	17.6%
Online information resource pack	62	26.1%
Interdisciplinary training course	115	48.3%
Printed information resource pack	89	37.4%
Role play/experiential training	76	31.9%
Missing	58	24.4%

5.4 Summary of Parent and Professional Response to Recommendations

The following section sets out the combined level of agreement with each recommendation, using the average of the parent and professional results in each case. When the opinions of parents and professionals were combined there was only one recommendation which did not receive majority agreement; the recommendation that the child should be present for the disclosure.

Table 5.85 - Setting/Location & People Present

Setting/Location & People Present	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
In future when parents are told of their child's disability…			
…the news is given in a private place with no interruptions	93.5%	95.4%	94.5%
Both parents are present when the diagnosis is given	88.6%	90.3%	89.5%
If only one of the parents is present, the choice of a family member or friend to be present is given	90.8%	92.4%	91.6%
During the consultation, the child is present	**38.6%**	**28.6%**	**33.6%**
The parents have seen the child before the diagnosis is given	81.0%	74.8%	77.9%
The parents have spent time with the child before the diagnosis is given	77.7%	75.6%	76.7%
The diagnosis is given by a senior staff member	88.0%	84.9%	86.5%
There is an extra staff member present as a support after the news is given	78.3%	84.0%	81.2%
No extra staff are present for training purposes	64.7%	37.4%	51.1%

Table 5.86 - Communication

Communication	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
The child is referred to respectfully; by name and not diagnosis	95.1%	95.8%	95.5%
Parents concerns are acknowledged	96.2%	96.2%	96.2%
Parents are listened to with respect, empathy and understanding	96.2%	95.8%	96.0%
Parents concerns are followed up	95.7%	95.8%	95.8%
Positive, realistic messages are given with the diagnosis	91.8%	94.1%	93.0%
Staff members giving the news use simple, understandable language	95.7%	95.4%	95.6%
The reaction of parents is acknowledged and supported	96.7%	95.8%	96.3%
The diagnosis is not rushed and parents are given time to ask questions	95.1%	95.0%	95.1%
Parents are told what will happen next (e.g. tests)	95.7%	95.4%	95.6%
Staff members are aware of all aspects of their communication, including body language and possible interpretations	92.9%	93.7%	93.3%
All medical terminology is explained	96.2%	94.5%	95.4%

Table 5.87 - Training

Training	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
Staff members are trained in communication skills	95.7%	94.5%	95.1%
Staff members are trained in good practice for informing families of their child's disability	95.1%	94.5%	94.8%
Staff members have a good understanding of disability	95.7%	95.0%	95.4%

Table 5.88 - Information & Support

Information & Support	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
Parents are asked how much information they wish to receive	82.1%	74.8%	78.5%
Parents are asked when they would like to receive information	80.4%	78.6%	79.5%
An interpreter is provided if English is not the first language of the parents	88.6%	94.1%	91.4%
Staff members check that parents have understood what has been discussed	89.1%	95.0%	92.1%
Parents are given a written summary of the consultation	81.5%	68.9%	75.2%
Parents are not left alone for a long period without support	79.3%	87.8%	83.6%
Parents are given time alone together to absorb the news	87.5%	88.7%	88.1%
Parents are given written information (leaflets, books etc.,) about their child's disability/diagnosis	87.5%	88.7%	88.1%
The written information given to parents is in their first language	89.1%	90.8%	90.0%
Parents are given the option of information about support groups	89.7%	93.3%	91.5%
Parents are given the option of contact with other families	79.9%	81.9%	80.9%
Parents are offered the option of counselling	84.8%	84.0%	84.4%
Parents are offered contact with a social worker/liaison person	85.3%	88.2%	86.8%
Parents are kept up to date at all times, with honest information	90.8%	95.0%	92.9%

Table 5.89 - Referral

Referral	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
Parents are referred to early services as soon as possible	91.3%	95.0%	93.2%
Parents are given information about the service they are referred to	91.8%	95.4%	93.6%

Table 5.90 - Organisation & Planning

Organisation & Planning	Parent Agree & Strongly Agree	Professional Agree & Strongly Agree	Amalgamated Agreement Percentage
Staff members share information, so that parents do not have to give the same history or information to many different people	88.0%	93.7%	90.9%
Staff members coming on to new shifts are informed that parents have been given the news that their child has a disability	90.2%	94.1%	92.2%
The GP is informed about the child's disability by those giving the news to the parents	90.8%	90.8%	90.8%
The Public Health Nurse is informed about the child's disability by those giving the news to parents	86.4%	82.8%	84.6%
If the diagnosis has been given in the maternity hospital and the mother is staying overnight, a partner or a family member/friend is offered the choice to stay also	87.5%	81.1%	84.3%
The family are offered the choice of accommodation on their own, after the diagnosis	80.4%	71.4%	75.9%
Parents are offered a follow-up appointment within a maximum of two weeks to discuss the diagnosis.	90.8%	87.8%	89.3%

A mother describes the communication that took place when her baby was transferred to a paediatric hospital while she remained an in-patient in a regional hospital.

"The communication between the [Regional Hospital] and [Paediatric Hospital] was just unreal. I had to ring, myself, every day. To get information was chaotic. If you would ring they would say 'oh the doctor is not here, they'll be around for their visits in the morning'. This went on. It was like it was a file you had sent up - it wasn't like a person. And when you did get through you felt like you were bothering them. I was on to different doctors every day... I had had a 'Section and had to get out of bed to make all of these phone calls."

Mother, Informing Families focus groups

CHAPTER 6
DISCUSSIONS AND CONCLUSIONS

Introduction

The data from the Informing Families study have described the experiences of 222 parents (184 through the national questionnaire survey and 38 through the focus groups) in being informed of their child's disability. In addition, the experiences of 331 professionals (238 through the national questionnaire survey and 93 through the focus groups) in communicating the diagnosis of a child's disability or supporting families who were receiving such a diagnosis were presented. In all, the direct contribution to the development of the Informing Families Best Practice Guidelines from these 553 individuals means that it is the most comprehensive Irish study to date carried out to ascertain how families are informed of their child's disability and the required supports and guidance for implementation of best practice in this area.

6.1 Discussion of findings

Addressing the research questions

In discussing the detailed findings of the qualitative and quantitative research it is useful to revisit the research questions which informed the design of Informing Families study. The questions posed were as follows:

1. How are families in Ireland today informed of their child's disability?
2. What is currently working well in how families are informed in Ireland?
3. What areas of the current process do families feel need improvement?
4. What areas of the current process do professionals feel need improvement?
5. What do families and professionals recommend should be included in future best practice for disclosing disability?
6. What are the support and training needs of professionals involved in informing families?
7. Validation of suggested best practice recommendations for the Irish context.

Following data analysis it was identified that there was very close concurrence between the opinions and recommendations expressed by parents and professionals in the focus groups, and an extremely high level of agreement with the recommendations put forward through the parent and professional questionnaires. For this reason the questions have been collapsed in this final analysis to be discussed under the following headings:

1. **How are families in Ireland today informed of their child's disability?**
2. **What is currently working well in how families are informed in Ireland?**
3. **What areas of the current process do families and professionals feel need improvement?** *(These areas for improvement naturally lead to the recommendations of families and professionals for future best practice).*
4. **What are the support and training needs of professionals involved in informing families?**
5. **Validation of suggested best practice recommendations for the Irish context.**

The details of the findings are discussed in the following sections, based on the results which are brought together from the literature review, the consultative focus groups and the national questionnaire survey of parents and professionals.

1. How are families in Ireland today informed of their child's disability?

The literature review highlighted the importance of how families are informed of their child's disability. The disclosure process has implications for the child, family, staff members communicating the news, and managers of staff members engaged in the process. Good disclosure practice can enhance the parent-professional relationship thereafter (Cunningham, 1994) and reduce parental dissatisfaction and anguish (Cunningham et al, 2002). Poor disclosure practice increases parental stress (Sloper and Turner, 1993), can impact on the welfare of the child when a lack of information leads to delays in accessing support, (Hatton et al, 2003) and can be associated with an increased risk of litigation (Fallowfield & Jenkins, 2004). Staff members may experience challenges in terms of the emotions and stresses that can be associated with communicating difficult news to the family. The provision of training and debriefing opportunities are positive supports that should be available for staff members in this regard. (Barnett et al, 2007; Abel, 2001)

Given the critical nature of the disclosure process, it was important for the current study to establish how families in Ireland are informed of their child's disability. The findings of the national parent questionnaire survey detailed the disclosure experiences of families whose children:

- Have physical, sensory, intellectual or multiple disabilities or autistic spectrum disorders
- With disabilities ranging in severity from mild to moderate, severe and profound
- Where the children were aged between two and a half years and 11 years at the time of responding
- And when the parents had received their child's diagnosis in hospital, disability and community service settings

The findings of the focus groups and national questionnaire survey of parents and professionals clearly indicated that in Ireland there are professionals from many disciplines and experience levels, working in many different service settings, who first inform families that their child has a disability, or provide support during the process of this disclosure. The data gathered from the various consultation and research strands confirmed the involvement of professionals:

- From hospital, community, and disability service settings
- Working across medical, nursing and allied health professional fields
- Whose levels of experience range from newly qualified to having over 35 years of experience
- And whose frequency of involvement ranges from less than once per year to over 35 times per year.

When the breadth of service settings and disciplines involved in informing families of their child's disability is considered, it is likely that this distribution of responsibility contributes considerably to the lack of consistent practice which was previously identified in the Irish literature (Redmond, 2000; Doyle, 2004), and was evidenced by the range of positive and negative experiences reported in the focus groups undertaken for this study. The dispersion of the disclosure process through many service settings, disciplines and experience levels of professionals strongly indicates the need for a coordinated approach to ensure consistency in the implementation of practices which lead to positive experiences.

A key finding from the professional questionnaire survey; and an important consideration in the dissemination of best practice guidelines for informing families of their child's disability, is that many of the professionals who inform families of their child's disability undertake this work only very occasionally. Perhaps it is not surprising; therefore, that there may be difficulties for some professionals in disclosing the news of a disability, when this is not a routine part of everyday work. Therefore it is essential that such staff have access to the Guidelines in order to act as a valuable resource for practice when faced with the situation of disclosure without significant training or experience in the area.

Satisfaction with disclosure

The literature relating to informing families of their child's disability reports varying levels of satisfaction with the process, with some parents very satisfied and others very dissatisfied within each study. Although Cunningham et al (1984) reported very high levels of parental satisfaction when they had experienced disclosure following the introduction of an 'ideal service', this involved a very small sample and specifically related to the diagnosis of Down Syndrome. Methodological variation between studies makes meaningful comparison of results problematic and the measurement of satisfaction as a concept complex. For example, some studies did not provide a 'Neither Satisfied Nor Dissatisfied' option, whilst others collapsed this option with the 'Dissatisfied' responses and reported it is a whole. Other studies examined parental levels of satisfaction with individual elements of practice, such as the provision of information (Hedov, 2002) or communication skills (Sharp, 1992) rather than reporting overall satisfaction. However, in order to put our findings in context some comparison with international experiences is required. The Informing Families study found that 36.4% of parents were either 'Satisfied' or 'Very Satisfied' with how they had been first informed. This is encouraging, as rates of 35% (Quine & Pahl, 1987), and 36.9% (Sloper & Turner,1993) have been reported elsewhere.

What is most encouraging, however, is that the levels of dissatisfaction found in the current study are significantly lower than those reported in previous studies. The parent questionnaire found that 27.2% of parents in the current study were 'Dissatisfied', or 'Very Dissatisfied' with how they had been first informed of their child's disability, and 23.9% were 'Neither Satisfied nor Dissatisfied'. Sloper and Turner (1993) reported 51.5% of parents as being 'Dissatisfied' or 'Very Dissatisfied', and 11.7% being 'Neither Satisfied nor Dissatisfied'. Quine and Pahl (1987) reported 60% of parents as being 'Dissatisfied' with just 5% being 'Neutral'.

Our results demonstrate that there is a basis for good practice already in place in Ireland with many parents experiencing the disclosure process in a supported way, and many professionals currently employing appropriate strategies to ensure that parents receive the news in the best way possible.

However, data from both the focus groups and the national questionnaire survey found that there were parents who expressed significant levels of dissatisfaction with how they were told, and professionals who expressed an urgent need for further support and training to assist in the application of best practice. These results clearly demonstrated that when there are deficits in practice the consequences for parental distress can be significant, and when professionals do not feel adequately trained or supported, it increases the stressful nature of the emotionally challenging task of communicating difficult news. Clearly then, there is a strong rationale for implementing guidelines that aim to ensure a more consistent approach to supporting parents and professionals.

2. What is currently working well in how families are informed in Ireland?

The national questionnaire survey of parents and professionals found that in many respects a good foundation of current practice exists on which to build improvements. The results showed that parents are being informed in person rather than on the phone or in writing almost without exception, and this is welcomed. The majority of parents in the questionnaire survey found that in communicating the news, professionals were empathetic, respectful and direct, and this was reinforced by the findings of the professional questionnaire. Parents in the majority of cases were given the news in a private environment, were given an opportunity to ask questions, and had next steps such as tests to be undertaken explained.

Professionals who took part in the focus group consultation indicated that the team approach is an aspect of current practice that works very well. Examples include Midwives/Ultrasonographers raising concerns during obstetric ultrasounds that are then followed up and confirmed by the Consultant Obstetrician/Gynaecologist; and inter-disciplinary or multi-disciplinary team assessments in Early Services which involve a range of team members such as Psychologists; Social Workers; Physiotherapists; Speech and Language Therapists, etc., and include parents as part of the team. There were significant benefits reported when Clinical Nurse Specialists or other team members were available to take on the role of liaising between internal and external teams on behalf of the family. The common feature of practice where the team approach is working well was good communication between team members leading to coherent and integrated communication with parents.

3. What areas of the current process do families and professionals feel need improvement?

There were several areas for improvement that were raised consistently throughout the research and consultation strands of the project. Parents and professionals who indicated the need for improvements commented specifically on inappropriate physical environments in which the news is delivered, an absence of liaison between services, inappropriate communication, and inconsistent provision of comprehensive, accurate and up to date information, as the areas requiring the most urgent attention.

Location for disclosure

The focus groups with parents demonstrated that great significance was attached to the actual room, corridor, ward or other location in which the news had been communicated. Parents recalling their diagnosis from over thirty years previously could still vividly remember where they had been told. A wide range of environments in which disclosure first took place was identified in the questionnaire survey, with varying levels of comfort, privacy and a sense of welcoming being reported. Given the significance with which parents remember the location of the disclosure, the findings of the consultation and research suggest that it is paramount that planning and consideration be given to the locations available in each local setting when potentially distressing news is being given, so that privacy can be ensured and settings can be made as comfortable and welcoming as possible. Although 71.2% of families received the news in a private environment, the impact for those who did not was significant. In particular, parents in the focus groups indicated the need for parents who receive the news in maternity hospital to be given the option of accommodation on their own, with the opportunity for their partner to stay overnight if possible.

Communication

While the majority of parents in the questionnaire survey found that professionals were empathetic, respectful, and direct in communicating the news, the literature suggests that there is a significant impact for the minority who were not satisfied with the manner in which the news is given (Sloper and Turner, 1993). Parents who attended the focus groups and who felt that the news was given in a blunt or insensitive way reported experiencing considerable distress regarding how they had been told, and some indicated that developing relationships and building trust with those professionals had been difficult following their adverse experiences. Almost one quarter of families in the parent questionnaire reported that they were not treated with empathy, and a slightly higher figure felt that the person giving the news was not approachable, not a good communicator, or did not have a good understanding of disability. Some families within the parent focus groups and questionnaires indicated an inappropriate excitement of junior members of staff when discovering rare syndromes, which left the parent feeling that the impact on the family and the needs of the child were not given due respect and consideration. Critically, over 40% of respondents to the parent questionnaire answered that following the diagnosis disclosure they did not feel that they had understood what they had been told, which indicates the need for communication of the diagnosis to be carefully managed to ensure that explanations are understood, and for staff members to check that parents have understood what they have been told. The overall findings of the research therefore indicate that the manner in which the diagnosis is communicated is generally appropriate, but that it is important to address the issue when this is not the case.

Hope and positive messages

While the majority (84.8%) of parents indicated in the questionnaire survey that the professional was direct, significantly fewer perceived that there were positive messages and hope delivered with the diagnosis (46.7%). The issue of providing positive messages was one which was raised repeatedly throughout the parent focus groups. In the professional focus groups there were some disciplines who noted the need for positive messages, but the overall emphasis was on honesty and not giving 'false' hope. What the figures from the parent survey may suggest is that professionals appear to have taken on board the need to be direct and honest but are less convinced of the necessity for positive messages. Families did not raise as an issue in the survey or focus groups, that their diagnosis had been given with too much hope. Parents instead reported the distress that had been caused when that they felt there had been an absence of celebration of the birth of their child or a lack of hope given. Providing hopeful messages in the future may necessitate clear definitions of the types of messages that parents find helpful – such as emphasising the child as a person with the disability a secondary consideration, and reassuring parents that support will be available to help them through the difficulties which may arise. Parents also indicated that merely being given the worst case scenario is not helpful, but would rather be informed of the range of possibilities; positive and negative; that exist with their child's disability. It was mentioned that it was particularly helpful when the professional indicated that there are particular aspects of the disability which happen to all children diagnosed with a given syndrome, and for example that there are other aspects that are present in 20% of children, thus allowing the parents to see that there is a spectrum of possibilities that could develop over time.

Improved Liaison & Named Contact/Liaison Person

Close liaison between maternity, community and disability services as envisaged by the 1990 Government policy document *Needs and Abilities* and reiterated in subsequent policies, is still not taking place on a consistent basis, according to the results of the parent and professional focus groups and the questionnaire survey. Professionals in the focus groups indicated their distress at the lack of continuity of care particularly in the initial period following discharge from hospital services into the community. Professionals also described the lack of linkage impacting on their practice, such as GP's and Public Health Nurses being unaware of the diagnosis of a child's disability before routinely meeting with the family. The professional questionnaire supports these findings, noting that less than half of GP's and Public Health Nurses were informed of the child's disability. The Irish literature, too, indicated that a lack of liaison between agencies means that parents are often unsure of where to go to access essential services, with many not even aware of the services that they may be entitled to (Redmond, 2000).

Parents participating in the focus groups described having to repeat their child's history frequently to different staff members, and receiving conflicting messages from various teams who were caring for the same child but had not communicated with each other. Professionals in the focus group report indicated their distress at not being able to spend adequate time with families due to the pressures of busy caseloads, and recommended that at least one staff member should be freed up to spend time with the family. It was also suggested that in the hospital setting, due to frequent rotation of staff, at least one person should be present at the initial disclosure who will be available to meet with the family again to provide continuity of care and information. Parents also strongly indicated the need for family-centred services, which included the scheduling of appointments to minimise overnight stays for parents, the co-ordinated scheduling of appointments for families with more than one child receiving services, and the co-ordination of appointments with members of the interdisciplinary team to allow the minimum amount of separate visits possible. The above results clearly indicate the need for improved links and communication within teams and between teams.

Along with improved links and team communication, Doyle (2004) specifically recommends the provision of a **liaison person or link worker** to be provided between maternity hospital, the primary care team and the family. This is a recommendation strongly supported by the results of the focus groups. Parent and professional participants repeatedly indicated the benefits of having a liaison person as part of the process of informing families of their child's disability, particularly where there is more than one team involved in providing care or diagnostic services, where there is more than one service setting involved, or when families are discharged from a hospital setting and await referral into disability services.

Information provision

Needs and Abilities, the most recently published Government strategy for intellectual disabilities, indicated at the time of writing in 1990 that:

> Personnel providing support to families should have available from their health board, for supply to parents, a dossier of printed material containing information on the disability; the name, address and telephone number of appropriate community care staff, and of the local services for intellectually disabled persons together with details of entitlements. (Review Group on Mental Handicap Services, 1990, p.21)

The report of The Commission on the Status of People with Disabilities, *A Strategy for Equality*, followed up on this information in 1996 and found that that families frequently have to go from organisation to organisation in an attempt to identify their options.

One of the most striking findings from the data of the current study is that seventeen years after the recommendations made in *Needs and Abilities* there is still a lack of coherent information provision to families, and a lack of comprehensive up-to-date information available to professionals for supply to families. Parents in the focus groups reported patchy provision of information, with staff members making every effort to supply information, but not always having appropriate sources available. Some parents reported receiving leaflets that were clearly out of date, whilst others only heard of support agencies through word of mouth, or their own investigation; often having waited for long periods of time before the information became available. These findings were supported by the results of the parent questionnaire which found that less than half of respondents felt that they had received enough information and one third of respondents received no written information either at the time of diagnosis or at a later stage. Those responding to the professional questionnaire also indicated that there were a significant amount of parents who did not receive written information at the time of diagnosis or at a later stage. Professionals participating in the focus groups indicated that the frequent rotation of staff members and lack of ownership of information within settings contributes to the lack of information provided, so that even when information is available to some staff members, others may not be aware of it. Professionals who participated in the focus group consultation indicated that there is a particular lack of information available for supply to families with limited English proficiency, and that there is inconsistent availability of interpretation services across the country.

The literature suggests that two of the most important areas of practice which are determinants of parental satisfaction with the disclosure process are the information provided to parents when a concern is raised or diagnosis provided, and the professional manner (i.e. communication skills) used when informing the family (Sloper and Turner, 1993). The national policy strategy has set out elements of best practice which are reiterated through successive policy documents. The assertion that there should be a dossier of printed material available to professionals (Needs and Abilities, 1990) is clearly not yet addressed, when we see from the parent and professional questionnaires that a significant proportion of parents did not receive written information.

Presence of Additional Staff Members

The presence of additional staff members at the diagnosis, while being comfortable and helpful for almost half of the families surveyed in the parent questionnaire, was not comfortable or helpful for over one third of parents, and it is interesting to note that for two thirds of parents the additional staff members present were not known to them. One possible avenue for improving the level of comfort and helpfulness for parents of having additional staff members present would be to aim to include staff members who are already familiar to the parents. Any staff members not known to the family should be introduced.

4. What are the support and training needs of professionals involved in informing families?

The survey fount that a sizeable majority (79.8%) of respondents indicated that they were unaware of any guidelines already in place that dealt with the practice of informing families of their child's disability. Our data are congruent with the findings of the ERHA study in 2004, which found that there was an absence of consistent policy or structure to guide professionals who inform families of their child's disability (Doyle, 2004).

Professionals, particularly in the focus groups, pointed to an absence of training in how to inform families of their child's disability leaving them to resort to a 'trial and error' process. Professionals still in training indicated that the structure of shift work means that trainee doctors are responsible at particular times (generally during the night) for providing the initial news of a concern to parents, and that there is a need for further support and training to ensure that those delivering the news feel confident to do so and in order for parents to receive optimum support. In addition the suggestion brought up by trainees during the focus groups that there can be a problem accessing debriefing, was reinforced by the professional questionnaire's finding that for approximately three quarters of staff members involved, no formal debriefing structures were in place.

Through the professional questionnaire a sizeable majority of respondents indicated the relevance of training in a number of key areas, reinforcing the information provided through the focus groups. Over 80% of respondents indicated the relevance of training in breaking difficult news; informing families of their child's disability; disability awareness; and adaptive/bereavement training. An even larger majority, (93%) indicated that they felt communication skills training was relevant to their post.

It is interesting to note that the questions regarding training elicited some of the highest response rates seen in the professional questionnaire, thus indicating the importance of this topic to the respondents.

Professionals who participated in the focus groups frequently referred to the increase in cultural diversity in Irish society and their corresponding need for training to guide them in providing culturally competent care. This is in keeping with findings in the UK, where 84% of nurses indicated that they would welcome further education to meet the cultural needs of their patients (Narayanasamy, 2003).

Parents, too, recognised the importance of training and indicated in the focus group consultation that they felt there was a need for those undertaking the disclosure consultation to be provided with appropriate training, as long as it is sensitively managed and does not impact on the disclosure process. Parents and professionals alike indicated the importance of including input from parents in the development and delivery of training.

What is very clear from the results of the study in relation to the training and support needs of those who are involved in the disclosure of a child's disability, is that professionals would welcome evidence-based guidance for best practice in this area, and are cognisant of the emotional challenges inherent in the process, and professionals have suggested that supports, including debriefing and supervisory support as well as practical resources such as appropriate information and environments in which to communicate the news, are required urgently.

5. Validation of international best practice recommendations for the Irish context

Best practice recommendations came from a collation of the results of the literature review combined with findings the focus groups, a concise form of which was then subject to the rating of parents and professionals in the national questionnaire survey.

A high level of agreement was apparent between the recommendations of parents and professionals made through the strands of research and consultation undertaken in this study. The recommendations which were validated through the national questionnaire survey had emerged from the literature and the focus group consultation. Overall, 45 of 46 of these recommendations received majority agreement from parents while 44 of 46 received majority agreement from professionals. The sole recommendation to which parents indicated either 'Agree' or 'Strongly Agree' in the majority of cases (64.7%) but professionals only indicated 37.4% agreement was the suggestion that "No extra staff are present for training purposes". This difference in opinion indicates that the provision of training will need to be very carefully managed to ensure that it remains sensitive to the needs and wishes of parents. The suggestions provided in the focus groups with professionals included a graduated introduction for trainees to the practice of informing families; providing opportunities for role-play training; and ensuring that any professional who is present for training also has a specific role in providing care to the family, rather than being an unknown presence for the family.

Presence of the child

The only recommendation which was not 'Agreed' or 'Strongly Agreed' with by the majority of respondents was the suggestion that the child should be present. From the focus groups, however, we have seen that there is a clarification to be made between the presence of the baby when the disclosure happens close to birth, and the presence of a child at a later time. Parents and professionals describe the key importance of the baby being present for bonding close to the moment of birth, so that the parents have an opportunity to see and know their child first and see the disability as secondary thus facilitating bonding. Furthermore significant distress can be caused by warning parents that there is adverse news when they cannot see their child in a hospital setting, as they may believe the child to have died or may be afraid to see the child if they have not yet had that opportunity.

On the other hand, parents also explained that it is very difficult to manage the emotions that may come to the fore when given the news of a child's disability if the child is present and the parents feel responsible for holding in their feelings and maintaining a sense of calm for the child. Our findings of a split of opinions when asked the question of whether the child should be present, match with the literature; in which Pearson et al (1990) found that the presence of the child was found to by 58% of parents to be useful, 10% said that it made no difference, and 30% said it was not helpful. They also match with the recommendations of the *Right From the Start Group*, which indicate that 'Consideration should be given to the presence of an older child' (p.3). In summary, the recommendation of the *Informing Families Project* is that the baby should be present when disclosure happens close to birth so that families have time to bond and in any in-patient hospital situation where parents need to be reassured that the child is alive. It is not recommended that the child should be present for diagnoses that come later, so that the parents have an opportunity to absorb the news and express their emotions at the time of disclosure.

It should be noted that when presenting the recommendations in the national questionnaire survey, it was not possible to provide the same detail as was reported in the literature review and focus group results, due to space and layout requirements of a questionnaire format. It was therefore necessary to prioritise the most important recommendations for inclusion in the questionnaires. The result was a very clear validation of the elements put forward. The final version of the Guidelines takes the pared-down elements from the questionnaires and further elaborates and informs them through the literature and focus group sources. The text captured through the open questions in the parent and professional questionnaires merits further, separate analysis and it is therefore not discussed here. However, it is noted that many of the themes emerging from this text are in line with those found in the *Informing Families* focus groups.

6.2 Validity of the findings

The methodology of the Informing Families Project was developed with the aim of producing National Best Practice Guidelines that are evidence-based and informed by the input of key stakeholders through comprehensive consultation. In so doing the study triangulates multiple data sources, i.e. the literature, the consultative focus groups, and the national questionnaire survey, to define its final recommendations. The research design of the parent questionnaires used the most representative sample of the national population of children of the selected age group with disabilities that could be managed within the ethical constraints of causing no harm to potential participants. The study used population figures broken down into specific service providers from the National Intellectual Disability Database (NIDD), and indicative sample sizes for physical and sensory disabilities from the relevant national service providers. The Health Research Board has indicated that the estimated coverage for the NIDD was 95% in 2005, the year from which the questionnaire sample was determined. The level of confidence that the sample was representative is therefore relatively high.

The response rate to the parent questionnaire was 31.5%, which is in keeping with similar postal questionnaires related to this topic, ranging from 27 - 33% (Down's Syndrome Association, 2006; Sharp et al, 1992; Pickering et al, 2004; Ormond et al, 2003).

There are a number of areas of concern relating to limitations of the findings reported in this study. The focus group and survey results provide a picture of how the diagnosis is given in Ireland as related by families of mostly English and Irish speaking families due to the ethical constraints of the methodological design, which did not allow secondary follow-up with specific families to pro-actively offer support such as interpretation. The parent questionnaires were filled out by mostly mothers, with a smaller number of fathers responding. This is a finding which matches with numerous previous studies (Herbert, 1995). To mention just such two examples, 189 of 190 respondents in a study by Quine and Pahl were mothers (Quine and Pahl, 1987), while 92% of respondents in a study undertaken by the UK Downs Syndrome Association were mothers. (Downs Syndrome Association, 2006) A relatively low response rate was recorded from participants from Ulster (3.3% of parents, and 5.5% of professionals).

With regards to the professional questionnaire, although it was not possible to sample each of the 27 disciplines in a manner that would provide statistically representative samples, in keeping with the theory of theoretical generalisability (Sim, 1998), the study does provide significant data on the experiences of professionals who are similar to the group who responded, and provides the most comprehensive current Irish databank of information regarding professional's practice in relation to informing families of their child's disability.

While concerns do exist about the limitations of the study as detailed above, the size of the study also means that a large number of parents and professionals have contributed their understanding, experiences and opinions to the recommendations. The triangulation of results, and the high level of agreement between parents and professionals on the aspects of practice put forward through the National Questionnaire Survey, which match closely with the recommendations of the international literature, supports the rationale for implementation of the Guidelines, and provides confidence in the data.

6.3 Conclusions

Conclusions

Analysis of the data of the *Informing Families Project* indicates the need for specific supports to be put in place in order to support the consistent and universal implementation of best practice guidelines for how families are informed of their child's disability:

- Government Strategy and Policy documents from the past 17 years call for the introduction of specific measures to support best practice, in how families are informed of their chid's disability. The measures relating to how families are informed largely remain unimplemented.
    a. Needs and Abilities (1990)
    b. A Strategy for Equality (1996)
    c. Towards an Independent Future (1996)
    d. Quality and Fairness (2001)
    e. Disability Act & Sectoral Plans (2005)
- International research indicates that the way in which families are given the news of their child's disability has an impact on levels of distress and anxiety for the family, has a bearing on the attachment process, and can influence parent-professional relationship thereafter (Cunningham, 1994; Sloper & Turner, 1993)
- Previous Irish research (Doyle, 2004) indicated **a lack of consistent guidelines or local policies** in place to guide professionals breaking the news to families that their child has a disability. The results of the focus groups of the Informing Families Project and the Informing Families Professional Questionnaire support this finding and indicate that professionals working in disclosure of disability or supporting families who receive the diagnosis would welcome clear guidelines and training in best practice.
- The results of the Informing Families national questionnaire survey indicate that there is good practice in place in many locations and that many parents indicate a high level of satisfaction with how they have been given their child's diagnosis. The results of the focus groups, and the areas of deficit highlighted through the national questionnaire survey indicate that where there are deficits in practice, they impact on families and professionals significantly, thereby reinforcing the need to build on the good practice already in place and provide consistent policies that ensure good practice is replicated in all locations.
- Existing Irish research (Redmond, 2000, WHB, 2003) and the results of the Informing Families research indicate that there are significant **deficits in the information** currently provided to parents. There is a need for co-ordination of the information available to professionals for supply to parents, as a lack of ownership of information in local settings is currently leading to many parents receiving out of date leaflets, or not receiving recommended literature due to professionals not knowing it is available. The findings of the research indicated that deficits include a lack of information in mainstream settings about the services available in disability service settings; a lack of information in languages other than English; a lack of guidance

on appropriate Internet sites for parents seeking information about a particular diagnosis; and dispersed and confusing information regarding benefits and entitlements. The information needs of parents, and of professionals seeking information to provide to parents requires widespread and equitable access to accurate, up to date and appropriate information and interpretation services.

- Through the focus group consultation with families of children with disabilities, parents spoke of the impact caused when poor practice caused additional stress at the time of diagnosis. Parents in the focus groups who were dissatisfied with how they had been told the news noted inappropriate physical environments in which the news is delivered, a lack of appropriate communication, a lack of continuity of care, and inconsistent provision of comprehensive, accurate and up to date information, as the areas requiring the most urgent need for improvements.
- Focus groups with professionals identified that the process of giving families the news that their child has a disability, or supporting the family immediately thereafter, is an emotional and challenging one, and that they have a requirement for support in this area. Professionals indicated that there is a need for training, supervision, and the introduction of local policies to guide practice on the front line.
- Through the focus group consultation and questionnaire survey, parents and professionals indicated the clear need for **continuity of care** to be provided within service settings (e.g. where more than one medical or social care team are involved in providing the diagnosis) and across settings (e.g. when families are discharged from hospital settings into the community, or are awaiting referral to Early Services). A **named liaison person** is required to provide continuity of care and co-ordinate the team approach in these situations, to avoid the very distressing vacuum that many parents and professionals described following discharge before reaching Early Services, and the mixed messages that were often received when internal teams did not effectively communicate.
- The range of disciplines involved in providing first information to families of children who have a disability is extremely broad, and encompasses professionals from across hospital, community, and disability services. The broad range of disciplines involved, many of whom are in mainstream rather than disability-specific services, means that clear planning and ownership of tasks within the disclosure and support process; interdisciplinary training; and a structured approach to dissemination of best practice is necessary.
- Existing strategies for implementing best practice in informing families of their child's disability in the UK were found through evaluation to have been ineffective when one third of key staff members were unaware of the guidelines (Fallowfield & Jenkins, 2004), indicating the need for a comprehensive communications strategy to accompany the dissemination and implementation of best practice guidelines.

International experience, and the non-implementation of existing policy recommendations, indicates that if Best Practice Guidelines are published and circulated without the back-up of a clear implementation strategy, the recommendations will remain just that, and the needs identified clearly over the past seventeen years will remain unaddressed.

This report therefore recommends the implementation of the following evidence-based best practice guidelines, and the undertaking of a coordinated, adequately resourced approach to implementation which is integrated across hospital, community, and disability service settings.

The National Best Practice Guidelines for Informing Families of their Child's Disability fall into two sections; Guiding Principles and Best Practice Recommendations. The Guiding Principles apply regardless of the circumstances of disclosure. The Recommendations are non-prescriptive, and in addition to being informed by the above principles will require adaptation to the circumstances of disclosure, including:

- Hospital / community / disability service setting / family home
- Ante-natal diagnosis[20] / diagnosis at birth / evolving diagnosis
- Physical / sensory / intellectual / multiple disabilities and autistic spectrum disorders
- Unexpected event / predicted disclosure following assessment or tests

The recommendations were finalised through triangulating the data from the focus groups, national questionnaire survey, and the national and international literature. Any recommendation which was indicated in at least two of those three strands of the research was adopted for inclusion. The recommendations have been categorised into the broad areas which emerged throughout the various stages of research in the project and which are listed below:

- Setting/Location and People Present at Disclosure
- Communication

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[20] Joan Lalor et al (2007) have conducted Irish research into the specific elements of practice that relate to disclosing a concern or diagnosis during pregnancy. A further reading list in this regard can be found on page 164 of the Reference section.

- Information and Support
- Culture and language
- Organisation and Planning
- Training, Education, and Support for Professionals
- Referral

It was agreed by the Informing Families Steering Committee at the outset of the project that the topic of referral was one meriting further, separate study, and that specifics relating to referral between hospital and community/disability services were outside the scope of the current project, which had a focus on the informing rather than the services which are subsequently required or provided. However, on a number of occasions references through the research were made to this important area, and for this reason a number of brief pointers are made in relation to referral, which constitutes the final category of best practice. It is suggested that further research take place into this area.

6.4 Recommendations: Informing Families Best Practice Guidelines

Guiding Principles

Whilst every disclosure event is unique, the *National Best Practice Guidelines for Informing Families of their Child's Disability* have identified that the following Guiding Principles should be applied in every case.

1. Family Centred Disclosure

Disclosure must be family-centred and tailored to the emotional and informational needs of each individual family. The family should be provided with choice and options in the support that they receive during the disclosure process (e.g. family-friendly appointment times, private accommodation, contact with other families, counselling, etc.).

2. Respect for Child and Family

At all times it is necessary to demonstrate respect for the child and family. This should include using the child's name, acknowledging and supporting the family's dignity, emotions and reactions, and respecting cultural and linguistic diversity.

3. Sensitive and Empathetic Communication

Sensitive communication that is open, honest, empathetic and understanding is essential. Whilst unavoidable difficulties in implementing best practice in other areas may be understood by parents, blunt or insensitive communication invariably leads to significant and lasting dissatisfaction.

4. Appropriate, Accurate Information

Meeting the family's information needs is a key priority that influences subsequent levels of parental stress and satisfaction. It is essential to pace the information in accordance with the needs of the individual family; (including how recently they have received the diagnosis, any current medical needs, and potential levels of distress or shock) to provide sufficient information whilst avoiding information overload.

5. Positive, Realistic Messages and Hope

Realistic, positive messages and hope should be given with the diagnosis - not merely the worst case scenario. The emphasis should be on the child first, and the disability second. Encouraging staff members to support parents who wish to celebrate their child may include disability awareness training and an exploration of various definitions of hope which parents find appropriate and helpful (e.g. reassurance that support and help are available).

6. Team Approach and Planning

Informing a family of their child's disability is a process rather than a once-off event. Preparation, planning, team work, close communication between staff members and liaison between agencies/service providers is essential to successful implementation of best practice.

7. Focused and Supported Implementation of Best Practice

Support for implementation of the Guidelines is required at all levels, including management, to ensure that planning takes account of the need for appropriate physical environments; provides for information ownership; and facilitates agreed protocols for dealing with different disclosure scenarios.

The Guidelines are non-prescriptive, and in addition to being informed by the above principles, will require adaptation to the circumstances of disclosure, including:

- Hospital / community / disability service setting / family home
- Ante-natal diagnosis / diagnosis at birth / evolving diagnosis
- Physical / sensory / intellectual / multiple disability and autistic spectrum disorders
- Unexpected event / predicted disclosure following assessment or tests

The Guiding Principles listed above emerged from the overview of the findings of all strands of the project's consultation and research, are in keeping with the philosophy of the National Federation of Voluntary Bodies and the National Health Strategy (Quality and Fairness), and were debated and endorsed by the Steering Committee of the Informing Families Project.

Recommendations for Informing Families of their Child's Disability

1. Setting/Location and People Present at Disclosure

In relation to the location and the people that are present, the Guidelines recommend that:

1.1 The diagnosis is given in a private place with no interruptions. The room in which this takes place is:

- Quiet
- Free from interruptions
- Comfortable and user-friendly
- Available for the family to spend time in, absorbing the news after the consultation
- There is a kettle, phone, tissues, tea, coffee and water available

Within the hospital setting there is a need for private rooms to be made available in both in-patient and out-patient settings. Ideally, the consultation does not take place in a room that the family will be using again such as the labour ward or ultrasound scanning room, as this may leave parents with a negative association with this room for the future.

1.2 The diagnosis is made verbally (not in writing) and in person (not over the phone).

1.3 Both parents are present when the diagnosis is given.

1.4 If it is only possible to have one parent present, the option is given to have another family member or friend present to provide support.

1.5 When a parent hears the news alone, arrangements are made as soon as possible to inform the other parent and close family members.

1.6 If the parents are very young, it may be appropriate to invite extended family members such as grandparents as support for the parents.

1.7 The news is given by an appropriately trained staff member who is responsible for delivering and confirming the diagnosis.

1.8 A second professional, preferably known to the family, is present and remains to support the family after the initial disclosure.

1.9 The number of professionals present is limited and does not greatly outnumber the family members.

1.10 No extra staff are present purely for training purposes. *(Any staff members in training that are present should also have a role in providing further care to the family).*

1.11 If the news of a child's disability is given close to the time of birth, it is important that the parents have seen the baby before the diagnosis is given, and if at all possible the parents are given the opportunity to spend some time with the baby before any disclosure takes place. *This can facilitate the parents in identifying with their infant as a child first and the disability as secondary.*

1.12 It is critical that the parents can see the baby when they are being prepared for difficult news. *(This is necessary to avoid any misunderstandings that may lead to assumptions that the child has died.)* If the baby cannot be present, the parents should first be sensitively reassured that the difficult news to be imparted does not mean that their child has died or is dying.

1.13 If a baby is being cared for in the intensive care unit, the parents are facilitated to visit as soon as possible after the diagnosis is given, including facilitating a mother who herself may be recovering from surgery such as a Caesarean section.

1.14 Unless the diagnosis takes place close to the time of birth, it is not recommended that the child should be present for the disclosure, so that the parents have an opportunity to absorb the news and express their emotions.

1.15 Parents are given time alone together to absorb the news in private, if they wish. They are made aware that there is a staff member who they can contact for support at any time.

1.16 Whilst respecting the parents' need for privacy it is also important to ensure that the parents are not isolated after being given the diagnosis – if parents wish, a staff member should engage with them at this time to sit and spend time with them.

2. Communication

In relation to the communication of the child's diagnosis to the family, the Guidelines recommend that:

2.1 The news is communicated with:

- Empathy
- Sensitivity
- Honesty
- Respect
- Compassion
- Understanding

2.2 It is important that positive, realistic messages are conveyed, and hope is given along with the diagnosis. Positive messages can include describing support and assistance that will be available to the family and focusing on the individual child as a person, with the disability secondary. *Rather than listing all possible negative implications of the diagnosis and presenting only the worst case scenario, parents have indicated that where possible it is helpful to be informed of the range of possible outcomes of the disability or condition, and the percentages of children who experience different aspects of the syndrome.*

2.3 Staff members giving the news use language that is:

- Simple
- Understandable
- Straightforward
- Appropriate

2.4 Prior knowledge of parents is assessed before explaining a diagnosis. *(Parents have suggested that open questions such as 'Have you any concerns?' or 'What have you heard so far?' are helpful, but closed questions such as 'Does he look like anyone else in the family?' are not.)*

2.5 Any medical terminology used is clearly explained, along with the implications and significance of any information given about the child's diagnosis.

2.6 Explanations are given at a level parents can understand, taking into account socio-economic, linguistic and cultural factors.

2.7 Listen to parents. *Listening to parents allows for communication to be tailored to the individual needs of the family.*

2.8 Parents are encouraged to ask questions.

2.9 Staff members check that parents have understood what has been discussed.

2.10 The child is shown respect; the child's name is always used, and they are not referred to by their diagnosis. *For example, instead of saying 'this Down Syndrome baby' staff members say 'Ben, who has Down Syndrome'.*

2.11 The appointment is **not** rushed. *Families and professionals agree that informing parents of their child's disability should be seen as a priority, and consequently adequate time must be allocated, including time for the parents to ask questions and express emotions without interruption.*

2.12 Pagers and mobile phones are switched off.

2.13 Team members reinforce the information already given at appropriate times so that families have several opportunities to absorb and clarify information provided.

2.14 Staff members are aware of their body language and how this can be interpreted by parents. Avoid whispering in front of parents, or giving negative non-verbal signals that could raise concerns with parents before the news has been communicated to them.

2.15 Parents' concerns are acknowledged, treated seriously and followed up.

2.16 The reaction of parents is acknowledged, supported and taken into account when communicating with the family. *(Parents will have different reactions and different coping mechanisms. Some may feel the need to 'walk away' for a period of time to come to terms with the news, others may be in shock and take in very little, still others may wish to have significant interaction, information and support from staff members.)*

2.17 Dismissive, impatient, aggressive or judgemental language is never used when speaking to parents or children.

3. Information and Support

In order to meet the information and support needs of parents at the time of diagnosis, the Guidelines recommend that:

3.1 Parents are kept up to date at all times, with honest information. *This includes acknowledging any uncertainty that exists about the diagnosis, and explaining any suspected diagnoses that are being investigated. There should never be a large gap between what parents know about the diagnosis and what professionals know or are investigating. Building trust with parents is a priority, particularly since the initial diagnosis may be the beginning of a long term parent-professional relationship.*

3.2 At the end of the initial consultation, parents are offered factual, accurate, up to date, relevant written material on the disability, support groups, entitlements and benefits, and on the Early Services that will be available for their child.

3.3 Information on support groups for specific syndromes is particularly important to parents and is therefore provided when at all possible. Where support groups do not exist in Ireland, contact with such groups in other countries is investigated and facilitated.

3.4 The amount of information provided is tailored to the individual parent's needs - avoiding information overload for parents who may feel overwhelmed, and meeting the information needs of parents who seek further details.

3.5 Care is taken in the timing of the delivery of news so that the consultation takes place at the appropriate time; taking into account for instance in a neonatal diagnosis that the mother may be recovering from the birth or surgery.

3.6 A contact number for a member of the staff team is provided to the family at the initial diagnosis, which they can use if they have questions or concerns.

3.7 A follow up appointment is **always** scheduled before the consultation is over so that the family leave with a plan, knowing when they will next have contact with those who provided the diagnosis, and giving them an opportunity to prepare questions and raise concerns. This appointment takes place no longer than two weeks after the diagnosis is given.

3.8 Parents are given a written summary of the consultation and receive copies of all correspondence between professionals relating to their child's diagnosis.

3.9 Next steps are carefully outlined and explained to the family – including any tests that will be carried out and any referral to other agencies.

3.10 Parents' preferences are sought and facilitated, including how much information they wish to receive, whether they would like to have visitors or support in limiting visitors while they come to terms with the news, whether they would like input from pastoral care teams. *Meeting this recommendation will include listening to parents during the consultation to assess whether they are overwhelmed by information already received or are seeking further information.*

3.11 The family are provided with guidance on appropriate Internet sites which contain relevant and accurate information for their child's particular disability. *This can avoid unnecessary anxiety when parents read information that may not be relevant to their child's particular case.*

3.12 The option of counselling is made available to families following the diagnosis, if appropriate.

3.13 The option of meeting the parents of other children with disabilities or similar diagnoses is offered following the diagnosis, where appropriate.

4. Culture and Language

In order to provide the diagnosis in a way which respects cultural and linguistic diversity, the Guidelines recommend that:

4.1 A formal interpreter is provided if the parents have limited English proficiency, and the role of the interpreter is explained.

4.2 Family members/friends are **not** nominated as interpreters. Formal interpreters should be used, as the use of family members/friends is inappropriate.

4.3 The interpreter is briefed on what will be discussed prior to the consultation so that he/she is prepared when the news is given.

4.4 The cultural and religious backgrounds of all families are acknowledged and respected.

4.5 When families from diverse cultural backgrounds are being given a diagnosis of their child's disability particular attention is paid to gaining an insight into the meanings that each family assign to disability. Accurate information is provided to explain the diagnosis and dispel any unhelpful misunderstandings of the disability that become apparent.

4.6 The written information given to parents is in their first language. *The information being explained to parents during disclosure of a child's disability can be quite complex and this is further complicated when there is a language barrier to be overcome.*

4.7 At a national level equitable access to appropriate professional interpretation services is provided, with interpreters available in person to attend consultations in which parents are informmed about their child's disability.

4.8 At a national level widespread access to written materials in languages other than English is provided to staff members, for supplying to parents.

4.9 The Informing Families Project recommends that further research is undertaken into how families of children with disability should be supported at the time of diagnosis to ensure culturally competent care.

5. Organisation and Planning

Interdisciplinary team working, preparation for the different circumstances of disclosure that may occur and strong team communication are important when informing families of their child's disability. The Guidelines therefore recommend that:

5.1 Staff members consult with one another and prepare individually and as a team prior to the consultation with parents. *Providing a diagnosis of disability to a family is a priority task, and therefore calls for adequate time to be allocated, along with good planning.*

5.2 All staff members who may come in contact with the family liaise to ensure that no conflicting information is presented to the family and that all members have the same picture of what has already been told to the parents, to ensure that families are not inadvertently told new information without adequate preparation.

5.3 Staff members share information, so that parents do not have to give the same history or information to many different people.

5.4 As family circumstances vary, the team share information on how best to facilitate each family.

5.5 Care is taken at staff shift changeover times to alert staff members coming on duty that a family has been given the news of their child's disability.

5.6 A liaison person is assigned to the family to provide support and information from the time of diagnosis until such time as the family are being supported by appropriate early intervention services. Some of the key aspects of the liaison person's role include:

- Providing a single point of contact for the family
- Providing information to the family on entitlements and benefits, and services and supports available
- Providing assistance with paperwork and applications for services if required
- Ensuring that an 'Informing Families' checklist is completed and that all tasks relating to best practice in the disclosure process are carried out
- Providing a central point of contact to support services and organisations for the supply of up to date information to the interdisciplinary team
- Providing a co-ordinating role within the interdisciplinary team, to ensure that information is shared and coherent communication takes place with the family (including, if necessary, team conferences with the family) and ensuring that at least one person is present at the initial disclosure who will be available to meet with the family again to provide continuity of care and information
- The liaison person should have appropriate training to understand the needs of families of children with disabilities.
- The liaison person will have a key role in disseminating best practice guidelines for informing families of their child's disability.

5.7 Written information is provided between professionals when referring on, detailing what parents have already been told, so that parents are not inadvertently given significant news without adequate preparation. Written information back to the referring party is also provided, to keep all parties up to date on the child's diagnosis. This needs to be sent to the parents, the GP (with parent's consent) and the referring party. Information is also written on the child's chart in the hospital setting, to ensure that all team members are kept up to date

5.8 Birth Notification to the Public Health Nurse includes information about how the family has received the news of their child's disability.

5.9 Preparation and planning at a local level is required to ensure the availability of private settings in which to communicate the news; to ensure that staff members have available accurate, up to date, relevant written material for supplying to parents; and to plan the team communication and response that should take place when a child is diagnosed with a disability.

6. Training, Education, and Support for Professionals

In order to provide appropriate training, education and support for professionals who undertake the task of informing families of their child's disability, the Guidelines recommend that:

6.1 Staff members are trained in best practice for informing families of their child's disability.

6.2 The training provided includes:

- communication skills training
- disability awareness training
- cultural awareness and diversity training
- listening skills
- skills to guide staff members on appropriate responses to reactions the news may cause, including shock
- reflective practice
- counselling skills

6.3 Role playing/experiential training forms a central part of training

6.4 As this can be a distressing area for professionals, it is important to have two staff members present at the sharing of the news.

6.5 Appropriate support is given (identified locally) including debriefing and mentoring by senior staff members for those in training.

6.6 There is an input from parents into training provision.

6.7 There are many disciplines across various settings who are involved in informing families of their child's disability. Good linkage across these disciplines and settings is central to a positive experience for parents. Therefore, interdisciplinary collaborative skills training should be provided to **all** members of staff who may be involved in communicating to families the news of a child's disability, or supporting them thereafter.

6.8 An ethos of continuous quality improvement is promoted, with quality assurance and feedback mechanisms put in place to evaluate practice in how families are informed.

7. Referral

The topic of referral pathways for a child diagnosed with a disability is an area beyond the scope of the current project and is an area in which further research is recommended. However, a small number of specific recommendations in relation to referral were brought forward through the various strands of consultation and research of the Informing Families project:

7.1 Parents are referred to Early Services as soon as possible.

7.2 Parents are given information about the service they are being referred to.

8. Dissemination

Professionals in the focus group consultation discussed the necessary actions that would be required for successful dissemination and implementation of the Guidelines. Their suggestions included the following:

8.1 Management buy-in at all levels for implementation of the Guidelines.

8.2 Various formats of information to be provided including leaflets, booklets, checklists and laminated sheets containing the Guidelines - displayed in staff areas in Primary, Community and Continuing Care (PCCC), disability and hospital service settings.

8.3 Training to be provided as detailed above.

8.4 Direct communication of the Guidelines through professional bodies, trade unions and academic faculties.

8.5 The Guidelines to be provided as part of hospital orientation/induction.

8.6 The Guidelines to be included in hospital accreditation processes.

The formats for training and dissemination most widely chosen by professionals in the course of this research were *'training course with peers'* and *'interdisciplinary training course'*.

These guidelines adopt a person-centred approach whereby the child and the family are at the centre of the measures undertaken at the time of disclosure and in the ongoing parent-professional relationship.

“I think, having worked in hospitals where there was a designated parent’s area, and having worked in hospitals where that isn’t present, you can really see the advantage of having it there. Just having a warm environment with simple things - a kettle and some tea make a huge difference. As well as that it gives you an area in which you are comfortable to deliver the news because you are used to that environment – it’s somewhere that is familiar.”

Trainee Paediatrician, Informing Families focus groups

CHAPTER 7

NEXT STEPS - IMPLEMENTATION PLANNING

The development of National Best Practice Guidelines for informing families of their child's disability was based on comprehensive consultation and research, with the aim of ensuring that they are evidence-based, and applicable within the current Irish context in which families are told the news of their child's disability. However, international experience indicates that if the Guidelines are published and circulated without the back-up of a clear implementation strategy, the recommendations will remain just that (Fallowfield & Jenkins, 2004), and the needs identified clearly through the research, and in policy documents such as *Needs and Abilities* (1990) and *A Strategy for Equality* (1996) over the past seventeen years will remain unaddressed.

Throughout the national and international literature a recurring point of concern has been the lack of evaluation of communication skills and 'breaking bad news' training in general (Fallowfield & Jenkins, 2004; Girgis & Sanson-Fisher, 1998) and of guidelines for disclosure of disability in particular (Baird et al, 2000; South Western Area Health Board & Rush, 2003).

With this in mind, the *Informing Families Project* made a proposal to the Health Services National Partnership Forum in May 2006 for a new phase of the project; to implement the Guidelines on a pilot basis over a two year period in the Cork Region and to evaluate the outcomes for parents and professionals of the implementation of this programme. Along with local implementation the wider aim will be to gather learning points for national roll-out beginning in 2008. This proposal received full funding support from the Health Services National Partnership Forum to proceed.

Objectives:
The key objectives of the Cork Project are:

- To pilot the implementation of the National Best Practice Guidelines
- To evaluate if the Guidelines ensure improved outcomes for families and professionals
- To research the key factors leading to the successful implementation of the Guidelines
- To develop a template to guide national implementation of the Guidelines

The work plan required to achieve the above objectives will be agreed by a local Steering Committee bringing together key stakeholders including parents and professionals, and management from across hospital, disability and community services in the region.

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APPENDIX I

The National Federation of Voluntary Bodies

The National Federation of Voluntary Bodies (NFVB) is a national umbrella organisation for voluntary/non-statutory agencies who provide direct services to people with intellectual disability in Ireland. It aims to promote the equalisation of opportunities for persons with intellectual disability through the provision and development of high quality, person centred services. In developing best practice guidelines for how families are informed of their child's disability, the NFVB has worked with the Department of Health and Children, and with physical and sensory disability service providers to ensure that the scope of the project includes how families are told of all disabilities; physical, sensory or intellectual.

The Health Services National Partnership Forum

The Health Services National Partnership Forum (HSNPF) is a joint management / trade union steering committee for workplace partnership in the Irish health service. The HSNPF was established in 1999 on foot of the provisions of Partnership 2000, the national agreement on social partnership then in place.

APPENDIX II

Informing Families Project Terms of Reference

The National Federation of Voluntary Bodies, with the support of the Health Services National Partnership Forum, has initiated a project to develop and implement national best practice guidelines for informing families that their child has a disability. This is a Department of Health & Children, and HSE supported initiative.

Project Aims

1 To develop National Best Practice Guidelines for informing families of their child's disability at the first stage of communicating a diagnosis or concern.

2 To recommend education and training for staff involved in informing families.

3 The guidelines will be developed through research involving hospital, community care and disability services; management and staff; and families of children with disabilities.

4 The intended outcome of the guidelines will be:

- National Best Practice guidelines implemented and in practice in effectively informing families about their child's disability
- Guidelines available in every hospital, community care setting and disability service provider in the country
- Improved communication with families - better outcomes for children and families
- Improved skill and confidence in staff in informing families, through training
- Improved information
- Improved practice at national level across all departments.

5 The research is guided by a Steering Committee, which is chaired by Dr. John Hillery, President of the Medical Council of Ireland (2004-2007), and is co-coordinated by Alison Harnett, from the National Federation of Voluntary Bodies. The Steering Committee has representatives from key groupings such as parents, professionals working in disability services, the Health Services National Partnership Forum (HSNPF), the Department of Health & Children, the HSE, the National Federation of Voluntary Bodies, and the relevant training bodies such as the Royal College of Physicians of Ireland.

APPENDIX III

Chairperson: Dr. John Hillery President of Medical Council of Ireland (2004-2007) and Consultant Psychiatrist with Stewart's Hospital

An Bord Altranais	Ms. Anne-Marie Ryan*
Brothers of Charity, Galway	Ms. Catherine Rourke
Department of Health and Children	Ms. Ann Field**
Health Services Executive	Ms. Evelyn Hall Ms. Breda Kavanagh Ms. Suzanne Kirwan
Health Services National Partnership Forum	Mr. Eamon Naughton
Irish College of General Practitioners	Dr. Claire Collins
Irish Nurses Organisation	Ms. Annette Kennedy
Irish Society of Speech and Language Therapists	Ms. Anne Mulvihill
Inclusion Ireland	Ms. Mary Egan
National Federation of Voluntary Bodies	Mr. Brian O'Donnell Ms. Alison Harnett Ms. Edel Tierney***
National Parents and Siblings Alliance	Ms. Karen Canning Mr. Anthony Casey
National Social Work Qualifications Board	Ms. Bernie Fay
Psychological Society of Ireland	Ms. Margaret Farrelly
Royal College of Physicians of Ireland	Dr. Tony Walsh Dr. Matt Conran
School of Nursing and Midwifery, Trinity College Dublin	Dr. Joan Lalor
Sisters of Charity of Jesus and Mary Services	Mr. Stephen Kealy
St. Michael's House	Ms. Anne Walker

* Previously represented by Mr. Thomas Kearns

** Previously represented by Ms. Mary O'Reilly

*** Previously represented by Ms. Maria Walls, who remains a part of the Project management team

APPENDIX IV
INFORMING FAMILIES PARENT QUESTIONNAIRE - ANNOUNCEMENT LETTER

Disseminating Agency logo/headed paper

Informing Families Project - Questionnaire

1st Date

Dear Parent,

The [Agency Name] Early Childhood Services team is working with an organisation called the National Federation of Voluntary Bodies, on a project called the 'Informing Families Project'. The aim of the project is to develop and implement national best practice guidelines for how families are informed that their child has a disability.

The project has been undertaken in recognition of the importance of sharing the news of a child's disability with a family in the most sensitive manner possible. Parents have reported positive and negative experiences of being given this news. The aim of the project is to produce guidelines that will help improve communication with families, improve skill and confidence in staff in informing families, and ensure that families throughout Ireland are informed of their child's disability in the best way possible.

To help gather information for this project, we are circulating a questionnaire to a sample of parents. This is a national survey, and a random sample of parents throughout the country is being invited to complete the questionnaire. Each of the parents has a child (or children) between the ages of 3 and 6, who have a disability or developmental delay. The questionnaire will invite parents to share their experiences of how they were told the news of their child's disability. The information gathered will be used as part of the development of best practice guidelines.

The purpose of this letter is to alert you that the questionnaire will be sent to you in the coming days and to stress that your participation is absolutely voluntary. If you do not wish to participate, please simply ignore the second letter which contains the questionnaire.

If you do wish to participate, the questionnaire will ask you questions describing how you were given your child's diagnosis, and the recommendations that you would make for future practice. The questionnaire will be returned directly to the National Federation of Voluntary Bodies, and not to the Early Childhood Services Team, so any details you include will not be known to anyone providing services to your child, to ensure your confidentiality.

The questionnaire will be sent to you in the coming days. If you wish to participate, please fill out the questionnaire. A stamped addressed envelope will be provided for you to send the questionnaire to the project co-ordinator in the National Federation of Voluntary Bodies, Alison Harnett. If you do not wish to participate please simply ignore the questionnaire and dispose of it.

If you have any questions about the Informing Families Project, please do not hesitate to contact the Project Co-ordinator, Alison Harnett, or myself.

If for any reason any of the issues raised by this letter or by the questionnaire cause you distress, if you would like any help filling out the questionnaire, or if you would like to discuss the project further, please contact me and I will be happy to provide you with support.

If you wish to receive the questionnaire in an accessible format please contact us and we will arrange this. If more than one parent/guardian wishes to fill out the questionnaire separately, or if a second parent/guardian wishes to include extra information, the questionnaire can be photocopied, extra pages can be attached, or you can contact Alison Harnett to request a second copy (contact details below).

We strongly acknowledge that how you were informed of your child's disability can be a very emotional subject. It is therefore important that you only provide information which you are comfortable sharing. The general information gathered through the survey may be published, however all information gathered will be treated with utmost confidence, and anonymity will be protected. Your name will never be used and you will not be recognised in any published material.

We have made numerous efforts to try to ensure that this questionnaire is only sent to people whose child has a disability. If you have received this questionnaire in error we sincerely apologise and please feel free to contact us with any feedback.

Best wishes,

Support Contact, Title

Address:
Phone:

National Federation of Voluntary Bodies Contact Details:
Alison Harnett, Project Co-ordinator, Informing Families Project.
National Federation of Voluntary Bodies
Oranmore Business Park, Oranmore,
Galway.
Phone: 091 792316
Email: *Alison.harnett@fedvol.ie*

APPENDIX IV

INFORMING FAMILIES PARENT QUESTIONNAIRE – INFORMATION LETTER

Informing Families Project - Questionnaire

Date (1 week after Announcement Letter)

Dear Parent,

As detailed in a letter that was sent to you in the past few days, the National Federation of Voluntary Bodies is running a project to develop and implement national best practice guidelines for how families are informed of their child's disability.

The project has been undertaken in recognition of the importance of sharing the news of a child's disability with the family in the most sensitive manner possible. Parents in Ireland have reported positive and negative experiences of being given the news. The project aim is to produce guidelines that will help improve communication with families, improve skill and confidence in staff in informing families, and ensure that families throughout Ireland are informed of their child's disability in the best way possible.

To help gather information for this project, the [Agency Name] Early Services Team is working with the National Federation of Voluntary Bodies to circulate a questionnaire to parents. This is a national survey, and a sample of parents throughout the country are being invited to complete the questionnaire. Each of the parents has a child or children between the ages of 3 and 6, who has a disability or developmental delay.

We would like to invite you to complete the enclosed questionnaire. The aim of the questionnaire is to gather parent's experiences of being told the news of their child's disability, and to listen to parents' recommendations for how the process should work. We intend to use the information gathered as part of the development of best practice guidelines.

Your participation is absolutely voluntary. If you do not wish to complete the questionnaire, please simply ignore this letter. If you do wish to participate, please complete the questionnaire and return it to the National Federation of Voluntary Bodies in the stamped addressed envelope provided. The questionnaire is returned directly to the National Federation of Voluntary Bodies, and not to the Early Childhood Services Team, so that any details you include will not be known to anyone providing services to your child, to ensure your confidentiality.

If you have any questions about the Informing Families Project or wish to discuss the project further, please do not hesitate to contact myself (Alison Harnett), or [Support Contact] in the Early Childhood Services Team. If for any reason any of the issues raised by the questionnaire cause you distress or if you would like help with filling out the questionnaire, please contact [Support Contact], who will be happy to provide you with support.

We strongly acknowledge that this can be a very emotional subject. It is therefore important that you only provide information which you are comfortable sharing. The general information gathered through the survey may be published, however all information gathered will be treated with utmost confidence, and anonymity will be protected. Your name will never be used and you will not be recognised in any published material.

If you wish participate, we would be grateful if you could send the completed questionnaire back to the Informing Families Project Co-ordinator by [Closing Date], (using the stamped addressed envelope provided), as this will be the closing date.

Please note that this letter was sent to you by the Early Childhood Services Team on behalf of the National Federation of Voluntary Bodies, so that your name and address remain at all times confidential. No names or addresses were provided to the National Federation of Voluntary Bodies.

If you wish to receive the questionnaire in an accessible format please contact us and we will arrange this. If more than one parent/guardian wishes to fill out the questionnaire separately, or if a second parent/guardian wishes to include extra information, the questionnaire can be photocopied, extra pages can be attached, or you can contact Alison Harnett to request a second copy (contact details below).

We have made numerous efforts to try to ensure that this questionnaire is only sent to people whose child has a disability. If you have received this questionnaire in error we sincerely apologise and please feel free to contact us with any feedback.

Best wishes,

____

Alison Harnett,

Informing Families Project Co-ordinator, Principle Researcher.
National Federation of Voluntary Bodies,
Oranmore Business Park, Oranmore, Galway.
PHONE: 091 792316
EMAIL: Alison.harnett@fedvol.ie WEBSITE: www.fedvol.ie

[Early Services team name] Contact Details:
Name, _________________________ Title __________
Address ____
____
Phone: ______________________

APPENDIX V

List of tables and figures in the Informing Families Project Report

Data from Parent Questionnaires

Data from Professional Questionnaires

APPENDIX V

Combined Validation of Recommendations

APPENDIX V

Figures

Data from Parent Questionnaires

Data from Professional Questionnaires

ACKNOWLEDGEMENTS

We would like to express our particular thanks to the many families who so generously shared their experiences of being told of their child's disability, and the numerous professionals who described their experiences in communicating this news to families and supporting them thereafter. Without these contributions this report would not have been possible.

Given the wide-ranging contributions from families and professionals into the project, there were a large number of people who assisted in many different ways; in providing expert advice on accessing groups of individuals; in distributing questionnaires, facilitating contacts for focus groups; and in providing support contacts for parents who participated. The contribution of these people, who are too numerous to mention, is hugely appreciated.

Our thanks are also particularly due to the Informing Families Project Steering Committee who have guided the research and consultation over the past three years.

The contribution of the Health Services National Partnership Forum was critical to the success of the Informing Families Project. Their support, both financially, and through the significant contributions of Tess O'Donovan and Marie O'Haire in facilitating all fifteen professional focus groups is gratefully acknowledged.

Dr. Suzanne Guerin from the School of Psychology, and Dr. Bairbre Redmond from the School of Applied Social Science in University College Dublin provided the Informing Families Project team with expert validation of the research design and statistical sampling employed in the consultation and research phases of the project, along with providing valuable guidance and support during the analysis and write-up phases, for which we express sincere thanks.

The following groups' contributions are gratefully acknowledged:

- The Early Services Teams in the National Federation of Voluntary Bodies member organisations, Enable Ireland, the Central Remedial Clinic, the National Council for the Blind of Ireland and Cork Deaf Association. The Department of Education and Science (Visiting Teachers for the Deaf)
- The professional bodies and trade unions who provided support for the focus groups and questionnaire dissemination (a list of which can be found on pages 50 and 85)
- St. Michael's House Research Ethics Committee
- St. John of God Hospitaller Services Provincial Ethics Committee
- The Library Staff in St. Michael's House and St. John of God Hospitaller Services
- The National Federation of Voluntary Bodies Research Ethics Committee
- The Health Research Board
- The HSE, and in particular Dr. Mary Hynes and Mr. James O'Grady
- The staff members in Cork University Hospital and Cork University Maternity Hospital,
- The Early Services teams of Ability West (especially Dóchas); St. Michael's House; and the Brothers of Charity, Galway and Limerick, who provided advice and guidance at the initial exploratory phase of the research, and in particular Mary O'Connor (St. Michael's House)

A special word of thanks to my colleagues in the National Federation of Voluntary Bodies, to Brian O'Donnell for his constant support throughout the project; to Maria Walls for her key role in shaping the development of research project and her guidance and support throughout; to Edel Tierney for her advice, support and expert contributions, and to Jillian Sexton, Breda Casey, Caroline Looney, Mary Barrett, Maria McMahon, Eamon Naughton, Brian Donohoe, Carla Ward and Brendan Dolan for their assistance and support. Sincere thanks, also to Oliver Donohoe for his valuable guidance and support. To my family - warm thanks for their love and constant encouragement.

To the numerous people who assisted in so many ways with the development of the Guidelines, many thanks.

Alison Harnett,
Informing Families Project Co-ordinator
National Federation of Voluntary Bodies.

NATIONAL FEDERATION OF VOLUNTARY BODIES
Providing Services to People with Intellectual Disability

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