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# NATIONAL FEDERATION OF VOLUNTARY BODIES

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*Providing Services to People with Intellectual Disability*

## Informing Families Project

### Introduction

In 2004 the National Federation of Voluntary Bodies, with support from the Health Services National Partnership Forum, began a partnership project to develop national best practice guidelines for informing families 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.



*Ms. Katherine O'Leary (Chair Informing Families Project Cork) Ms. Mary Harney TD (Minister for Health and Children) and Ms. Miriam O'Callaghan, (RTE) at the launch of Informing Families Guidelines Dec 2007.*

The *Guidelines for Informing Families of their Child's Disability* were developed through a wide ranging consultation and research process and were launched on 3<sup>rd</sup> December 2007, by Minister for Health and Children, Mary Harney. The Guidelines are currently being implemented on a pilot basis in the Cork region, and this implementation will be evaluated to inform national roll out of the Guidelines.

Following the successful launch in 2007 of the Informing Families Project there has been overwhelming welcome and endorsement of the Guidelines from all key parent and professional stakeholders, with national and international interest continuing to develop.



*Mr. Larry Walsh (HSNPF), Ms. Alison Harnett and Mr Brian O'Donnell (National Federation of Voluntary Bodies) at the launch of Informing Families Guidelines Dec 2007.*

Work has been undertaken to utilise a wide range of opportunities to publicise the Guidelines at a national level, thus allowing the evidence-based best practice recommendations to be made available to professionals requiring support in this area. This dissemination has in turn led to strong demand for the Guidelines from medical, nursing and allied health professionals and from hospitals and organisations throughout the country.

At a local level in the Cork Region there has been significant engagement from a substantial range of organisations and individuals who are working in partnership to implement the Guidelines on the ground in a pilot project and thus to provide learning to inform national roll-out. Through a representative Steering Committee and a series of Working Groups a range of initiatives have already taken place and are in planning to ensure that professionals receive the necessary support to empower them to make effective use of the best practice guidelines when supporting families at the time of their child's diagnosis.

The National Federation of Voluntary Bodies gratefully acknowledges the significant and generous support of the Health Services National Partnership Forum in its work with the Informing Families Project to date, and in facilitating the progress of a project which has benefit for parents and professionals at the very sensitive time of a the diagnosis of a child's disability.

## **Guideline Development**

The development of the Guidelines for Informing Families of their Child's Disability was guided by a national Steering Group, which was 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 Hospitaller services). The Steering Group had representation from key stakeholders such as parents, disability service providers, the Health Services National Partnership Forum, 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.

The Guidelines are robustly evidence-based, having been developed through the following process:

### **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

Best practice recommendations emerged from a collation of the results of the literature review combined with the findings of the 22 focus groups. These recommendations in concise format were then rated by parents and professionals in the national questionnaire survey. The guidelines received overwhelming validation, with many of the individual recommendations receiving over 90% agreement in the combined parent and professional ratings. A full Consultation and Research Report was published, which provides the most comprehensive Irish data currently available describing how families are informed of the news of a child's disability.

## Some Key Findings of the Research

- 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.
- Levels of parental satisfaction were in line with levels of satisfaction with disclosure reported internationally. Therefore there is a good basis for practice already in place.
- However, parents spoke of some deficits in current practice causing additional distress at what can already be a very stressful time. Parents 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.
- 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.
- 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.

## **‘Words You Never Forget’ Short Film**

With the support of the Health Services National Partnership Forum, a short film entitled ‘*Words You Never Forget*’ was produced to support the Informing Families Project launch and publication of the best practice guidelines. This DVD was produced to professional broadcast standard and tells the stories of two families; one who received their child’s diagnosis in a positive way and another who received their child’s diagnosis in an unhelpful way. The DVD also provides input from the perspectives of professionals who are involved in informing families of this news, and was made in conjunction with Cork University Hospital, Cork University Maternity Hospital, St. Michael’s House, and the Brothers of Charity Services in Galway.

Following significant media coverage at the time of the Project launch there have been many requests for copies of the DVD ‘*Words You Never Forget*’, and as a result it was packaged, duplicated and made available using the ISBN system to ensure availability through national and international publication channels. The DVD has been widely disseminated for use as a training aid and for use in hospital, community and disability services. The film has proved to be one of the most valuable resources available to the Informing Families Project, giving audiences an opportunity to understand the emotional and sensitive issues at the centre of the disclosure process as told through the eyes of parents and professionals on the front line. To order the DVD ‘*Words You Never Forget*’ please contact [alison.harnett@fedvol.ie](mailto:alison.harnett@fedvol.ie) .

## **Welcome for the Guidelines & Dissemination Initiatives**

The Guidelines have received endorsement, welcome and strong support from all key stakeholders; including parents of children with disabilities, the Informing Families Project National Steering Committee, the Department of Health and Children, the Minister for Health and Children, and the HSE. Parents particularly welcomed this development as addressing long-standing needs whilst professionals frequently expressed that they felt ill-equipped to deal with the emotionally challenging task of breaking the news to families that their child has a disability, a topic which has not received significant attention at undergraduate level. A cross-border report published by RehabCare in June 2008 entitled ‘*An investigation into the social support needs of families who experience rare disorders on the island of Ireland*’ made the following statement as one of its 9 key recommendations:

*“The successful implementation of the guidelines set out as a result of the ‘Informing Families of their Child’s Disability Project’ in the Republic of Ireland would greatly benefit people with rare disorders”*

## **National Dissemination of the Informing Families Best Practice Guidelines**

A key task for the Informing Families Project has been the dissemination of the Guidelines, to ensure that all professionals for whom this guidance is relevant have access to the recommendations. To this end presentations have been made to stakeholder groups across the relevant disciplines and organisations, and opportunities for publication and media coverage have been pursued. Examples of these dissemination initiatives are set out below.

### **Presentations:**

- Bi-Annual Conference of the Irish Association of Speech and Language Therapists (IASLT), March 2007.

- National Disability Authority (NDA) 2007 Research Conference - Evidence Based Practice in Early Intervention for Children with Disabilities Aged 0-6. Plenary Session Presentation
- Psychological Society of Ireland Annual Conference, 16 November 2007
- Health Services National Partnership Forum, 29<sup>th</sup> January 2008.
- Health Services National Partnership Forum Facilitators Meeting, 11 April 2008.
- Inclusion Ireland AGM and Conference, 12 April 2008
- National Hospitals Office - Executive meeting of Hospital Network Managers and Assistant National Directors, 14 May 2008
- Clinical Conference, National Maternity Hospital, 10 June 2008
- Central Remedial Clinic (CRC) multi-disciplinary team meeting 12 June 2008, Clontarf (also video-conferenced to CRC Waterford, video retained for further use in training)
- Clinical Indemnity Scheme Bi-Annual Obstetrics Forum, 20 June 2008
- Irish Association of Directors of Nursing and Midwifery Annual Conference, 2 October 2008

Upcoming presentations include:

- Trinity College Dublin School of Nursing and Midwifery- 9th Annual Interdisciplinary Research Conference 5th - 7th November 2008 *"Transforming Healthcare through Research Education and Technology"*
- Irish Society of Audiology, Annual Conference, November 6th 2008

Work is ongoing with many other professional bodies and trade-unions to identify dissemination opportunities.

## **Undergraduate and Postgraduate Training**

The Informing Families Guidelines were included for the first time in 2008 on the curriculum of the postgraduate medical course in the University of Limerick. As part of the input Katherine O'Leary, a parent of two grown-up children with disabilities and Chair of the Cork Informing Families Project provided valuable insights into the experience of receiving the diagnosis from the parent perspective. The inclusion of the Guidelines on this course will continue in coming years and the involvement of the National Federation will be developed to include various aspects of the lifecycle with regards to disabilities. Work is continuing to develop further opportunities on other medical, nursing and allied health professional courses.

## **International Research Collaboration**

Comparative research by the Informing Families Project with Harvard Medical School and Boston Children's Hospital is underway. The research is examining the findings of the Irish national research into how families are informed of their child's disability, in comparison with research carried out in the US and Spain by Harvard Medical School. The partnership developed through working on this research has led to the development of further opportunities and exciting possibilities for future collaboration.

## **Cork Implementation Project**

An examination of international findings and evidence of the non-implementation of previous Irish policy recommendations in relation to informing families of their child's disability indicated clearly that a structured, coherent and co-ordinated approach to implementation was required in order to give effect to the Guidelines. The Health Services National Partnership Forum therefore provided

generous support to the Informing Families Project to pilot the Guidelines within one local setting (Cork); thereby providing a vital opportunity to begin the process of transitioning these important recommendations from theory to practice.

Following the completion and launch of the National Best Practice Guidelines the pilot project was established to begin the implementation of the guidelines in an integrated model that works across the boundaries of hospital, community and disability services in Cork. The project employs a work-based partnership model linking with existing partnership relationships developed through the Informing Families Project consultation programme and through the Health Services National Partnership Forum's Partnership Committee in Cork University Hospital.

The objectives are:

- a) To pilot the implementation of the Guidelines.
- b) To verify that the Guidelines ensure improved outcomes for families and professionals.
- c) To research the key factors leading to the successful implementation of the Guidelines.
- d) To develop a template to guide national implementation of the Guidelines.

The key aims of the pilot project are to provide:

- a) Improved outcomes for families receiving a diagnosis of their child's disability
- b) Improved skills and confidence of professionals providing a diagnosis or supporting the family who have just received the news.
- c) To foster and encourage Partnership working amongst all participants in the project.

The project builds on the learning from the Informing Families Project to explore the factors which lead to successful implementation of the Guidelines. Various strategies are being deployed to transition the Guidelines from theory to practice. An action-research methodology is employed to evaluate the implementation interventions and training provided. The results of these evaluations will inform future implementation strategies on a national basis. The implementation of this project is carried out through the use of the partnership principles i.e. consensus building, joint problem solving etc.

## **Structure of Cork Implementation Pilot Project**

The work of the Informing Families Cork Implementation Pilot Project is guided by a Steering Committee of parents and professionals from across all relevant service settings. The Steering Committee is chaired by Ms. Katherine O'Leary; a parent of two children with disabilities and a director of Inclusion Ireland. In accordance with the findings of the research, professionals are included from varied clinical backgrounds including nursing, midwifery, medical and allied health professions, representing management and unions, and bringing together a diverse range of statutory organisations and voluntary bodies.

The aim of the project at all times is to place the child and family at the centre of the measures undertaken at the time of disclosure and in the on-going parent-professional relationship.

A full list of the Steering Committee members is provided below:

## Informing Families Project Cork Implementation Project Steering Committee:

Discipline/Organisation	Represented by:
Line Manager Audiology	Mr. Michael Butler, Care Group Co-ordinator for Physical and Sensory Disability, West Cork
Clinical Nurse Specialist Early Intervention	Ms. Yana O'Donovan, Co-Action
Cork Deaf Association	Ms. Gerrie O'Grady, Manager, Cork Deaf Association
Partnership Facilitator	Mr. Eamon Naughton, Health Services National Partnership Forum
GP	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
HSE Primary, Community and Continuing Care	Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
IMPACT Trade Union	Ms. Maeve McCarthy Barrett, Branch Secretary Cork
Midwifery & Nursing	Ms. Geraldine Keoghane - Director of Midwifery, Cork University Maternity Hospital
National Council of the Blind of Ireland	Ms. Kathleen Vickers, Regional Manager NCBI Southern Region
Neurologist	Dr. Olivia O'Mahony, Consultant Paediatric Neurologist, Cork University Hospital
Neonatologist, IHCA Representative	Dr. Brendan Murphy, Consultant Neonatologist Cork University Maternity Hospital
Obstetrician/Gynaecologist	Dr. Dan McKenna, Consultant Obstetrician Cork University Maternity Hospital
Ophthalmologist	Mr. Gerry O'Connor, Consultant in Ophthalmic Surgery Cork University Hospital
Parent	Ms. Katherine O'Leary, Parent & Director Inclusion Ireland
Paediatrician	Prof. Jonathan Hourihane, Professor of Child Health and Paediatrics, Cork University Hospital
Project Co-ordinator	Ms. Alison Harnett, National Federation of Voluntary Bodies
Psychiatrist	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
Psychologist	Dr. Mary Desmond, Principal Psychologist COPE Foundation
	Dr. Margaret Farrelly, Principal Psychologist St. Joseph's Foundation, Charleville
	Ms. Hilary Lane, Senior Clinical Psychologist, Enable Ireland
Public Health Nurse	Nomination in progress via Ms. Gabrielle O'Keeffe, General Manager South Lee LHO
Research/Evaluation	Ms. Edel Tierney, Director of Research and Policy Development - National Federation of Voluntary Bodies
	Dr. Margaret O'Rourke, Senior Lecturer & Director of Behavioural Science, University College Cork
	Dr. Suzanne Guerin, Lecturer in research design & analysis – University College Dublin
Speech and Language Therapist	Ms. Breda Long, Early Intervention Project Officer
Social Worker	Ms. Joan Cronin, Head of Social Work Department, Brothers of Charity Southern Services
National Hospitals Office Representative	Ms. Mary Owens, Director of Nursing, Mallow General Hospital

The range of organisations taking part includes amongst others: Cork University Hospital, Cork University Maternity Hospital, the four Local Health Offices in the catchment area representing HSE Primary, Community and Continuing Care, the National Council of the Blind of Ireland, Cork Deaf Association, COPE Foundation, St. Joseph's Foundation, the Brothers of Charity Southern Services, Co-action West Cork, and Enable Ireland. In this way the integrated approach being taken to implementation is fully in line with the goals of the HSE Transformation Programme and its goal to ensure that the patient/service user is provided with a seamless service. Through its links with University College Cork the academic aspects of training and evaluation are integrated

into the project to ensure that the professionals of the future as well as those currently in practice receive training and information in this area.

## **Working Groups**

The Steering Committee of the Implementation Project is by necessity relatively large in order to accommodate participation and representation of all the key stakeholders. In order to ensure a pragmatic and efficient approach to the tasks that need to be undertaken to support implementation, the Committee has divided up into six Working Groups which meet on a regular basis, with the full Steering Committee meeting less frequently to provide and overseeing the work of the smaller groups. Initiatives across hospital, community, and disability service settings are being undertaken through the six working groups who are looking at the different aspects of good practice as follows:

- Information Working Group
- Training Working Group
- Teamwork & Liaison Working Group.
- PR, Dissemination & Mainstreaming Working Group
- Built Environment Working Group
- Evaluation Working Group

To ensure efficiency the majority of the work of these groups takes place using e-mail and conference call communication, which minimises the cost of travel and meeting room bookings.

### **Information Working Group**

The main work of the Information Working Group is to develop an accessible, up-to-date, culturally appropriate information resource readily available to professionals for supply to parents at the time of diagnosis disclosure. Work is underway on gathering English language information on the following:

- General disability support information for supply to parents at the time of their child's diagnosis (e.g. signposts to Entitlements and Benefits, emotional support, advice on searching the Internet, informing siblings, etc.)
- Diagnosis-specific information, (gathered by relevant clinicians and from specialist support groups for individual disabilities)
- Information specifically for professionals (e.g. Informing Families Guidelines, HSE Intercultural Health Strategy, protocols, checklists etc)

It is proposed that these resources will be made available online, and that a localisation project will take place to provide translation and cultural review of the English resources to ensure equality of information provision.

### **Training Working Group**

Research from the national Informing Families Project indicated that staff members should be trained specifically in good practice for informing families of their child's disability, with key elements such as parental input, communication skills, disability awareness, and reflective practice forming central pillars of the training. The key task therefore, of the Training Group, in close consultation with the Evaluation Group, is to develop training materials that provide this learning experience to staff members.

Materials have been developed and are currently being piloted with various groups within the academic and service settings. In collaboration with the Evaluation Working Group this training will be assessed, amended where necessary and rolled out on a wider basis throughout 2009 to the wide range of organisations and disciplines participating in the Cork Implementation Project.

### **Teamwork & Liaison Working Group**

Given that one of the key findings of the national research was that deficits currently exist in the continuity of care provided to families at the time of their child's diagnosis, the central task of the Teamwork & Liaison Working Group is to ensure continuity of care for families who are being informed of their child's disability, and to promote teamwork, partnership and liaison between professionals who communicate the news to the family.

Outcomes already achieved by this Working Groups include the creation of a protocol for informing families, the development of quality indicators for the implementation of the respective recommendations of the best practice guidelines, and the development of an initiative to create shared documentation between acute and community services to ensure that the family do not have to repeat their history over and over, and that services have a consistent picture of the needs of the family. Planning is also underway for a cross-organisation and cross-discipline workshop to identify liaison requirements. The learning from this workshop will inform future tasks to be undertaken

### **PR, Dissemination & Mainstreaming Working Group**

The central aims of this group are to ensure that all professionals who are involved in the disclosure process in the Cork region are aware of and have access to the Guidelines and to ensure mainstreaming of the Guidelines following the pilot.

The dissemination is taking place in a phased and planned manner to ensure that the communication is undertaken effectively – providing management buy-in and support to those implementing the Guidelines on the front line. The dissemination is being accompanied by an evaluation and tracking sheet to ensure that learning points can be transferred.

### **Built Environment Working Group**

The work of the Built Environment Group is to assess the privacy of spaces available within all service settings where families are informed of their child's disability; to address issues that arise and to report to management on areas that require additional improvement. The planned actions of this group include a photographic depiction of the areas available, with changes being documented to demonstrate the possibilities of improvements for family comfort and privacy.

The Working Group are also examining an innovative proposal to provide web-cams for families when a child is separated from parents for treatment, for instance when a mother may be recovering from a Caesarean Section and the child is in the Special Care Baby Unit.

### **Evaluation Working Group**

The role of the Evaluation Working Group is to examine the process of implementation to determine learning points and assess outcomes. As discussed above, the aims of the Cork Pilot Implementation Project are:

1. To pilot the implementation of the National Best Practice Guidelines for Informing Families of their Child's Disability
2. To evaluate outcomes for families and professionals as a result of implementation of the Guidelines
3. To research the key factors leading to successful implementation of the Guidelines, including barriers and enablers
4. To develop a template to guide national implementation of the Guidelines
5. Through the progress of the project to advance and support partnership working

Evaluation of the Cork Pilot Project will be achieved in two ways:

- Outcome Evaluation
- Process Evaluation

The objective of the *Outcome Evaluation* is to address Aim 2 of the Implementation Project, i.e. to evaluate the outcomes for families and professionals as a result of the implementation of the Guidelines. The objective of the *Process Evaluation* is to address Aims 3, 4 and 5; namely to research the key factors leading to successful implementation and through this to develop a template to guide national roll out. This will involve specifically identifying barriers and enablers to implementation. The Evaluation Working Group is guiding the methodology, research tools, sampling frame and ethical considerations for the evaluation of the Guidelines.

For further information on the Informing Families Project, please contact Alison Harnett, Project Co-Ordinator, National Federation of Voluntary Bodies, Tel: 091-792316, Email: [alison.harnett@fedvol.ie](mailto:alison.harnett@fedvol.ie).

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