Informing Families of Their Child's Disability

Best Practice Guidelines The Cork Pilot Implementation Project

> Recipient of Taoiseach's Public Service Excellence Award 2010

Translating Research into Practice



Cover Picture: Katherine and Diarmuid O'Leary, dairy framers, Co. Cork

Informing Families of their Child's Disability:	Translating Research into Practice - The Cork Pilot Implementation Project
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NATIONAL FEDERATION OF VOLUNTARY BODIES Providing Services to People with Intellectual Disability HEALTH SERVICES NATIONAL PARTNERSHIP FORUM







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Introduction



Foreword

In line with its strong traditional role as an advocate for people with intellectual disability, the National Federation of Voluntary Bodies developed 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 who work in disability services, the National Federation identified the need to develop *National Best Practice Guidelines for Informing Families of their Child's Disability.* The guidelines were launched in 2007.

Funding for this project was made available by the Health Services National Partnership Forum, to whom we are extremely grateful, to enable us to develop the guidelines through rigorous research and exhaustive consultation. The challenge then for us was to convert this evidence based research to evidence based practice and in this regard it was decided that the best approach for us would be to pilot the guidelines in the Cork area.

We adopted a collaborative approach, involving families, and professionals working in the statutory and voluntary sectors, in both hospital and community settings, and this representation constituted our Pilot Project Steering Committee, so capably led by our Chairperson Ms. Katherine O'Leary. I am delighted to say that the outcome of our Pilot Project is extremely positive. The guidelines have been proven to support best practice and are now making a real and positive difference in the lives of families, and the people who support them, at the time of disclosure of the diagnosis of a disability.

I am particularly thankful to Ms. Alison Harnett, our Project Co-ordinator, whose professionalism and commitment ensured that we have a roadmap for implementation. I would also like to pay tribute to every member of our Project Steering Committee and to the many families and professionals in the Cork Region, who contributed to the pilot phase. I would also like to re-iterate my appreciation to the Health Services National Partnership Forum, the HSE Department of Social Inclusion, and to the Board and Member Organisations of the National Federation of Voluntary Bodies, for their ongoing support to the Project.

It is indeed a fitting tribute to everybody concerned with this Project that the Cork Implementation Project of the *National Best Practice Guidelines for Informing Families of their Child's Disability* has in March 2010 been awarded the Taoiseach's Award for Excellence in Public Services.



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



I was deeply honoured to be asked by the National Federation of Voluntary Bodies to act as the parent chairperson of the Cork Implementation Project Steering Committee. Over the period of the two years duration of this pilot project we have implemented the National Best Practice Guidelines for Informing Families of their Child's Disability throughout the Cork region and overcome many obstacles through determination and hard work. I've seen what can be achieved with goodwill and cooperation. I hope this report will serve as a blueprint for other groups who wish to implement these guidelines. The outcomes detailed in the report are testimony to the value of these guidelines for professionals and families alike.

Difficult news is never easy to give or receive. During the pilot scheme in Cork I have witnessed extraordinary collaboration by professionals across all disciplines. Empathy with families and confidence in this delivery of news is enhanced. The news may be difficult but when parents feel that there is genuine concern for them, their dignity remains intact and there is room for hope. These guidelines provide the road map to guide national roll out. The expertise is already there to implement these guidelines. The project in Cork has proved this. This is far too important to let it stop at the Cork project. My dream is that over time this blueprint will be adapted to encompass the delivery of all difficult medical news.



Katherine O'Leary,

Parent of two children with disabilities, Chair of the Cork Implementation Project

About this report

Best practice guidelines for informing families of their child's disability and for supporting families receiving this news were developed through extensive research and consultation with parents and professionals by the National Federation of Voluntary Bodies. The guidelines were launched in December 2007 by the Minister for Health and Children, Mary Harney. You can download the guidelines at www.informingfamilies.ie.

Having identified the evidence-based recommendations, we understood that the most important challenge was then to ensure that the research was translated into practice and that the guidelines were implemented on the ground. This report details the implementation of the *National Best Practice Guidelines for Informing Families of their Child's Disability* on a pilot basis in the Cork region over a two year period from January 2008 to December 2009. The overarching aim of implementation was to improve the experiences of children and families at the time of diagnosis and be a real support to professionals in their disclosure practice.

The aim of the report is to present the initiatives undertaken by the implementation project in Cork in order to provide groups who wish to implement the guidelines with a roadmap from that experience which can be consulted in designing and implementing local responses in their area. The report provides practical information on how challenges were identified and solutions found in the key areas of disclosure practice. The key areas identified for implementation were as follows: *dissemination of guidelines; training; locations for communication; information provision and teamwork*. Further information on each of the initiatives taken can be accessed by contacting info@informingfamilies.ie.

The chapters of this report follow a common format to illustrate the initiatives taken in the key areas described above. The following sections are presented in each chapter:

- 'Needs Identified'
- 'The Gap'
- 'Personal reflections and quotations'
- 'What we did pilot implementation and solutions'
- 'What we heard'
- 'Recommendations for implementation'
- 'Resources Access the Materials'

The format is designed to be a user-friendly guide to the implementation that was undertaken in Cork, with the pictures and personal reflections illustrating the project as it happened on the ground. The aim of using this format is to present the action-research project in a way that can be adapted and used to suit local requirements and circumstances.



Evidence base for the National Best Practice Guidelines:

The National Best Practice Guidelines for Informing Families of their Child's Disability were developed through a comprehensive consultation and research process.

The scope of the research included:

- Physical, sensory, intellectual disability and autistic spectrum disorders
- Ante-natal, at birth and evolving diagnoses
- Hospital, community and disability services
- Professionals in 27 involved nursing, medical and allied health disciplines

The methodology used to develop the guidelines consisted of 3 stages:

Stage 1

National and international policy and literature review

Stage 2

22 focus groups

- 7 with parents of children with disabilities
- 15 with professionals in the key disciplines involved in communicating with and supporting families at the time of their child's diagnosis

Stage 3

National questionnaire survey

- 584 families (31.5% response rate)
- 1588 professionals in 27 disciplines (response rate varied per discipline)

Each stage built on the previous one, and from these three phases came the Consultation and Research Report, Best Practice Guidelines and DVD 'Words You Never Forget' (Find all of these resources on <u>www.informingfamilies.ie</u>)

Importance of the disclosure process

For families¹, the manner in which they are informed of their child's disability² or additional needs is of key importance:

- it has an impact on levels of distress and anxiety
- it has a bearing on the attachment process
- and can profoundly influence the evolving parent-professional relationship. (Cunningham, 1994)

For professionals, disclosing a diagnosis of disability³:

- can be an emotional and challenging experience
- requiring training and support
- and requiring clear policies to guide practice on the front line

(Western Area Health Board & Brothers of Charity, 2003; Right from the Start, 2003; Doyle, 2004)

Previous research indicates that it is vital that those informing families of their child's disability do so in a sensitive manner, giving the facts truthfully and positively, providing support, accurate information and showing respect for the child and family (Cunningham, 1994; Right from the Start, 2003; Sloper and Turner 2003). Poor disclosure can lead to an increased risk of litigation when communication is badly handled (Fallowfield & Jenkins, 2004; Harnett et al, 2009).

'The term 'Family' is used in this report to describe any unit of parent(s), guardian(s) and/or sibling(s) who are the primary care-givers of child with a disability and is not restricted to a particular definition of the family unit.

²The terms 'disability' and 'disabilities' are used frequently throughout the report for readability but it is recognised that it may be more appropriate to simply use the name of a particular syndrome that a child is diagnosed with rather than referring to a 'disability', and that for some children concerns about delays in development may later become resolved. In all cases what is important is the recognition and acknowledgement of every child as an individual, with an emphasis on the strengths and abilities of the child and an explanation of the needs and disability as secondary to the individuality of the child.

³Over the course of the research and implementation it has become clear that the best practice guidelines are relevant for those who **inform** families and those who **support** families of children with disabilities.



Results of the Irish research

In 2007, the national survey of the Informing Families Project (Harnett et al, 2007) found that there was a gap between the satisfaction levels of parents and professionals in relation to disclosure. While just 34.6% of affected families in Ireland were either 'Satisfied' or 'Very Satisfied' with the way they had been informed of their child's disability, 62.2% of professionals indicated that they were 'Satisfied' or 'Very Satisfied' with their disclosure practice. These findings indicate that there is a significant gap between how parents and professionals perceived the quality of the disclosure and underlines the need to address the issues leading to parental dissatisfaction.

Prior to the publication of the Informing Families Guidelines, the national survey of professionals found that 79.8% of those involved in the disclosure process were unaware of any recommendations or training in best practice to guide them in this task. In spite of this, the report found that the levels of satisfaction in the Irish study were in line with international findings and that many parents were given the news in an appropriate manner. However, there were also some significant deficits in disclosure practice highlighted, which means that the current challenge is to maintain existing good practice and bring about more consistent implementation of good practice where there are difficulties.

The deficits identified were in the following key areas: insensitive or inappropriate communication; unsuitable environments for communication that lacked privacy; inconsistent provision of comprehensive, accurate and up-to-date information and a lack of continuity of care. Professionals spoke of their need for training and clear evidence-based guidance and many reported struggling with inadequate or inappropriate physical environments with little privacy available for communicating with families (Harnett et al, 2007).

The research also showed that where there are deficits in practice this can impact on families and professionals considerably, thereby reinforcing the need to build on good practice already in place, implement the national best practice guidelines and to provide a template for making practice improvements where necessary on the ground.

The remainder of this report describes the development of such a template through a pilot implementation project in the Cork region.

Informing Families of their Child's Disability - Best Practice Guidelines

The Cork Implementation Project

Following on from the launch of the National Best Practice Guidelines for Informing Families of their Child's Disability in December 2007, an interdisciplinary, cross-sectoral project was established to pilot the implementation of the guidelines on an integrated partnership basis between health and social care providers and families in the Cork region. The aim of the project was to improve the experiences of parents who are informed of their child's diagnosis of disability and to improve support for professionals involved in the communication of the diagnosis. In so doing the project goal was to provide a template for implementation of the best practice guidelines and to inform national roll-out.

The project was guided by a Steering Committee chaired by a parent of two children with disabilities and was implemented in acute, community and disability service settings in the Cork region. Professionals from medical, nursing and allied health disciplines in the following organisations participated in the project:

Hospitals	Community Services	Voluntary Disability Services	Universities
 Cork University Hospital (CUH) Cork University Maternity Hospital (CUMH) Mercy Hospital Cork Mallow General Hospital 	 HSE Primary Community and Continuing Care (PCCC) in the Cork Region: North Lee South Lee North Cork West Cork GP's in Cork Region 	 Brothers of Charity Southern Services Co-Action West Cork Cope Foundation Cork Deaf Association Enable Ireland Southern Services Inclusion Ireland National Council of the Blind of Ireland (Southern Region) National Federation of Voluntary Bodies St. Joseph's Foundation (Charleville) 	 University College Cork (UCC) University College Dublin (UCD) (Methodological Support)



Structure of the Project

The initiatives of the Cork Implementation Project were undertaken by a series of Working Groups overseen by the Steering Committee of stakeholders from acute, community and disability service settings in the Cork region (see page 8). A full list of the membership of the Steering Committee can be found on page 78 of this document. A project coordinator from the National Federation of Voluntary Bodies supported the work of the Steering Committee throughout the pilot project. Needs and deficits were identified through the national research of the Informing Families Project. These were grouped into 5 key areas, each of which was assigned a Working Group. Desired outcomes were agreed and achieved for each working group and a sixth group, the Evaluation Working Group evaluated progress and outcomes. The Evaluation Working Group was comprised of several members of the Steering Committee, and defined methodologies for the evaluation of the initiatives. The working groups are outlined below.



Informing Families of their Child's Disability - Best Practice Guidelines

Partnership

The work of the Cork Implementation Project was characterised by partnership:

Cross sectoral partnership – acute, community and voluntary disability organisations worked together to increase communication, share knowledge and information and enhance continuity of care for families using services in the region. This partnership is an example of the integrated approach being adopted by the HSE.

Interdisciplinary partnership – staff members from medical, nursing and allied health professions worked together to find solutions to issues affecting quality, parent and child experiences and staff supports. Parent-professional partnership – the work of the Cork Implementation Project brought professionals and those using services together in a very tangible partnership by having a parent as chairperson of the project and with parent involvement central in the development of solutions such as room design, information development and training provision.

The partnership work undertaken by the Cork Implementation Project resulted in specific initiatives with measurable outcomes. These initiatives are described in detail throughout this report.





Steering Committee

At the beginning of the Cork Implementation Project the project coordinator met with groups in acute, community and disability services across the Cork region to provide them with information and to secure support for the pilot project. Nominations were requested from each of the participating organisations and from a range of the disciplines identified through the national research (Harnett et al, 2007; p. 85) as having a key role in communicating with families and supporting families at the time of diagnosis. Care was taken to ensure that nursing, medical and allied health professionals; and each of the sectors – acute, community and voluntary disability services, were well represented.

Having managers and decision makers represented and involved in the project was essential to ensuring changes were implemented and staff members were supported in adopting the guidelines on the ground. This initial stage of establishing the Steering Committee took some time and was one of the most important of the project, since the involvement and engagement of all key stakeholders was essential to a comprehensive implementation strategy. In consultation with Inclusion Ireland a parent of two children with disabilities, Katherine O'Leary, was invited to be the Chairperson of the pilot project.

The Steering Committee met on 13 occasions over the two year duration of the project. Initially meetings alternated between locations in the community, voluntary and acute settings, however as travel restrictions became more pronounced over the course of the project, travel was cut down by holding meetings in the location with the highest concentration of members i.e. Cork University Hospital and Cork University Maternity Hospital. In between Steering Committee meetings actions were progressed by the Working Groups. The Working Groups held the majority of their meetings via conference call. Throughout the project communication took place via email to make best use of time and resources.

The Working Groups were made up Steering Committee members and of individuals working on the ground with a particular focus on the topic of the Working Group.



Members of the Cork Implementation Steering Committee (see pg.78 for full details of the Steering Committee and their representative organisations) (Back row left to right: Ms. Hilary Lane, Dr. Mary Desmond, Dr. Jo Duncan, Dr. Margaret O'Rourke, Prof. Jonathan Hourihane, Ms. Yana O'Donovan, Ms.Margo Fenton, Dr. Brendan Murphy, Mr.Carl Plover, Ms. Gabrielle O'Keeffe) (Front row left to right: Dr. Suzanne Guerin, Ms. Alison Harnett, Ms. Katherine O'Leary, Ms. Edel Tierney, Ms. Breda Long.)



Reflections of the Cork Implementation Steering Committee:

At the end of the pilot project, the Steering Committee came together with the assistance of an independent facilitator from the Health Services National Partnership Forum to reflect on the implementation, to evaluate the project and to provide recommendations based on their experience to groups who may implement the guidelines in the future.

What worked well?

The Steering Committee indicated that there were numerous elements of the Cork Implementation Project that worked well and put forward the following points as critical success factors:

- Focusing on the needs of parents and involving parents throughout the pilot project
- Having a broad range of representation of stakeholders from all of the services working with children in the region
- Partnership working between the disciplines, organisations and between parents and professionals leading to improved communication between acute, voluntary and community services

- Steering Committee members giving freely of their time; the goodwill and commitment of those working on the project to take on extra responsibility
- A 'can-do' attitude
- The evidence-base for the guidelines and clear direction from the research
- The relevance of the project
- Acknowledgement of the sadness felt by clinicians as well as families
- Leadership, flexibility and responsiveness in the running of the project
- Clear objectives and goals; and clear division of tasks leading to well-formed outcomes (eg. the Informing Families website, enhanced privacy for communication, delivery of training, evaluated training materials for future use, an eLearning module, protocols for communication and liaison)
- Practical and accessible tasks
- Good record taking including minutes, outcomes and delineation of next goals
- Use of conference calls in Working Groups
- Evaluation 'asking the right questions in the right way'
- Having an independent project co-ordinator (where funding allows)

What were the difficulties experienced?

- The large number of representatives on the Steering Committee was sometimes a challenge for coordination; however the Steering Committee also indicated that this reflected the fragmentation of service delivery. It was agreed that it was important to have all key stakeholders involved.
- Travel restrictions presented challenges for co-ordinating a project in a wide geographical area.
- 'Real world' issues such as an outbreak of mumps and the swine-flu epidemic impacted on the work of the project.
- It was difficult to ascertain the amount of work that Steering Committee members would need to put in and the precise plan of the overall goals in the early stages

 a clear roadmap from as early as possible in the project is recommended.
- Gaining organisational/institutional support for initiatives on the ground was occasionally challenging in some of the locations, meaning that there could be an over-reliance on good will of individuals.
- Some meetings were difficult to get to because of timing but the meetings were of value and worthwhile.

Recommendations of the Cork Steering Committee for implementation

- Keep the needs of children and families as the centre. Focus the project and plan activities on that basis.
- Ensure significant parent involvement at all stages of the project.
- Provide information to all involved professionals on how to access the guidelines and materials.
- Develop a roadmap early in the process (the roadmap from the Cork project (pg 16) can be used as a basis to develop plans locally).
- Identify the key people/organisations prior to starting

 establish an executive committee and subgroups
 (executive members may not necessarily be on working groups). Replace non-attenders at meetings to ensure best use of committee time and resources.
- Secure management support from the outset to ensure that staff members are supported on the front line in their implementation of the guidelines.
- Assign a project coordinator with protected time if possible.
- Acknowledge that comprehensive implementation of the best practice guidelines does require a time commitment on behalf of those participating.
- Formalise training to ensure that it becomes embedded in the system. Offer annual training in each sector to take account of staff/student turnover.
- Providing training to medical students in their fourth year is ideal timing for maximum impact.



Key messages from the Cork Steering Committee

- The Cork Implementation Project has demonstrated that the National Best Practice Guidelines can be successfully implemented across sectors, locations and disciplines.
- Through the implementation that took place in Cork tools have been created which can assist in implementation and are now available to be used in implementation in other locations.
- The project has shown that it is possible to change practice with goodwill, clear goals and commitment.
- Involvement across all sectors is necessary it results in better communication and cooperative working. This results in practical benefits for families.
- This wasn't an area previously given a lot of attention but the needs have now been articulated by families through the national research and the pilot project in Cork.
- Cross sectoral partnership and co-operation were fostered by the project.
- Many of the changes made were not resourcedependant. The pilot project provides information on how thinking might be changed (rather than resources) to implement best practice.
- It is important to have the key people sitting together from across all of the relevant areas to define locally how the guidelines can be implemented – each group should draw on local expertise and knowledge to decide how best to implement in their own locality.

The central message that the Steering Committee wish to impart is to communicate the availability of guidelines for best practice in informing families of their child's disability; and to demonstrate that the implementation of these guidelines is possible and has been successfully achieved in the Cork region. The Steering Committee recommends that groups in other areas should consider implementing these guidelines.

See page 16 for the Roadmap for Implementation deveoped by the pilot project.

Including parents is very positive.

Roadmap for Implementation



* National Study Informing Families Consultation and Research Report, see www.informingfamilies.ie

** See www.informingfamilies.ie and www.hseland.ie for elearning module

You can download a copy of the Roadmap for Implementation on www.informingfamilies.ie

Chapter 1 Dissemination



The national research of the Informing Families Project (see page 5 of this report) (Harnett et al, 2007) and previous studies (Doyle, 2004; Redmond 2000; Western Health Board & Brothers of Charity Galway, 2003) highlighted the need in Ireland for training, clear policies and evidence-based guidance for professionals involved in informing families of a child's disability.

In the UK, guidelines for informing families were implemented in one particular region. Research showed, however, in a subsequent evaluation, that only one third of key professionals in the area were aware of the guidelines, demonstrating difficulties in the key task of dissemination (Fallowfield & Jenkins, 2004).

Initiating change and good practice demands that all of the key personnel involved believe the change in practice to be of value and can support this belief **(Cunningham 1994, p.99)**. It is therefore essential to widely disseminate best practice guidelines and the evidence base for their development in order to effectively initiate change.

In the Irish research conducted to develop the national best practice guidelines 79.8% of professionals surveyed in Ireland were previously unaware of guidelines or training in how to inform families of their child's disability (Harnett et al, 2007). It was therefore a key aim of the Cork Implementation Project to ensure that all relevant professionals in the Cork region would be provided with access to the National Best Practice Guidelines for Informing Families of their Child's Disability.

The Communication Gap

The national research of the Informing Families Project (Harnett et al, 2007) found that there is a wide range of professionals involved in communicating with families and supporting families at the time of their child's diagnosis of a disability or developmental concerns. Disclosure is, and should be, a process rather than a one-off event, and can involve professionals from across hospital, community and disability service settings, from nursing, medical and allied health disciplines. In addition those supporting families may have varying levels of experience and involvement in the disclosure process (Harnett et al, p.85).

With such a complex and varied range of professional involvement the responsibility for training and co-ordinating a cohesive response to family needs has not fallen to any one group and this is likely to have been a contributory factor in the lack of clear guidance and training to date for professionals who inform families. The Informing Families Guidelines are the first national guidelines to be published to support professionals in Ireland in their disclosure practice. Given that, as stated previously, 79.8% of the professionals surveyed nationally were previously unaware of any guidelines or training in this area the first priority of the Cork Implementation Project was the dissemination of the evidence-based recommendations to the wide and varied professional population identified as playing a role in the disclosure process. "...and it's not just a sentence, every word is important because you are hanging on to everything 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 participant in focus group: Harnett et al, 2007)

> "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 in focus group: Harnett et al, 2007)

"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 one from the other. There are different skills... so it's an ongoing process that you have to learn." (Trainee Paediatrician: Harnett et al, 2007)

For further detail on the national consultation and research undertaken to develop the *National Best Practice Guidelines for* Informing Families of their Child's Disability see Page 5 of the introductory chapter and find the full report online at: http://informingfamilies.ie/about-the-project/consultation-&-research

What we did: Pilot Implementation and Solutions

The National Best Practice Guidelines for Informing Families of their Child's Disability were disseminated to professionals in acute, community and disability service settings across the Cork region. Dissemination was targeted to staff members who communicate the news of a child's diagnosis to families or support families through this process. The following steps were taken to achieve this goal:

Initial Briefing Meetings

The project coordinator met with participating groups in acute, community and disability services across the Cork region and provided information on the guidelines to each. (The participating organisations are listed on page 8 of this report). The initial meetings consisted of a presentation of the guidelines to members of the management team in order to secure support for dissemination to the wider organisation. Where pre-planning allowed and where practical on the same day the findings and recommendations of the evidence-based guidelines were also presented to the relevant teams present. Nominations to the Steering Committee of the pilot project were requested from each organisation and from relevant disciplines.

Dissemination spreadsheet

Once the Steering Committee had been established the Dissemination Working Group created a spreadsheet of all of the involved disciplines and organisations in the Cork region and used this to develop strategies to reach all of the relevant professionals in each location and discipline. The findings of the national research, which had identified 27 disciplines as having involvement in the disclosure process, were used to guide this process (see Harnett et al, 2007 p.85). The identified disciplines were from nursing, medical and allied health professions in a wide range of service settings across acute, community and voluntary service provider sectors. Individual members of the Working Group took responsibility for communicating in various areas and the final result was an over-arching strategy designed to ensure that the Guidelines reached all relevant professionals in the region.

Structured dissemination in organisations, using tracking sheets

Using the dissemination spreadsheet as a guide, the Guidelines and a DVD entitled 'Words You Never Forget' (which was produced for the pilot project and provides an insight into the disclosure process through the stories of two families of children with disabilities) were made available to a wide range of staff members across the participating organisations. Tracking sheets were used to



assist management staff in ensuring that all team members had both seen the DVD and read the guidelines and these sheets also provided space for feedback. Steering Committee members disseminated the guidelines to their own disciplines in some cases, for instance at team or regional meetings, study days and journal clubs, particularly in the community areas where staff members do not all work in one location. In other locations, e.g. in the hospitals, the DVD was put playing on a loop in nurses stations and presented at lunch-time training. Staff members signed the tracking sheets to indicate they had read the guidelines and watched the film. (You can order the DVD on www.informingfamilies.ie)

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Tracking sheet from dissemination of guidelines (Sample tracking sheets available on www.informingfamilies.ie)

Train the Trainers Programme

A 'Train the Trainers' programme was run on 14 May 2009 for 30 key staff members from across the relevant disciplines in hospital, community and disability service settings in the Cork region. These staff members were identified as 'champions for change' who could further disseminate the national best practice guidelines amongst colleagues. The aim of the programme was to encourage sustainable implementation and to achieve a multiplier effect in dissemination. A training programme was developed and evaluated by the Training Working Group (see chapter 2 of this report for full details) and found significant increases in knowledge, comfort and confidence of the participants with respect to their disclosure practice. The materials from this course were provided to the participants of the 'Train the Trainers' programme, along with all of the project materials and guidance on delivery of the training. The 'champions for change' then began to roll the training out to professionals from their discipline or location. A second 'Train the Trainers' workshop was planned but due to pressure on resources during the swine-flu epidemic, it was not possible to go ahead with it. It was agreed that the trainers who had already participated in the programme could potentially provide training in the areas where there were remaining gaps.

Email through HSE communications

Bearing in mind that there are always logistical challenges that can impact smooth roll-out of projects such as these (in this case an outbreak of mumps and the swine flu in particular) and given the wide range of disciplines that needed to be informed, it was recognised that there would be gaps in coverage when disseminating the guidelines. Therefore an email was sent to 'all users' in collaboration with the HSE Communications Department (southern area) advising them of the availability of the guidelines and the pilot project that was taking place. The guidelines were provided in electronic format and recipients were advised of contact details if they required further information.

Open training session

The email from the HSE Communications Department also advised recipients of an open session on the guidelines held in the lecture theatre in Cork University Hospital (as the largest available venue in the participating organisations). The session followed the structure of the training course i.e. film showing parent stories and professional perspective; presentation of the research findings and guidelines; parent input and group discussion. The aim of having an open session was to contact groups who may have been overlooked in developing the spreadsheet for dissemination, or who had missed previous opportunities to participate.

National conferences/study days of participating professional disciplines

During the course of the pilot project opportunities were pursued by members of the Steering Committee and the project co-ordinator to disseminate the Guidelines at a national level to further support and reinforce the dissemination taking place at a local level in the Cork region. The Guidelines were presented and disseminated at the following annual conferences and study days as part of the pilot scheme:

- Irish Association of Directors of Nursing and Midwifery Annual Conference, October 2008
- The Psychological Society of Ireland Annual Conference, November 2008
- Royal College of Physicians of Ireland: Faculty of Paediatrics Spring Study Day, 2009
- Joint Irish Faculty of Paediatrics and Welsh Paediatric Society Meeting May 2009
- Institute of Obstetricians and Gynaecologists Study Day & AGM September 2009

Following on from these presentations various developments took place, including an invitation from the Faculty of Paediatrics to provide the training course developed through the Cork Pilot Implementation Project on the paediatric training course delivered by the Royal College of Physicians of Ireland.



Some of the project materials and resources disseminated through the Cork Implementation Project



Members of the Brothers of Charity Southern Services multi-disciplinary teams taking part in group discussion during dissemination of the Informing Families Guidelines



Parent and Chair of the Cork Implementation Project Katherine O'Leary sharing her personal family experiences during the 'Train the Trainers' programme



Project co-ordinator facilitates discussion at the 'Train the Trainers' course

Evaluation of dissemination What we heard

The dissemination of the National Best Practice Guidelines for Informing Families of their Child's Disability was evaluated over the course of the Cork Implementation Project through a variety of means:

- The dissemination spreadsheet was used to check coverage of the target areas and to develop strategies to address gaps identified.
- The tracking sheets were used by managers to ensure that all relevant staff members had received the guidelines.
- Feedback from staff members on the tracking sheets was recorded and taken on board.
- The 'Train the Trainers' programme was evaluated using a questionnaire survey circulated at the end of the session.
- The 'champions for change' evaluated the training pack materials after they delivered training to colleagues. Their feedback was returned on a feedback form included in the pack.

What we heard following dissemination

"Excellent presentation. You sometimes forget the impact you make" Feedback in tracking sheet from participant having watched DVD and read the guidelines

"Wonderful guidelines for staff that will benefit families and patients" Feedback in tracking sheet from participant having watched DVD and read the guidelines

"I thought it was a good way to reach a wide range of professionals quickly and effectively" Feedback from participant in evaluation of 'Train the Trainers' programme

"These guidelines are excellent. It may have been beneficial for us in NEPS [National Education Psychology Service] working with school-going children to see/hear DVD footage of older children's parents' experiences of receiving information re their child's needs" Feedback from participant in training session delivered by one of the 'champions for change'

"The session was clearly laid out and easy to deliver. What I was given was perfect. The checklist of tasks and running order was helpful" Feedback from a 'champion for change' on the materials and support provided in the 'Train the Trainers' programme following their delivery of a session to 35 members of their own discipline at a regional meeting.



What we learnt

- There was widespread welcome and support for the dissemination of the Informing Families Guidelines and the pilot implementation project.
- Participants indicated the key reasons they had gotten involved:
 - meeting the needs of families
 - the clear evidence base for the guidelines
 - the teamwork approach taken by the project
 - opportunities to reflect on practice
 - the implementation of a quality initiative
- Management support was a key facilitating factor in the dissemination in the various organisations.
- It works well to use a structured approach to dissemination such as a spreadsheet to identify all stakeholders (location and discipline).
- It works well to access groups as natural opportunities arise. Existing study days, regional or team meetings, journal clubs, etc are ideal ways to reach groups of professionals.

- Circumstances sometimes intervene to cause challenges to dissemination (in the case of this pilot implementation project these included the outbreak of mumps and swine flu; competing priorities; demands on time and difficulty in securing nominations to training in some locations) so it helps to have an alternative plan for reaching all relevant professionals (e.g. email to 'all users').
- A flexible approach is necessary which takes account of the organisation size, management style, setting, disciplines and diagnoses encountered, but which remains consistent in terms of the delivery of the evidence-based guidelines and materials.
- Using a 'Train the Trainers' approach is helpful for extending the reach of dissemination and getting information out quickly. On this project there was a great willingness to take-up the Train the Trainers programme – the programme initially sought 20 participants but had a take-up of 30 places.
- Having the 'Words You Never Forget' DVD, which shows the stories of two families and the professional perspective, was an important advantage. Video footage is very helpful in putting across the real experiences of families and underlining the need for implementation of best practice.
- In the acute setting it worked well to have the DVD running on a loop e.g. at the nurses station, thereby catching the attention of a wide range of staff members, including support staff such as porters and cleaners who may meet and interact with families in their day to day work.

- Using a variety of channels and formats to communicate the message of the pilot project was an effective strategy. For instance the guidelines were disseminated through local organisations; presented in training courses; staff members saw practical measures being rolled out (e.g. room refurbishments) and heard about the guidelines from professional bodies at a national level. Professionals were particularly willing to participate when they had already heard about the guidelines.
- Alternative or supplementary materials are required to fully cater for the variance in experience between diagnoses at birth and those that evolve over long periods such as autistic spectrum disorders or needs picked up at school-age. Whilst those working in early services and schools (e.g. National Educational Psychological Service) reported that the guidelines were applicable and relevant to their practice, they indicated that the supporting materials (e.g. DVD) required some tailoring to place greater emphasis on the evolving diagnosis scenario. It would be beneficial if funding could be secured to produce an additional segment of video to supplement the existing film in this regard.
- Having a specific project such as the dissemination of the Informing Families
 Guidelines provides a focus which facilitates reflection on practice, team discussion and interaction, and listening to feedback from those using services (in this case parents and families).

Recommendations for implementation

- The development and implementation of best practice guidelines will only be effective to the extent that the information is disseminated to the relevant professionals. It is therefore essential to plan distribution of guidelines using available fora, networks and information mechanisms in order to reach all of the relevant staff members and to appropriately support implementation on the ground.
- It is important to secure management support in each location and organisation to facilitate dissemination and to fully support staff members on the front line to implement the best practice guidelines.
- The incorporation of local knowledge and expertise is essential to achieving successful dissemination.
- Different approaches work for different circumstances and groups so a flexible and co-ordinated approach is essential.
- It is recommended to plan dissemination through the use of tools such as a spreadsheet of relevant disciplines and locations.
- It is helpful to use a variety of formats and channels to publicise the guidelines hearing about a project from a variety of sources helps people to recognise and remember the initiative.
- Evaluation of dissemination initiatives is recommended in order to facilitate staff members in providing feedback and putting forward their viewpoints.



Access the materials

Recommendations on dissemination of the National Best Practice Guidelines for Informing Families of their Child's Disability are on page 20 of the guideline booklet. The full booklet can be downloaded from <u>www.informingfamilies.ie</u>

Hard copies of the Informing Families Guidelines, Consultation & Research Report and the DVD 'Words You Never Forget' can be ordered through the Informing Families website. You can also download the Tracking Sheet for Dissemination template from this site.

The course materials for the 'Train the Trainers' programme piloted and evaluated in the Cork Implementation Project are available for use. If you wish to deliver the training course for the Informing Families Project contact info@informingfamilies.ie

The dissemination of best practice guidelines for informing families of their child's disability across the Cork region is a quality initiative centred on improving the service provided to parents at the time of diagnosis and supporting professionals in their disclosure practice.



Chapter 2 Training

use



Needs identified:

Professionals may experience challenges in terms of the emotions and stresses associated with communicating difficult news to families. International research has shown the benefit of the provision of communications skills training (Farrell et al, 2001; Abel et al, 2001) and disability awareness training in supporting professionals who inform and support families at the time of diagnosis (Ferguson et al, 2006).

The consultation and research phase of the Informing Families Project highlighted the need for training, clear policies and evidence-based guidance for professionals in Ireland involved in informing families of a child's disability (Harnett et al, 2007).

93% of professional respondents to the national survey felt that training in communication skills was relevant to their work and 80% supported the need for specific training for the task of communicating the news of a child's disability (Harnett et al, 2007).

The Communication Gap

The results of the Informing Families national survey of parents and professionals (Harnett et al, 2007) revealed some difficulties in communication. For instance, parents and professionals were asked to what extent they agreed or disagreed with the following recommendation being included in the good practice guidelines: "In the future when parents are told of their child's disability, positive; realistic messages are given with the diagnosis." The responses indicate a high level of agreement between parent and professional respondents - 91.8% of parents either agreed or strongly agreed that in the future the diagnosis should be given with positive, realistic messages and 94.1% of professional respondents indicated their agreement or strong agreement with the statement.

However, in spite of this very high level of agreement, difficulties emerged when parent participants reported on their own experiences of being told of their child's disability. When asked "During the consultation did you feel that you were given the news with hope and positive messages" and "[did you feel that] the person giving the news was direct?" 84.8% of parents indicated that they felt that the person who informed them of their child's disability was direct, but less than half; just 46.7%, felt that they had been given the news with positive or hopeful messages.



Reasons for the Gap

In 2009 a study looking at the underlying reasons for the gap between the recommendation supported by parents and professionals that positive, realistic messages should be given with the diagnosis and the reality of the experiences as reported by the parent participants, concluded that the key reasons were a need for training and evidence-based policies; concerns on the part of professionals not to give false hope; and a fear of litigation (Harnett, Tierney & Guerin, 2009). Training in good disclosure practice can provide clear guidance on best practice, good communication and examples of positive messages that do not provide false hope (emphasising the dignity and individuality of the child; indicating that there is help available, acknowledging uncertainty and presenting the range of possible outcomes rather than merely the worst case scenario) (Harnett, Tierney & Guerin, 2009). Lloyd and Hastings (2009) found hope to be a key factor of psychological resilience in mothers and fathers of children with intellectual disabilities and noted that hope as a resilience factor predicts positive well-being and decreased psychological distress in parents.

The need for change

The rationale for providing training in best practice for informing families of their child's disability is clear; poor communication impacts significantly on the family (Cunningham 1994; Sloper and Turner 1993), increases the risk of litigation (Fallowfield & Jenkins, 2004; Harnett et al; 2009) and when professionals do not feel adequately trained or supported it increases the stressful nature of communicating difficult news to parents (Harnett et al, 2007).



For further detail on the national consultation and research undertaken to develop the National Best Practice Guidelines for Informing Families of their Child's Disability see Page 5 of the introductory chapter and find the full report online at: http://informingfamilies.ie/about-the-project/consultation-&-research "Our experience, based on our engagement with plaintiffs' solicitors, is that a large percentage of cases are taken precisely because the medical staff have not engaged or [have] improperly communicated with parents of children. To clarify this, these plaintiffs stated that but for badly handled or inappropriate or insensitive disclosure, they would not have elected to sue." (Mr. Ciarán Breen, Director of the State Claims Agency in Ireland 13 June 2008, reported in Harnett et al, 2009)

"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 participant in focus groups: Harnett et al, 2007)

"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 in focus groups: Harnett et al, 2007)

"I don't actually remember getting a minute of training – I suspect the curriculum nowadays does cater for it." (Consultant Obstetrician in focus groups: Harnett et al, 2007)



What we did: Pilot Implementation and Solutions

To address the training needs identified in the national research, the Training Working Group of the Cork Implementation Project undertook the following initiatives:

- Development of a 2-hour training course
- Piloting and evaluation of the training course with a range of medical, nursing and midwifery, and allied health participants at undergraduate, post-graduate and in-post level
- Development of an E-learning module based on best practice for informing and supporting families when a child is diagnosed with a disability

Training Development

The Cork Implementation Project developed a classroom-based training course based directly on the findings of the national study. The 2-hour course includes the following elements:

- a DVD film of parent stories and professional advice
- a presentation of the research and recommendations of the guidelines
- group discussion
- a half-hour parent input describing how a family were given the news and family experiences of childhood disability.

Pilot Training

The programme was piloted through a range of courses delivered at undergraduate, postgraduate and in-post levels.

Participants in training and academic settings:

- 80 4th year medical students (UCC)
- 130 2nd year nursing students and post-graduate Public Health Nurses (UCC)
- 25 Paediatric and Neonatal Non-Consultant Hospital Doctors (Cork University Hospital and Cork University Maternity Hospital)

In-post participants:

- 34 professionals from the Early Services and Autistic Spectrum Disorder teams
- Early Intervention Coordinators
- Pre-School Therapists
- Nurses
- Psychologists
- Social Workers
- Physiotherapists
- Speech & Language Therapists
- Occupational Therapists



Participants in training in CUMH putting their hands on their hearts during an exercise in which Katherine O'Leary explains the importance of empathy when working with families.



Screenshot from the 'Informing Families' eLearning Programme developed through the Cork Pilot Implementation Project



Training with Nursing & Midwifery students, University College Cork



Members of the Brothers of Charity Southern Services multidisciplinary teams listening to parent, Katherine O'Leary, sharing family experiences during training


Evaluation of pilot training

The Evaluation Working Group of the Cork Implementation Project oversaw an evaluation of the pilot training delivered during the two year project. For each of the courses run, a voluntary, anonymous pre- and post-training questionnaire was administered to measure knowledge, confidence and comfort levels before and after training.¹ The National Federation of Voluntary Bodies collaborated with Harvard Medical School in the analysis of the data gathered through the evaluation of the pilot training.²

Further analysis including the in-post training will be published in due course and details of this will be provided on <u>www.informingfamilies.ie</u>. You can contact the project co-ordinator at <u>info@informingfamilies.ie</u> for further information on the methodology and training materials.

Student evaluation:

154 participants from training and academic settings completed matched pre- and post-training questionnaires. A significant improvement in knowledge, comfort and confidence was found when all matched questionnaires were compared.

The average comfort levels of the participants improved significantly from the "moderately uncomfortable" range to the "somewhat uncomfortable" range (p = < 0.001) following training. Average confidence scores improved significantly from "moderately confident" to "strongly confident" (p = < 0.001). Average knowledge scores improved significantly by a 13% increase in correct answers.

Medical students showed the largest improvements in both confidence and knowledge. Nursing students showed the greatest improvement in comfort scores pre- and post-training.

¹The survey was adapted with kind permission from a questionnaire developed by the 'Brighter Tomorrows' programme in the US. Brighter Tomorrows is funded through a grant to the University of Kentucky from the U.S. Centers for Disease Control, National Center for Birth Defects and Developmental Disabilities through a cooperative agreement with the Association of University Centers on Disabilities. (See Ferguson et al, 2006)

²This collaboration was supported by a grant from the National Institute of Mental Health in the United States.

Train the Trainers

In addition to the training piloted and evaluated, a **'Train the Trainers'** programme was rolled out by the Dissemination Working Group of the Cork Implementation Project to achieve a multiplier effect and increase access to the guidelines in each of the relevant disciplines and geographical areas. You can find out more about the 'Train the Trainers' programme in Chapter 1 on Dissemination (see Page 21)

Development of E-Learning Module

Following on from the successful classroom-based training, an eLearning module was developed to provide alternative access to training for staff members who can follow the programme at a time and location convenient to them. The module consists of a range of interactive learning tools structured into a programme that can be taken over a series of visits or in one session, according to the learner's preference. The tools used to communicate the central messages of the National Best Practice Guidelines for Informing Families of their Child's Disability include video, research findings, practical recommendations for best practice, exercises applicable to the learner's own setting and circumstances, resource materials and assessments. The module makes use of the learning gained through the experience of providing the classroom training and adapts this for the electronic environment. The eLearning module of the Informing Families Project is available on www.informingfamilies.ie and the HSE online learning and resource portal www.hseland.ie.

What we heard



"It was a resounding success, the students loved it. I am delighted to incorporate this training onto the curriculum" Dr. Margaret O'Rourke, Director of Behavioural Science, Behavioural Medicine Consultant Forensic Clinical Psychologist, Medical School, University College Cork.

"Congratulations to you and all the team working on the "Informing Families Project," you are to be commended for the work you have done in raising awareness among health professionals of the importance of this subject area. In addition I would like to confirm that the two-hour "Informing Families of a Child's Disability" programme has been formally added to the B.Sc. General Nursing, Integrated Children's General Nursing and Intellectual Disability Nursing year two curriculum." Josephine Hegarty, PhD, MSc, RNT, BSc, RGN Associate Professor, Director of Undergraduate Education, Catherine McAuley School of Nursing & Midwifery, University College Cork.



What we learnt

- Training in best practice for informing families of their child's disability increases knowledge of participants about best practice measures in disclosure practice, their comfort in communicating with families and their confidence in delivery of difficult news.
- Training was not previously available in this area in Ireland.
- Professionals and students at undergraduate and post-graduate level welcomed the provision of training, evidenced in feedback from the training sessions delivered.
- The optimum amount of time required for the training developed for the Informing Families Best Practice Guidelines is two hours.
- We found that showing the 'Words You Never Forget' DVD as the first element of the training was a powerful learning tool. It shows the personal stories of families who have experienced being informed of their child's disability and in our experience engaged the participants in the training from the start.
- We found that it does not work to provide the DVD to participants ahead of class time and ask them to watch it in their own time – very few actually did this, so we recommend that the DVD is shown in class time.
- Participants on the course commented that the element they found most helpful was the parent input and hearing the direct experience of families.
- One of the challenges involved in disseminating information such as this is the need to be aware and sensitive to the needs of those receiving information on the guidelines, which can include pregnant women and parents who themselves have children with disabilities.

Recommendations for implementation

- It is important to secure support from senior management and academic supervisors in order to successfully roll-out training. Start this process as early as possible as it can take time and schedules for training tend to be very packed from early on.
- It is best to show the DVD at the start of class rather than providing it separately
- It is important to secure 2 hours for training in order to adequately deal with all elements.
- Parent involvement in delivery of the course is an essential element.
- A positive addition to the existing 2 hour course would be the inclusion of an experiential role-play element.

Access the materials

Recommendations on training from the National Best Practice Guidelines for Informing Families of their Child's Disability can be found on page 17 of the booklet (www.informingfamilies.ie)

The course materials for the training programme piloted and evaluated in the Cork Implementation Project can be accessed through the Informing Families website <u>www.informingfamilies.ie</u>

The DVD 'Words You Never Forget' can also be ordered through the Informing Families website or by contacting <u>info@informingfamilies.ie</u>

Training in the national best practice guidelines increases participant's knowledge of appropriate practice when informing families of their child's disability, increases their comfort in communicating this news to families and increases their confidence in their disclosure practice, all of which supports professionals to provide appropriate communication to families at the time of diagnosis.



Informing Families Project April 2009.



Informing Families Project April 2009.

Chapter 3 Built Environment

(Private, appropriate spaces for communication with families)

Needs identified:

Parents remember where they were informed of their child's disability, some for many years afterwards and often in 'vivid flashbulb' detail (Cunningham, 1994).

The experience of telling parents about a child's diagnosis or suspected diagnosis of disability begins with the location in which the news is communicated and the people present. As well as being private, the space where the news is given should be comfortable, free from interruptions and available for the family to spend time in after the communication (Doyle, 2004; Right From the Start Working Group, 2003; Harnett et al, 2007).

Being told in a public environment or an inappropriate location greatly increases the distress experienced by families (Harnett et al, 2007). It is therefore important to create the best possible environment and conditions for disclosing difficult news to parents and families.

The report of the national research to develop the Informing Families Guidelines found that many professionals struggle with inadequate facilities and a lack of private space in which to communicate with families (Harnett et al, 2007).

The Communication Gap

The results of the national survey of parents and professionals revealed mixed experiences in terms of the locations and privacy in which the news of a child's diagnosis is communicated (Harnett et al, 2007). For a majority of parents (71.2%) the news was given in a private place but one fifth (20.1%) of those who responded did not receive the news in private. In the experiences of 84.8% of participants there was no interruption during the disclosure. However, only a third of parents (33.7%) found the environment welcoming and only two fifths (41.8%) found it comfortable. Parents who received their diagnosis in maternity hospitals indicated the need for a private room to be available (with an option for a partner to stay overnight if possible), as many mothers recounted distressing stories of being told of their child's diagnosis on crowded wards where other mothers were caring for their own babies.

Professionals who participated in the research expressed frustration with an existing lack of private or appropriate facilities in which to give news to parents and indicated that this added stress to the challenge of sensitively communicating important news (Harnett et al, 2007).

As you will see from the following quotations, the impact of being told in an inappropriate place was particularly distressing for those who experienced a lack of privacy, whilst the provision of a designated area assisted professionals in their communication.

For further detail on the national consultation and research undertaken to develop the National Best Practice Guidelines for Informing Families of their Child's Disability see Page 5 of the introductory chapter and find the full report online at: http://informingfamilies.ie/about-the-project/consultation-&-research "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 participant in focus groups: Harnett et al, 2007)

> "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 in focus groups: Harnett et al, 2007)

"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 another chair. We sat down and our knees were kind of pressed together with their knees, it was a very awkward situation to be honest. So they 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 participant in focus groups: Harnett et al, 2007)

Best practice guidelines

The national survey of the Informing Families Project provided evidence-based best practice recommendations for disclosure of a child's disability through consultation and research (Harnett et al, 2007). In relation to the location or environment in which the diagnosis is given, the following recommendation was rated by parents and professionals in the questionnaire survey *"In the future when parents are told of their child's disability the news is given in a private place with no interruptions".* The results showed that 93.5% of parents and 95.4% of professionals either 'Agreed' or 'Strongly Agreed' that this statement should be included in the best practice recommendations. The specifics of the guidelines for preparing the location in which diagnoses are delivered are as follows:

Recommendation 1.1 from Physical and Social Setting section

The diagnosis is given in a private place with no interruptions. The room that this takes place in 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



Family Room, Cork University Maternity Hospital



What we did: Pilot Implementation and Solutions

Taking into account the needs identified by the national research, the Built Environment Working Group of the *Cork Implementation Project* set out to **optimise and enhance environments for communication with families.**

The pilot project took the following steps to achieve this goal:

- The participating organisations in acute, community and disability service settings were invited to identify locations in their own settings in which parents typically receive the news of their child's disability or news relating to concerns about a child's development
- Using the National Best Practice Guidelines for Informing Families of their Child's Disability, the participants assessed the suitability of available facilities for the purpose of communicating difficult news.
- Improvements were made to take account of the best practice guidelines and to optimise the spaces where families receive difficult news
- Photographs were taken by the staff members in the participating locations to record the changes that took place over the lifetime of the pilot project

Assessment of existing locations in the Cork Region

The Cork Pilot Project found that there was wide variation across settings in the facilities available for communicating with families. In some settings there were no private rooms available. Improvements were made in various settings. This included the provision of a private room, previously unavailable, adjacent to the Paediatric Department in Cork University Hospital and the refurbishment of rooms in the community and disability sectors. The room in Cork University Hospital was identified by members of the multi-disciplinary team from within existing resources and was refurbished through fundraising.

It was found that even where high quality private facilities were already available it was possible to make improvements in practice to ensure best use of resources. For example - in Cork University Maternity Hospital, a new hospital with private facilities available, a review of practice indicated the need to remove staff lockers from the family room to ensure interruptions do not occur during the time that news is being communicated or families are using the room.

Case Study - Cork University Hospital (CUH) Paediatric Unit igvee

The work of the Built Environment Working Group included the Paediatric Unit in Cork University Hospital. As an older unit, private space for families had not been built into the design and there was no available space within a department already at full capacity in which to create a new family or counselling room. As a result staff members working in the Paediatric Unit had no choice but to communicate difficult news to families in treatment rooms, or at a child's bed with just a curtain separating beds from one another. This did not leave room for privacy, or for parents to remain after consultations if they wished to spend some time absorbing information.



Examples of places in the Paediatric Unit where families received difficult news before a new solution was identified.

Through innovative thinking and teamwork a solution was found to alleviate these difficulties. The Social Work Department responded to the needs expressed by families by identifying one of their own offices as being suitable for adaptation and reconfiguration. This room is not directly in the Paediatric Unit but is adjacent and easily accessible to it. In consultation with parents and staff members and with funding provided through fundraising, the room was refurbished and made available for use to the Paediatric Unit. The space has been made comfortable with quality seating in warm and welcoming colours, along with high quality flooring and well designed storage units for tea and coffee. A phone has been included for parents' use. All surfaces are washable and adhere to health and safety standards.



The end result is a designated, private and comfortable space where difficult and challenging information and diagnoses can be imparted. In keeping with the partnership approach of the project the room is also made available to staff members from other units who wish to communicate difficult news or to provide private space to patients or family members.



Family room "Seomra 7" in Cork University Hospital for private communication

Before refurbishment ...

... after refurbishment.

One of the most distressing aspects of poor disclosure is being told of a serious diagnosis in a public ward or in an inappropriate location. The staff members of Cork University Hospital have provided an example of how best use of available resources can improve the quality of service and experience for those who use the service and for the professionals providing communication. While the appropriateness of the physical space does not change nor mitigate the gravity of news that is imparted, it does allow for privacy and time in surroundings which allow for dialogue and support.



'FAMILY ROOM' CORK UNIVERSITY MATERNITY HOSPITAL

Even in services with existing high quality private facilities available, such as in Cork University Maternity Hospital, it is important to examine the day to day *use* of these facilities to ensure that best practice is implemented. As the maternity unit in Cork is a new and modern facility, the design included private space with a family room (pictured left) and 'care by parent' rooms which allow parents to comfortably stay overnight (shown below left). Through looking at the use of the family room the need to remove lockers was identified, to ensure that private family time would not be interrupted as staff members accessed lockers situated in the room.



'CARE BY PARENT' ROOM IN CORK UNIVERSITY MATERNITY HOSPITAL

The 'care by parent' room in Cork University Maternity Hospital (pictured above) is used as a bedroom for parents whose baby is almost ready for discharge (for a practice run with baby!) and can be also used by day when the main family room is already in use.

CONSULTATION ROOM IN ENABLE IRELAND, BALLINTEMPLE, CORK

At Enable Ireland, parents usually receive their child's diagnosis (or clarification and information about an existing diagnosis) in this room (pictured below), which is bright and airy with a child and family-friendly atmosphere. It is a comfortable room and is in a quiet area with no interruptions. Because this room is used for appointments families may be brought to another quiet room if they wish to spend time absorbing news they have been given.





FAMILY FEEDBACK ROOM' REGIONAL AUTISM SERVICE (BROTHERS OF CHARITY) TOGHER, CORK.

Many of the changes contained in the best practice guidelines are simple and inexpensive to achieve, but can have a positive impact on the experience of families. For instance, measures to reduce interruptions (e.g. signage on the door; agreement at team meeting on procedures to avoid interruption) can ensure privacy at no additional cost. The 'family feedback room' used by the Regional Autism Team at the Brothers of Charity in Togher, Cork (pictured above) was updated inexpensively with a new coat of paint, pictures and a beanbag. A sign was made available for the door to indicate a meeting taking place and tea and coffee making facilities have been brought into the room.





What we heard

"I remember the big, bare, yellow wall. I was thinking why couldn't someone hang up a picture or something. I was conscious of being told that my son may not make it through the night. Yet all I could think about was the wall. It is so important that the surroundings where news is being delivered are pleasant and appropriate. Little things matter when you are receiving news that will change your life forever. Unfortunately shock can sometimes lead you to dwell on something that is totally irrelevant." Katherine O'Leary, Parent of two children with disabilities, Chair of Cork Implementation Project.

"The opening of 'Seomra 7' in Cork University Hospital may seem like a small initiative in the scheme of the larger HSE projects happening presently. However this small space was designed with a lot of care and attention to detail and with full awareness of the nature of its use. Informing families of difficult news concerning a child or much loved family member is never easy and the manner and environment in which this is done will leave a lasting memory. With 'Seomra 7' we hope to proffer families a helping hand, an ease of pace and above all respect. The Social Work Dept CUH is very proud to be closely associated with this wonderful initiative." Mary Casey, Manager/Social Work Services, Cork University Hospital.

"Anywhere that is dedicated to sensitive or life-changing discussion with parents is essential to modern paediatric care, so the provision of the new room in CUH for communication with families is a very welcome development. Every hospital should have a room like this." Professor Jonathan Hourihane, Professor of Paediatrics and Child Health, Cork University Hospital.

What we learnt

- At the beginning of the pilot implementation the Built Environment theme was the most challenging area of the project to plan. It was very difficult to see how spaces could be found in already cramped units and with tight budgets how improvements could be made to existing facilities.
- However, the evidence base from the national research provided the most important catalyst for change.
 Hearing of the needs of families and of the impact of being given difficult news without privacy motivated staff members to innovatively and creatively change the configuration of rooms to meet the expressed need.
- Goodwill of staff members was a key driver of the improvements which took place in the physical environment during the pilot project.
- Having specific guidelines helped staff members to audit the spaces that were available and to make changes in the environment (often small but significant) to improve the experiences of families and professionals.
- Parent input when redesigning rooms was of central importance.

 There can be a tendency for rooms designated for private communication or family use to be informally used for storage, and over time they can then become unsuitable or unavailable for communication. We found that keeping the needs of families at the centre of the initiatives taken and focusing on the evidence of additional distress that a lack of privacy can have on families receiving difficult news helps to prioritise the provision and maintenance of private space.

 It is possible to make changes that meet with many of the key areas of best practice in the setting for diagnosis without incurring significant financial expense e.g:

- ensuring no interruptions by removing staff lockers or other sources of interruption to another area and putting up an 'occupied/available' sign on the door
- agreeing at team meetings how a room should be booked/utilised to optimise privacy
- providing tea, coffee, water and tissues in the room as a standard measure (rather than leaving the room to get these items during a consultation)
- scheduling of appointments where news will be given to parents at the end of the day to ensure that the minimum amount of other clients are in the area, and to minimise the possibility of interruptions



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Tips for refurbishment

In addition to the best practice recommendations from the national guidelines, parents and professionals who worked on the pilot implementation project in the Cork region have provided the following tips from their experiences, which you may find useful:

- •Surfaces should be scrubbable and meet with health and safety standards in relation to hygiene.
- •Chairs should be comfortable enough for sitting in for an extended time.
- •Fabrics chosen should be in warm and welcoming colours and shouldn't be either garish or very dull.
- •If possible having curtains on windows makes the room look more comfortable.
- •Pictures should not be overly fussy or striking. Participants recommended calming colours, horizontal lines (e.g. horizons), hopeful scenes (e.g. the sea).
- Parents advised that it is possible to get fixated on items in the room during news that is difficult to absorb, for instance items in a bin. Therefore it was recommended that if the room where parents are given the news has a bin, it should be closed with a lid, rather than being open.

Recommendations for implementation

- When designing new buildings and facilities, a key requirement in providing a quality service to families is the inclusion of private family rooms in which to communicate.
- The rooms for private communication should not include clinical or administrative equipment, so that interruptions are minimised.
- In acute settings a key requirement of quality service provision is the provision of rooms which allow family members to stay overnight when their child is an in-patient.
- It is important to secure support from senior management to prioritise the configuration of space in order to meet the needs of families for privacy and the needs of professionals to have appropriate spaces in which to communicate.
- Parent involvement in design and refurbishment is of significant benefit.
- It is important that tissues (in particular) and tea and coffee are already in the room before a consultation starts, as it can be distracting and unhelpful if professionals have to leave the room during the conversation in order to find these items. If possible it is best to have these items in situ as a matter of course.
- It is important to ensure that there isn't a mess in the room from tea & coffee of previous occupants before bringing families to the room.
- There are often practical and administrative challenges to be overcome when changing the purpose/use of a room or in refurbishing existing private spaces. In addressing these challenges it is important to maintain focus on the evidence that the provision of private spaces is a quality initiative which keeps the needs of families at the centre of service provision, improves the experiences of families at disclosure and reduces the additional distress that can be caused by being told difficult news in inappropriate places.

Access the materials

You can find the full recommendations on locations/settings for disclosure and the people who should be present when communicating with families in the 'Physical and Social Setting' section of the *National Best Practice Guidelines for Informing Families of their Child's Disability* on pages 10 and 11 of the booklet. www.informingfamilies.ie

Photos from the rooms featured in the Cork Implementation Project Pilot can be found on: www.informingfamilies.ie

If you would like to tell us about a room refurbishment that your team has made to enhance parent and professional experiences or if you would like to share your experience on the <u>www.informingfamilies.ie</u> website, you can contact us at <u>info@informingfamilies.ie</u>.

The work of the Built Environment Working Group of the Cork Implementation Project has enhanced the environments in which professionals communicate with families, which in turn has the potential to improve the experience of parents and professionals at the time of diagnosis by addressing one of the key needs in the disclosure process.

The initiatives undertaken by this group provide examples which can be useful for groups in other areas to adapt locally to suit the needs and environments they are working in, in order to optimise the service provided to children and families. Translating Research into Practice - The Cork Implementation Project

Chapter 4 Chape Information Provision Orman Provision

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FORMATION

Feeding & Supporti

PARENTS

Why Our Baby?



Needs identified:

Government policy and strategy documents from as far back as 1990 have specifically indicated the need to provide comprehensive information to the families of children with disabilities at the time of diagnosis, including information on the diagnosis, entitlements and benefits, and local services and supports available to the family. **Department of Health and Children, 1990. ("Needs and Abilities")**

63.6% of parents who participated in the research to develop the *National Best Practice Guidelines for Informing Families of their Child's Disability* received no written information. (Harnett et al, 2007).

40.8% of parents did not feel they had understood what they had been told at the time of their child's diagnosis. (Harnett et al, 2007).

Throughout the Irish research to date a consistent finding has been that parents have not received adequate or appropriate information at the time of their child's diagnosis, and that professionals struggle to find such information for supply to parents. (Redmond 2000; South Western Area Health Board, 2003; Harnett et al, 2007)

"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". **Department of Health and Children, 2001** ('Quality and Fairness' p.131)

The Communication Gap

Michael Guralnick (1997), in his evaluation of the effectiveness of early intervention, described a 'crisis of information' many families experience when faced with the news of their child's disability. This crisis of information, according to Guralnick, includes guestions 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 potential information crisis is the provision of information on services, entitlements and sources of support for parents (Doyle 2004; Right From The Start 2003).

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% of respondents 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. The national research of the Informing Families Project found that 39.7% of parents in a representative sample felt that they had received 'too little information' at the time of diagnosis, while 63.6% of parents had not been given written information at that



time, a finding closely corresponding with that of the South Western Area Health Board. As described above 40.8 % of parents in the Informing Families study did not feel they understood what they had been told about their child's diagnosis (Harnett et al, 2007).

Reasons for the Gap

Professionals who participated in the national study (Harnett et al, 2007) identified a lack of coordination and 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. Frequent turnover of staff members means that even if information has been provided by support groups or services to those communicating the diagnosis to families, the 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.

Although professionals in acute settings 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. Difficulties are encountered when Internet access is not available, particularly when trying to find information for families late at night. Even when access to the Internet is possible, in some locations the 'Net Nanny' software makes searches so restricted that it is not possible to access relevant articles.

The amount of information that parents wish to receive can vary, depending on their own coping style, and the circumstances of the diagnosis. Parents who participated in the national study 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. It is therefore important to carefully gauge the level of information provided to suit the individual pace needed by parents.

The importance of providing honest information to parents at all times was reiterated in the national study; it was strongly recommended that 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. Families recommended that guidance should be provided by professionals on reputable and reliable sources of information on the Internet. Professionals also 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.

The theme of supporting individual choice was highlighted again in relation to the support options offered to parents at the time of diagnosis. 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.

For further detail on the national consultation and research undertaken to develop the National Best Practice Guidelines for Informing Families of their Child's Disability see Page 5 of the introductory chapter and find the full report online at:

> http://informingfamilies.ie/about-the-project/ consultation-&-research

Online information



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 level of accuracy and compliance with best practice that is extremely poor (Speedwell 2003, HRB 2008.). It can be particularly 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).

Consequently a key aim of the Cork Implementation Project has been to develop high quality, accurate and reliable on-line information and also to provide parents and professionals with a guide for assessing the quality and reliability of materials accessed on the Internet, based on the 'HON Health on the Net' principles (see www.HON.ch)'. To access advice on accessing reliable information online see www.informingfamilies.ie/early-information/advice-oninternet-searching.232.html

¹The Health On the Net Foundation (HON) promotes and guides the deployment of useful and reliable online health information, and its appropriate and efficient use. Created in 1995, HON is a non-profit, non-governmental organization, accredited to the Economic and Social Council of the United Nations. "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 participant, Informing Families Focus Groups (Harnett et al, 2007)

> "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, Informing Families Project Focus Groups (Harnett et al, 2007)

"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 diagnosis] mean to you? So tailor to their understanding." Consultant Paediatrician, Informing Families Project Focus Groups (Harnett et al, 2007) "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, Early Intervention Services, Informing Families Project Focus Groups (Harnett et al, 2007)

"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, Informing Families Project Focus Groups. (Harnett et al, 2007)

"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 participant, Informing Families Focus Groups (Harnett et al, 2007))

What we did: Pilot Implementation and Solutions

Taking into account the needs identified through the national research the Information Working Group had the following aims:

- 1. To provide appropriate, accurate, up to date multilingual information for parents.
- 2. To develop an online information system to distribute this information.

The pilot project took the following steps to achieve these goals:

- All of the agencies involved in the Cork Implementation Project were invited to provide information which they found helpful, accurate, and up to date to the Information Working Group.
- A focus group of parents of children with physical, sensory and intellectual disabilities was organised to gather the views of families on the types of information required.
- Using information recommended through the national research and the information gathered from parents and professionals in the Cork Implementation Project a catalogue of information resources was created.
- The information was reviewed and categorised according to the following three types:

- a. Information not specific to a particular diagnosis but helpful to parents of children receiving news about their child's needs
- b. Diagnosis specific information
- c. Information directed specifically towards professionals (e.g. training materials, guidelines, information on best practice)
- A website of appropriate and up-to-date information for parents was developed, using the information gathered above (www.informingfamilies.ie).
 Support for this initiative was kindly provided by the HSE Department of Social Inclusion,
- A structure for the website was agreed, using the three categories above and including information on 'Entitlements and Benefits' linked through to the Citizen's Information Board website, which is the most up to date source of this information.
- The Department of Health and Children, HIQA and the HSE were consulted, and a literature review carried out to determine quality indicators in the provision of online health and social care information. The HON 'Health on the Net' Foundation guidelines were found to be the most suitable and frequently used and were therefore implemented throughout the website.
- Accessibility was a key feature of all design decisions. An audit of the accessibility of the website was undertaken with WAI Accessibility Level AA being the minimum requirement for all features.
- The Cork Implementation Project is currently working with HSE to provide multilingual information based on the approved English materials developed.



What we heard

"[The information is...] clear, practical and succinct..." Gabrielle O'Keeffe, General Manager, South Lee Local Health Office reviewing website materials during development

"I found the material very helpful and in my view covers the areas that need to be addressed. The issue of informing siblings is very important and was well done. I liked the piece on the telling family and friends. In general, it is important to speak about the elephant in the room I believe that people then respond more positively." Parent feedback on reviewing the information materials in evaluation facilitated by Enable Ireland

"Professional and easy-to-read ..."

Dr. Mary Desmond, Principal Psychologist Cope Foundation, Montenotte, Cork.

"It will be very useful to have all that information easily accessible on one site. Before now it's been difficult to access information in the different geographical areas. The ready availability of this will allow a more timely access and referral for families."

Dr. Olivia O'Mahony, Consultant Neurologist Cork University Hospital, reviewing information for the Informing Families website

What we learnt

- Parents who participated in the review of the website advised of the need to include a 'slow down' page (which is currently achieved through a welcome page on the website by Chair of the Cork Implementation Project Katherine O'Leary). The aim of the 'slow down' page is to advise parents that there is a huge amount of information available on this and other websites and that they should take the information at their own pace as it can be overwhelming.
- It is best to put translated materials in a paragraph beside the English text rather than putting entire documents in a translated language at the end of the English text or separately. This helps with learning and understanding the English terms for those reading in another language and also expedites the updating of translation if particular paragraphs need to be changed in the future.
- The cataloguing of the information provided by the Cork Implementation Steering Committee showed that there is a lot of information available on services, supports and diagnoses, but it often is not known to all team members/organisations, meaning that families do not always receive it in a timely manner.
- It is important to gather relevant information and have a clear policy of ownership and updating so that team members are confident of where they can quickly access important and high quality information.



Recommendations for implementation

- The Cork Implementation Project has developed a website of appropriate and quality assured information for professionals to print and provide to parents, or for parents to access directly. It is recommended that professionals informing and supporting parents use this website or other accredited and quality assured information sources to ensure that the information they provide to parents is accurate, up to date and appropriate.
- The work of defining ownership of information is closely linked the recommendations of the Teamwork & Liaison section of this report (Chapter 5). It is beneficial to develop a catalogue of appropriate information sources for use by your local team and to define processes for gathering, validating and updating information available for supply to parents either as part of a Teamwork & Liaison meeting, or by organising a specific Information meeting.
- For groups implementing the Informing Families Guidelines an important starting point is to gather information on local services and supports and make these available to all professionals and organisations that inform and support families.
- Provision of information needs to be paced to the parents' preferences and circumstances – some may be hungry for information and others may feel overwhelmed.
- It is important to recognise that the provision of written information is supplementary to good communication and does not replace it.

Important tips to remember when providing information and support options!

Here are some tips from the Informing Families national research dealing specifically with the provision of information:

- Staff members should have available for supply 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 families can 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.
- 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. (One useful site in this regard is www.cafamily.org.uk.)
- 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.

- A sizeable proportion of the parents participating in the national research 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.
- 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.
- 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.
- 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 key 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.
- Always use professional interpreters never family members!



Access the materials

You can find all of the information materials developed through the Cork Implementation Project on <u>www.informingfamilies.ie</u>. This website will continue to develop as new materials are identified and updated.

You can find the full recommendations on meeting the information needs of families in the 'Information and Support' section of the *National Best Practice Guidelines for Informing Families of their Child's Disability* on pages 14 and 15 of the booklet.

You can download the booklet at <u>www.informingfamilies.ie</u>.

The development of the Informing Families website through the Cork Implementation Project makes best use of resources by providing quality assured accessible, up-to-date information materials that will be readily available to professionals across the country, for supply to families. The materials have been developed specifically to meet with the information needs identified by families of children with disabilities through national research and consultation undertaken locally for the pilot project.

Professionals involved with informing and supporting families at the time of diagnosis can readily access this information and pace it to according to the individual information needs of the families they support.

Chapter 5 Teamwork & Liaison

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Needs identified:

Inter-agency co-ordination and collaboration, along with a family-oriented approach and individualised programmes, are key indicators of best practice in the provision of highquality Early Intervention Services (Hanson & Lynch, 1995).

Inter-agency 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).

The report of the national research to develop the Informing Families Guidelines (Harnett et al, 2007) found that one of the four key deficits in disclosure practice which impacts on family experiences is a lack of continuity of care.

Parents and professionals indicated the need for continuity of care to be provided in two key ways. Firstly, it is needed *within service settings* (e.g. when more than one medical or social care team in the same organisation are involved in informing and supporting the family). Secondly, continuity of care is needed *across settings* (e.g. when families are discharged from acute to community or voluntary services, for instance when referred to Early Services), (Harnett et al, 2007).

The Communication Gap

The diagnosis of a child's disability can take place during pregnancy, around the time of a child's birth, or in an evolving diagnosis which can take weeks, months or years. For some children a firm diagnosis never emerges. Professionals take on various roles within the disclosure process, i.e. communicating with the family, supporting the family and clarifying information. These professionals can be situated in different service settings (e.g. hospital, community or disability service), or can be on different teams within a given setting (e.g. psychology and social work teams; medical and nursing teams; cardiac and renal teams (Harnett et al, 2007).

If communication between the professionals or the organisations in each of these situations is not sufficient, families can fall through the gaps and can receive conflicting messages, a lack of information and can experience delays in accessing essential services for their child **(Redmond, 2000, Harnett et al, 2007)**. Since early intervention is an essential part of supporting families and maximising a child's development and potential, delays in accessing the most appropriate supports and services can impact on the child and family considerably.

"The communication between the [Regional Hospital] and the [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 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 participant in Informing Families Focus Groups (Harnett et al, 2007)

"We need to develop communication between professionals in hospitals and in community and if 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 its 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 the parents. Paediatric Nurse: participant in Informing Families Focus Groups (Harnett et al 2007) "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." Parent participant in Informing Families Focus Groups (Harnett et al, 2007)

"At the 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 contact, whatever. But do not let them walk out that door without giving hem a contact number, knowing when you will next talk." Midwife participant in Informing Families Focus Groups (Harnett et al, 2007) Parents and professionals who participated in the national research for the Informing Families Project were unanimous in agreeing that the links between settings are not sufficient and identified a lack of a joined-up systems approach (Harnett et al, 2007). Some examples from this report include for instance the experiences of families whose child has an evolving diagnosis. For many of these families there were periods of uncertainty with no clear contact person and no-one to advise the family of the next steps or supports available. In the case of children with significant medical needs some families described how they struggled to gain an overall picture of their child's health and needs from various medical teams who had not communicated with each other to provide comprehensive or consistent information to the family.

Teamwork and liaison are the keys to bridging the gaps brought about by the fragmentation in service settings and delivery, thus providing the continuity of care so vital to a quality child and family centred service.



Interdisciplinary, cross-sectoral and parent-professional partnership working on the Informing Families Cork Implementation Project

For further detail on the national consultation and research undertaken to develop the National Best Practice Guidelines for Informing Families of their Child's Disability see Page 5 of the introductory chapter and find the full report online at: http://informingfamilies.ie/about-the-project/consultation-&-research



What we did: Pilot Implementation and Solutions

The Teamwork and Liaison Working Group had three key aims for enhancing communication between professionals in order to provide improved support for children and families:

- 1. To enhance continuity of care for parents
- 2. To encourage cross-sectoral and interdisciplinary collaboration
- 3. To identify disclosure planning needs

The pilot project took the following steps to achieve these goals:

- The multiplicity of agencies and disciplines involved in communicating with families of children with disabilities in the Cork region was identified through a series of initial meetings in acute, community and disability organisations.
- A workshop was organised with 23 professionals from across sectors and disciplines, together with parents, to define goals for improving continuity of care. A series of typical situations were chosen in which parents and children would require the services of a number of teams or team members during the disclosure process. The participants broke into smaller groups and identified the priorities for improving communication and liaison for each of the scenarios, including communication within a given setting, and communication when referrals take place between sectors or agencies.

- The pilot project facilitated communication between organisations and disciplines on key issues throughout the life of the project, including very positive and detailed discussions between acute, community and disability service providers in relation to discharge summaries, the Early Intervention in-take forum and enhancing and fine-tuning communications.
- A poster based on the 'Safe Cross Code' was designed using the national best practice guidelines to provide a quick reference guide for professionals in any setting involved in communicating with families.
- A new discharge procedure was introduced at Cork University Maternity Hospital, meaning that parents receive a discharge summary on leaving the neonatal unit which they can then bring to any professionals working with their child to assist in communication. A copy of the discharge summary is also sent to the GP.
- A checklist for 'Communication & Liaison for Ante-natal Diagnosis' was developed and piloted. Links were made with tertiary hospitals to begin the process of developing a liaison procedure to enhance communication in both directions when a referral is made from regional to tertiary hospitals.
- Recommendations from the working group were incorporated into the development of the HSE Maternity and Neonatal Clinical Management System, a project which is developing electronic patient records for maternity units nationwide.

Through working on the above initiatives the Teamwork & Liaison Working Group identified four levels at which the national best practice guidelines have relevance for implementation for professionals involved in informing and supporting families. Each level was examined when working on the initiatives to inform progress:

Building Blocks for Continuity of Care





' Liaison & Communication Checklist for Antenatal Diagnosis`developed by the Teamwork & Liaison Working Group (available on www.informingfamilies.je)



Professionals from acute, community and voluntary disability services working together with a parent to enhance continuity of care



'Safe Cross Code' poster designed by the Teamwork & Liaison Working Group (also available on www.informingfamilies.ie)



Interdisciplinary, Cross-sectoral and parent-professional partnership working on the Informing Families Cork Implementation Project

Evaluation of initiatives

An anonymous survey was circulated at the end of the Teamwork & Liaison workshop to ask participants if it was beneficial to bring together a group from across disciplines and sectors to discuss liaison and continuity of care needs. The survey consisted of a two page questionnaire with open and closed questions regarding whether this type of workshop is an effective way to implement guidelines on the ground and whether the format of the workshop worked: The following comments were included in the responses:

"Communication is key to any process. There has been such a chasm between health & social services for so long. It is rare for disciplines to communicate in such a forum." Participant Feedback from Teamwork & Liaison Workshop, November 2008

"More of these workshops would be extremely beneficial for the wider HSE level of participation" Participant Feedback from Teamwork & Liaison Workshop, November 2008

"Was good to meet other disciplines within the healthcare professions and to become aware of their roles within this sector" Participant Feedback from Teamwork & Liaison Workshop, November 2008 We asked respondents which elements of the workshop worked well:

- "Group work. Various disciplines with various organisations"
- "Mix of medical, health & social disciplines"
- "Small groups, discussion sessions were very good"
- "Meeting of different multi-disciplines was helpful. Able to put faces to names that I may have spoken with by phone"
- "Got me thinking learnt a lot from other professionals, learnt a lot re best practice guidelines."
- "Learning from each other"
- "Very interactive and useful exchange of ideas"
- "Small groups for exchange of ideas. Groups well structured with mix of disciplines with backgrounds across acute/community/voluntary sectors."
- "As a group it was informative. I hope to bring back information to my area."


What we heard



"The huge benefit for me was sitting face to face with colleagues, teasing out ways of simplifying referral from acute to community early intervention services and at the end saying yes this is how it will happen and now finding that it actually works. The group found ways of simplifying processes and procedures by discussing and developing ideas. It struck me how much can be achieved when the various agencies and services meet and have open discussion and communication." Breda Long, Early Intervention Project Officer HSE, Principal Speech and Language Therapist

"Without doubt the best outcome for me was witnessing the point where, as chairperson, I was no longer a necessary part of the project. Professionals began to talk across the table. Plans were made and there was openness and determined cooperation. All the stakeholders had taken ownership and the resounding "I can do that" attitude was for me the icing on the cake of success. There is no doubt but that teamwork is the key to successful roll out of these guidelines." Katherine O'Leary, Parent of two children with disabilities, Chair of Cork Implementation Project.

"The Cork project generated a special energy bringing people from different organisations and disciplines together to find real and tangible ways of implementing the National Guidelines... There was a real sense of working together to make a difference with improved communication between sectors allowing for improvements to happen all through the Pilot Project" Hilary Lane, Principal Psychologist, Enable Ireland.

What we learnt

- Gathering professionals from the various sectors together to meet in one location brings benefits as the discussions lead to enhanced understanding of ways in which even simple measures can provide mutual benefits and an improved service to parents and families.
- Opportunities for professionals working in different sectors to meet and discuss the best ways to communicate in order to enhance continuity of care and efficiency do necessarily happen as a matter of course.
- It is important therefore to schedule and plan such meetings.
- Developing new networks and strengthening existing links promotes cross-sectoral working, interdisciplinary team work, relationship building and ultimately improves liaison.
- The outcomes from improved liaison include practical tools such as protocols and checklists to support professionals in their communication as well as enhanced communication with colleagues.
- The inclusion of parent representation is a key benefit in ensuring that the liaison measures keep the child and family at the centre of service provision.
- Professionals greatly welcomed opportunities to meet and discuss ways in which communication can be enhanced and found these opportunities beneficial to their practice.

- It works well to link with existing fora, structures and initiatives to optimise communication (e.g. we worked with the Early Intervention in-take forum and the HSE Maternity and Neonatal Clinical Management System).
- It was not possible within the course of this implementation project to assign a specific liaison role. This remains the recommendation of the best practice guidelines for optimum continuity of care for families. However, within the available resources it was possible to make considerable improvements by working together and introducing measures to support communication such as checklists, discharge summaries and the enhanced communication that comes about from meeting face to face and discussing best ways of collaborating.
- The Teamwork & Liaison Working Group noted the importance of all team members communicating and liaising, even if a specific liaison role is created.
- It was challenging to work towards improving teamwork and liaison across a wide geographical region at the time when travel restrictions were introduced in the HSE. In overcoming this challenge, best use was made of available resources through conference calls to cut down on travel and much of the work was facilitated through email contact. Meetings that involved travel were kept to a minimum (although some were very necessary given the aim of bringing community and hospital staff closer together in providing a family centred service). Meetings were held in locations that had the most amount of professionals in situ, to minimise the number of people who had to travel.

Recommendations for implementation

- Planning and communication within teams and between teams is needed in order to provide continuity of care and good support for families when their child is diagnosed with a disability.
- It works well to get together with relevant staff members in your organisation or team and in organisations/teams that you liaise with to enhance communication and planning.
- The people who need to be involved in this planning exercise may work in different settings. Having a cross-sectoral meeting can enhance communication and promote integrated working, all of which puts the child and family at the centre of the services provided.
- To assist in disclosure planning it works well make a list of the type of diagnosis scenarios your team (or teams) are likely to encounter so that the team members can be prepared when they occur. It is also important to list all of the people that should be contacted when a child is diagnosed: this can be used as a checklist for communication when the diagnosis occurs.
- It is important to identify key staff members in each team/location who can maintain liaison links, keep information up-to-date and communicate changes in procedure or systems.
- The focus on the needs of the child and family as well as enhanced inter-professional communication should be maintained in pursuing all of the above actions.



Recommended items to consider/ discuss at Teamwork meeting to support good communication:

- It works well to make a list of the measures that can be taken to ensure that families receive continuity of care (e.g.):
 - Families are provided with a named person they can contact with questions
 - Families receive good information about the links between organisations so that they do not have to search for information about where they should go next
 - Agree methods of encouraging good sharing of information between teams and within teams to avoid families having to constantly repeat their child's history (e.g. case conferences, meetings with the family)
 - Agree a protocol for communicating at shift changeovers to ensure that all staff members are aware of the information that has been communicated to families and how they are doing
 - Planning for information provision: make sure that there is plenty of up-to-date information on the services available in other teams so that families know where they are going next, and professionals have access to up to date information.
 - Assign a team member to keep information up to date, and ensure all relevant professionals know where to find it.



Access the materials

You can find the full recommendations on teamwork and liaison in the 'Organisation and Planning' section of the National Best Practice Guidelines for Informing Families of their Child's Disability on pages 18 and 19 of the booklet. www.informingfamilies.ie

You can find the 'Safe Cross Code' poster and sample liaison checklists available for download on: www.informingfamilies.ie

If you would like to share tips on enhancing continuity of care and teamwork to support families at the time of diagnosis from experiences in your organisation you can contact us at info@informingfamilies.ie

Planning, communication and liaison within teams and between teams enhances continuity of care and support for families, and assists professionals in developing interdisciplinary and cross-sectoral partnership. The development of strong communication and relationships between professionals is essential given that disclosure is a process which will continue over time and which will require good sharing of information in order to support families appropriately.

The importance of this communication is further underlined by the fact that informing families of their child's disability is often the first communication of an on-going relationship with the child and family.



Conclusion

The implementation of the *National Best Practice Guidelines for Informing Families of their Child's Disability* is firmly in line with current national and international policy objectives. The national health strategy 'Quality and Fairness' (2001) indicates the importance of providing up to date, accessible and appropriate information to those accessing health services, a challenge taken up by the Information Working Group of this project. The HSE Transformation Programme 2007-2010 envisages clear and consistent communication with enhanced co-operation and integration between acute and community services across all stages of the care journey (p.11). This was achieved through the work of the Teamwork and Liaison Working Group. The UN Convention on the Rights of Persons with Disabilities (2006), which Ireland has signed and plans to ratify, highlights the importance of recognising the individuality, potential and dignity of every child with a disability. These important themes are central to the delivery of the training programme of the Informing Families Project, developed through the Cork Implementation Project.

Continuity of care is at the centre of quality service provision throughout a child's life. A key issue identified in the national research (Harnett et al, 2007) was lack of liaison and communication leading to significant deficits in continuity of care for families at the time of their child's diagnosis with a disability. To improve communication across sectors, disciplines and organisations, the wide range of stakeholders detailed on Page 8 of this report participated in the Cork Implementation Project.

To provide a child and family centred service, communication between organisations and disciplines must **keep the service-user as the focus and centre of service provision.** The Informing Families Cork Implementation Project gave expression to this commitment through the chairing of the project by a parent of children with disabilities, and the integral involvement of parents in the various initiatives undertaken.

PTO...

The implementation of the National Best Practice Guidelines for Informing Families of their Child's Disability was welcomed by professionals on the front line, who found them to be a support in their practice when working with children and families. The partnership working, and improved communication that characterised the project has the potential for replication and benefit far beyond the specific topic of informing and supporting the families of children with disabilities.

It is hoped that the learning gained through the Cork Implementation Project and presented in this report will be useful for groups who wish to implement the guidelines in their own areas and that the tools and materials developed through the Cork Implementation Project, which are available from **www.informingfamilies.ie**, will be a support in further roll-out of best practice.

Implementing best practice in informing families of their child's disability involves the dissemination of guidelines, training, the provision of quality information, identifying and providing appropriate environments, and good continuity of care through teamwork and liaison. This report has developed a roadmap for how this can be achieved effectively in a way that supports the child, family members and professionals. The evidence has shown that the task of breaking difficult news (related to disability or otherwise) requires planning, co-ordination, good communication skills, appropriate information and support for all involved. We hope that professionals will find this report a useful and easy to use resource in their vital role in supporting families.



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Notes





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