



Informing Families

OF THEIR CHILD'S DISABILITY

National Best Practice
Guidelines

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.

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 the *Informing Families Project* was therefore 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 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 and exhaustive consultation carried out over the past two and half years. I am delighted to present these Guidelines which come directly from that research and consultation process.

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.



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

*For details of the Project Steering Group Membership please see page 22

DEVELOPMENT OF NATIONAL BEST PRACTICE GUIDELINES

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 informed of their child's disability. The development of these Guidelines 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 the Informing Families Steering Group which 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. John of God Hospital Services). The Steering Group has representation from key stakeholders 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.

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 Guidelines includes the disclosure of a child's diagnosis of physical, sensory, intellectual, and multiple disabilities, and autistic spectrum disorders. The Guidelines relate to the diagnosis of a child's disability during pregnancy; at birth; or in the case of a diagnosis which evolves over time.

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 Group 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.

The findings of the consultation and research led to specific recommendations in a number of key areas that are relevant to the process of informing a family of their child's disability:

1. The Setting/Location and the People Present at Disclosure
2. Communication
3. Information and Support
4. Culture and Language
5. Training, Education and Support for Professionals
6. Organisation and Planning
7. Referral
8. Dissemination

Further details on the *Informing Families Project* and a comprehensive report of the findings of the consultation and research is available at www.fedvol.ie .

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:

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

“...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*

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 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.

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- 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 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.

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- 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.

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- 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 on 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 informed 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. 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:

- 5.1 Staff members are trained in best practice for informing families of their child's disability.
- 5.2 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
- 5.3 Role playing/experiential training forms a central part of training
- 5.4 As this can be a distressing area for professionals, it is important to have two staff members present at the sharing of the news.
- 5.5 Appropriate support is given (identified locally) including debriefing and mentoring by senior staff members for those in training.
- 5.6 There is an input from parents into training provision.
- 5.7 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.
- 5.8 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.

6. 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:

- 6.1 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.*
- 6.2 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.
- 6.3 Staff members share information, so that parents do not have to give the same history or information to many different people.
- 6.4 As family circumstances vary, the team share information on how best to facilitate each family.
- 6.5 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.
- 6.6 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

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- 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.
- 6.7 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
- 6.8 Birth Notification to the Public Health Nurse includes information about how the family has received the news of their child's disability.
- 6.9 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.

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 who took part in the research of the *Informing Families Project* 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.

“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*

PROJECT STEERING COMMITTEE

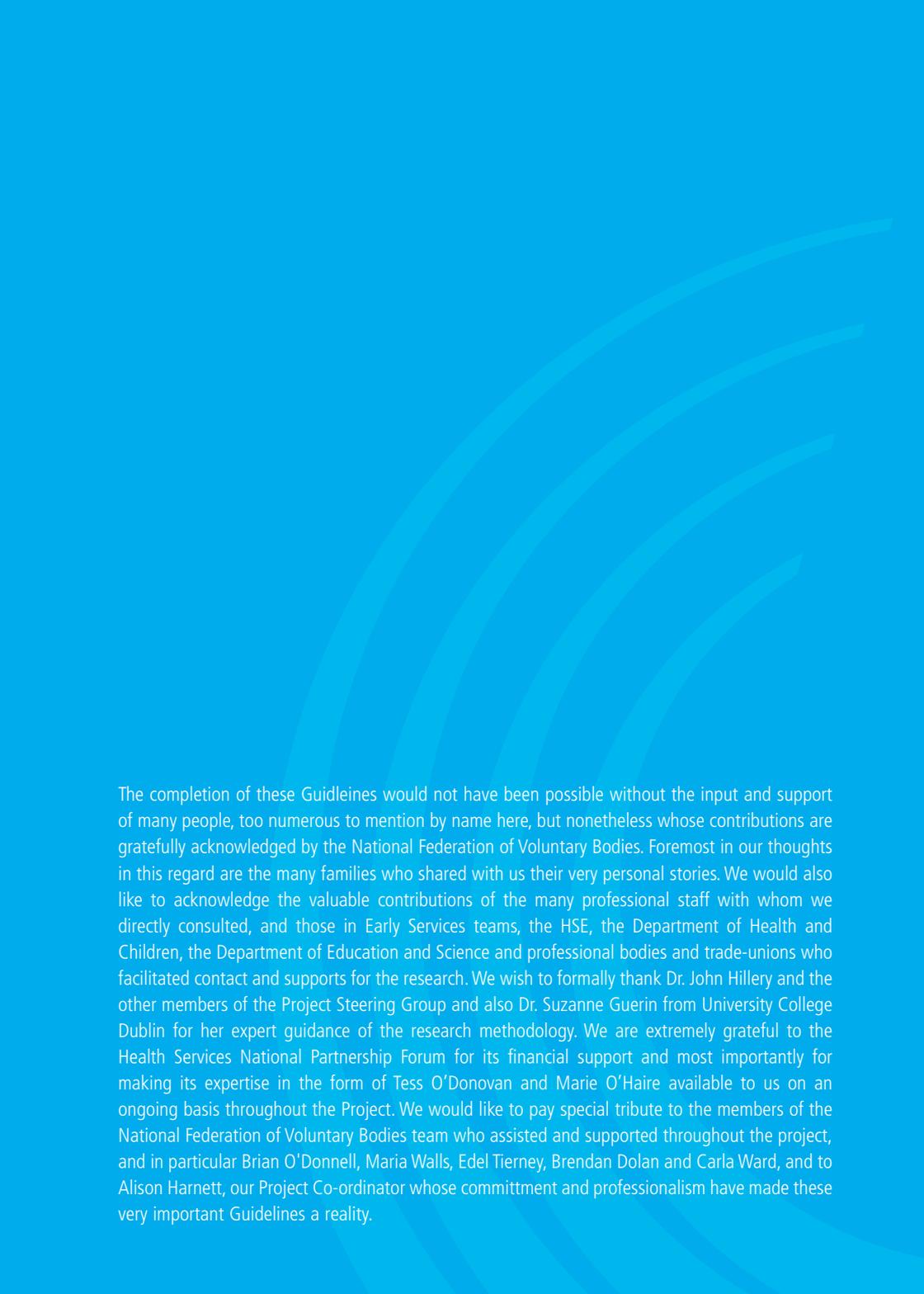
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* Previously represented by Mr. Thomas Kearns

** Previously represented by Ms. Mary O'Reilly

*** Previously represented by Ms. Maria Walls, who remains a part of the Project management team



The completion of these Guidelines 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. We would also like to acknowledge the valuable contributions of the many professional staff with whom we directly consulted, and those in Early Services teams, the HSE, the Department of Health and Children, the Department of Education and Science and professional bodies and trade-unions who facilitated contact and supports for the research. We 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. We would like to pay special tribute to the members of the National Federation of Voluntary Bodies team who assisted and supported throughout the project, and in particular Brian O'Donnell, Maria Walls, Edel Tierney, Brendan Dolan and Carla Ward, and to Alison Harnett, our Project Co-ordinator whose commitment and professionalism have made these very important Guidelines a reality.

NATIONAL FEDERATION OF VOLUNTARY BODIES

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