



Informing families sensitively about their child's disability

Country: **Ireland** Organisation: **National Federation of Voluntary Bodies**

MANAGEMENT SUMMARY: The activities of the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation) focus on ensuring that member organizations are supported to provide high-quality, person-centred services and support to people with an intellectual disability. The National Federation has developed the Informing Families Project, the goal of which is to ensure that the communication process of informing families that their child has a disability is undertaken appropriately, sensitively, and using a family-centred model.

- Information for families who have recently received their child's diagnosis with a disability is available in seven languages on the website: www.informingfamilies.ie
- This includes information on how parents might feel about the diagnosis, how to tell other people about the diagnosis, how to search for reliable information on the Internet, descriptions of what early interventions are available, and who the relevant professionals are that families may wish to consult.



Trusting relationships between families and professionals are built right from the beginning



Education sessions for doctors and nurses create understanding for families needs

The goal of the project is to support professionals who communicate the news of a child's disability to families by providing them with evidence-based best practice guidelines and training. Positive parent-professional relationships are central to a family-centred approach to early intervention, and the disclosure process can be seen as the very first opportunity for good practice in early intervention.



THE PROBLEM:

Negative messages prevail

Before the development of the "National Best Practice Guidelines for Families of Children with Disabilities," there was no known comprehensive, evidence-based best practice guidance available in Ireland to support professionals in positive and appropriate family-centred disclosure practice.

Many families had told the National Federation of Voluntary Bodies that the news of their child's disability had been communicated to them in an insensitive,

inappropriate, or overly negative way that did not take account of the individuality of their child or of the child's full potential.

Without evidence-based best practice to guide them, many professionals have previously believed that providing the worst-case scenario was the most appropriate communication. The Informing Families Steering Group directed the undertaking of a comprehensive consultation and research programme in order to ensure that the guidelines would be informed by wide-ranging consultation and partnership with all key stakeholders and would be grounded in evidence-based research.

ABOUT IRELAND:

After drastic spending cuts, getting ready for an economic comeback

- The Republic of Ireland is a parliamentary democracy with a written constitution. The country has a population of approximately 6.3 million, including some 400,000 children under five years.
- A period of rapid economic expansion from 1995 onwards that became known as the Celtic Tiger period ended in 2008 with an unprecedented financial crisis and an economic depression in 2009. This has led to steep cuts in Social Budgets: "Since 2008, there has been a steady erosion of the kinds of flexible supports that facilitate choice, autonomy, and independent living for people with disabilities." After drastic spending cuts and with the help of the European Union and the International Monetary Fund, Ireland is once again showing positive economic growth.
- The Human Development Index of 2015 shows that Ireland's per capita gross national Product was \$39,568, ranking it 6th worldwide.



THE DEVELOPED SOLUTION:

An appropriate, evidence-based practice is established

The overall goal of the Informing Families Project is to ensure that the communication process of informing families that their child has a disability is undertaken appropriately and sensitively, using a family-centred model and in line with evidence-based best practice. This initial disclosure is the first step in building a family's understanding of their child's disability, and thus it is central to how the family initially adjusts to the information and to how they view disability itself.

The communication that takes place at the time of a child's diagnosis is also the first step in the building of a trusting relationship between the family and the professionals with whom they will interact. Positive parent-professional relationships are central to a family-centred approach to early intervention, and therefore the disclosure process can be seen as the very first opportunity for good practice in early intervention.



THE MODEL:

Thorough testing led to an adequate method

The project was developed at the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation), which is an umbrella group of intellectual disability service



Katherine O'Leary, Chairperson of Informing the Families Cork Project, with her son Diarmuid

According to a recent study, parents as well as professionals want to have positive, but also realistic messages at the time of diagnosis

providers in Ireland. This umbrella group collaborated with organizations supporting children with physical disabilities and sensory disabilities to develop cross-disability guidelines.

The National Federation undertook a national quantitative and qualitative research project, distributing a representative survey questionnaire to 184 families and professionals along with conducting 22 focus groups (7 with families and 15 with individuals from medical, nursing, and allied health backgrounds). The results were as follows:

- A set of evidence-based best practice guidelines for informing families of their child's disability.
- A consultation and research report describing the development of the guidelines.
- A DVD ("Words You Never Forget") providing parent stories and professional guidance based on evidence found in the consultation and research report.
- A one-hour online-accredited training course for professionals.

- An informational website (www.informingfamilies.ie) for families immediately following the diagnosis of their child's disability (in seven languages).
- A report on the outcomes of a pilot implementation of the guidelines in the southern region of Cork.
- A pilot implementation project for the guidelines across hospital, community, and disability service settings in Cork from 2008 to 2010.

An evaluation was carried out on training that was delivered to 235 participants, including 80 fourth-year medical students, 130 second-year nursing students and post-graduate public health nurses, and 25 paediatric and neonatal non-consultant hospital doctors (junior hospital doctor). Participants were chosen for the study using an opportunistic, purposive sampling process.

A training programme is established

Conclusion: The improvements in levels of confidence and knowledge reported by participants of the training programme demonstrated the potential benefits of providing communication skills training that specifically addresses the needs of families at the time of their child's diagnosis. The wide range of professionals and the broad range of experience levels involved in the disclosure process indicate the need for training to be delivered across medical, nursing, and allied health disciplines.

This project has received the "Award for Public Service Excellence in 2010" by the Irish Prime Minister. Implementation of the developed guidelines includes the following actions:

- Half-day "training of trainers"
- 2 hour on-site training course (e.g., in hospitals, community health care settings, and universities)
- 1 hour e-learning module
- Tailored training where required

Further, the curriculum includes detailed teaching on the research findings and resultant best practice guidelines. A DVD has been produced depicting the personal stories of two families and their children as well as 45-minutes of input from a mother of two children with disabilities on her experiences of being told the news and her recommendations for how professionals can best support families at the time of diagnosis.

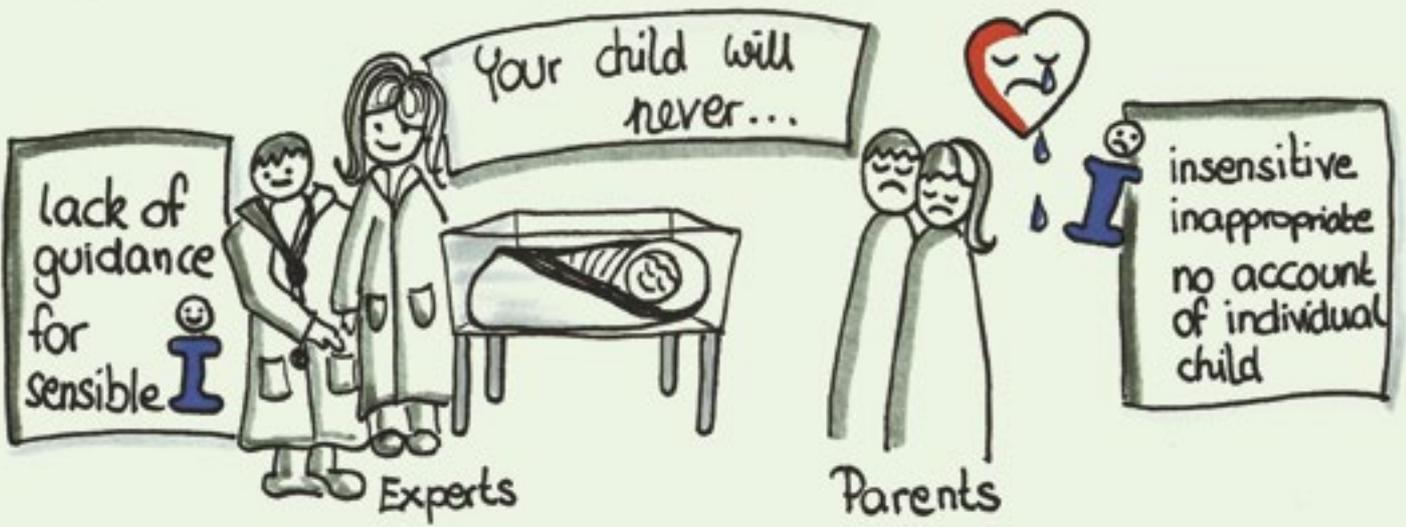
Results have improved

Finally, a study on the project's best practices traced the convergence between the guidelines and the UN Convention on the Rights of Persons with Disabilities, in particular with regard to the provision of positive, realistic, and hopeful communication. The study employed a mixed methodology, involving 22 focus groups and a questionnaire survey of 1,588 profes-

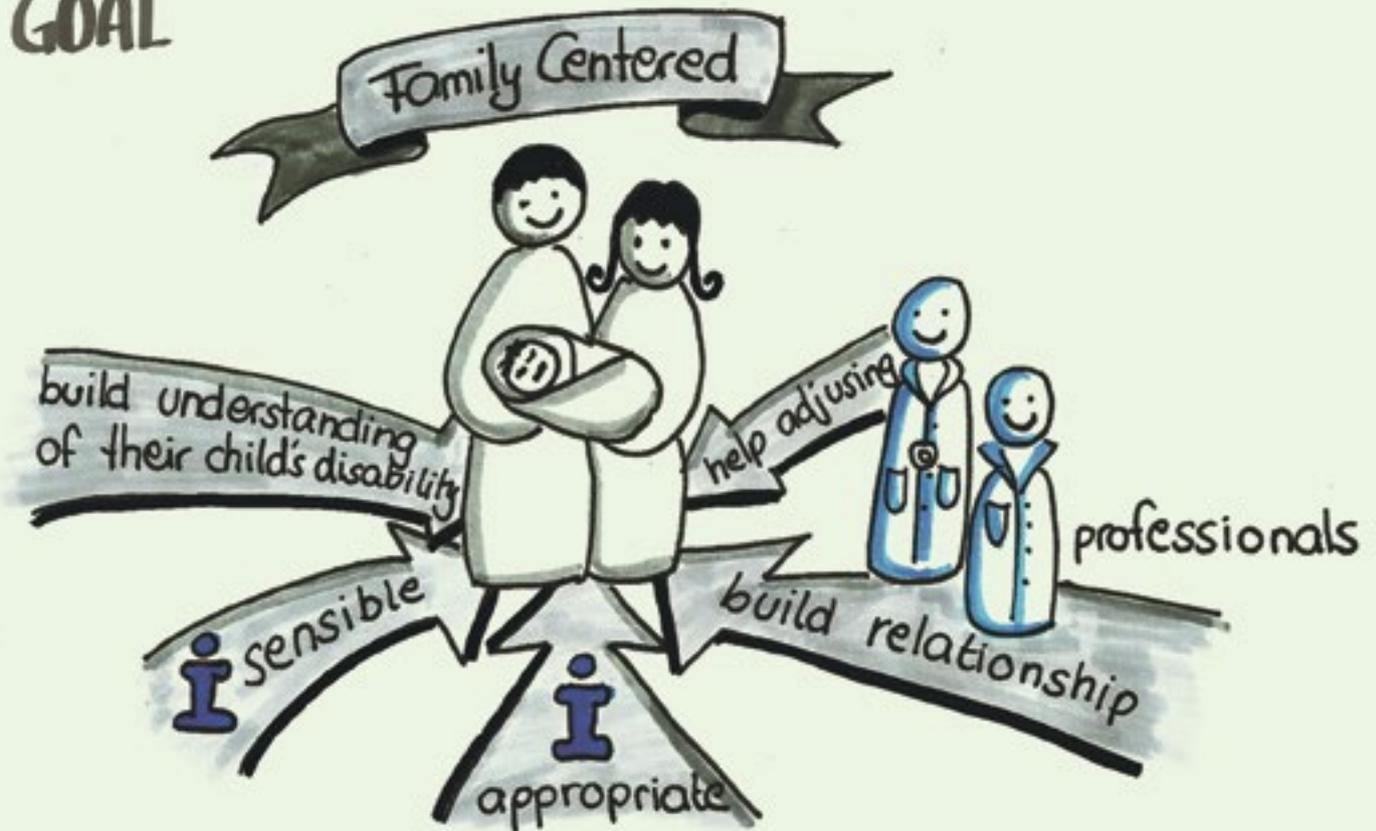


Families cutting the ribbon for the opening of a private room in Cork University Hospital where they can receive difficult information and discuss news

PROBLEM



GOAL



FACTS AND FIGURES:

A mandatory course for paediatricians how to inform families

All paediatricians in Ireland who wish to become consultant doctors must provide a certificate of completion of the Informing Families e-learning training with their application. The Royal College of Physicians of Ireland introduced this measure in 2013.

Training has been provided to:

- Trainee paediatricians at the Royal College of Physicians of Ireland
- Fourth-year medical students in University College Cork
- Second-year nursing, midwifery, and post-graduate public health nurse students in University College Cork
- First-year post-graduate medical students in University College Limerick (since 2009)
- Post-graduate nursing students on the Children's Palliative Care module in Trinity College Dublin (since 2007)

sionals and 584 families. The study found that a large majority of parents and professionals supported the recommendation of providing families with positive, realistic, and hopeful messages at the time of diagnosis, but fewer than half of the parents surveyed reported receiving communication of this type. The findings indicated that some professionals struggle with fears of providing 'false hope', a fear of litigation, and a lack of training when communicating with parents about their child's condition. However, the research also identified positive and hopeful messages that are not in conflict with providing honest and realistic communication. These include acknowledging the dignity and worth of the child as an individual, indicating that there is help available for parents, and informing families about the spectrum of possible outcomes for their child rather than the worst-case scenario.



FUNDING:

Public funding has been obtained

The Health Services National Partnership Forum and the Health Services Executive in Ireland funded the original project to develop the evidence-based best practice guidelines for informing families of their child's disability. Moreover, funding has been provided by the Department of Health to support and facilitate the future national implementation of the guidelines through a National Lottery Funding grant scheme.



OUTLOOK:

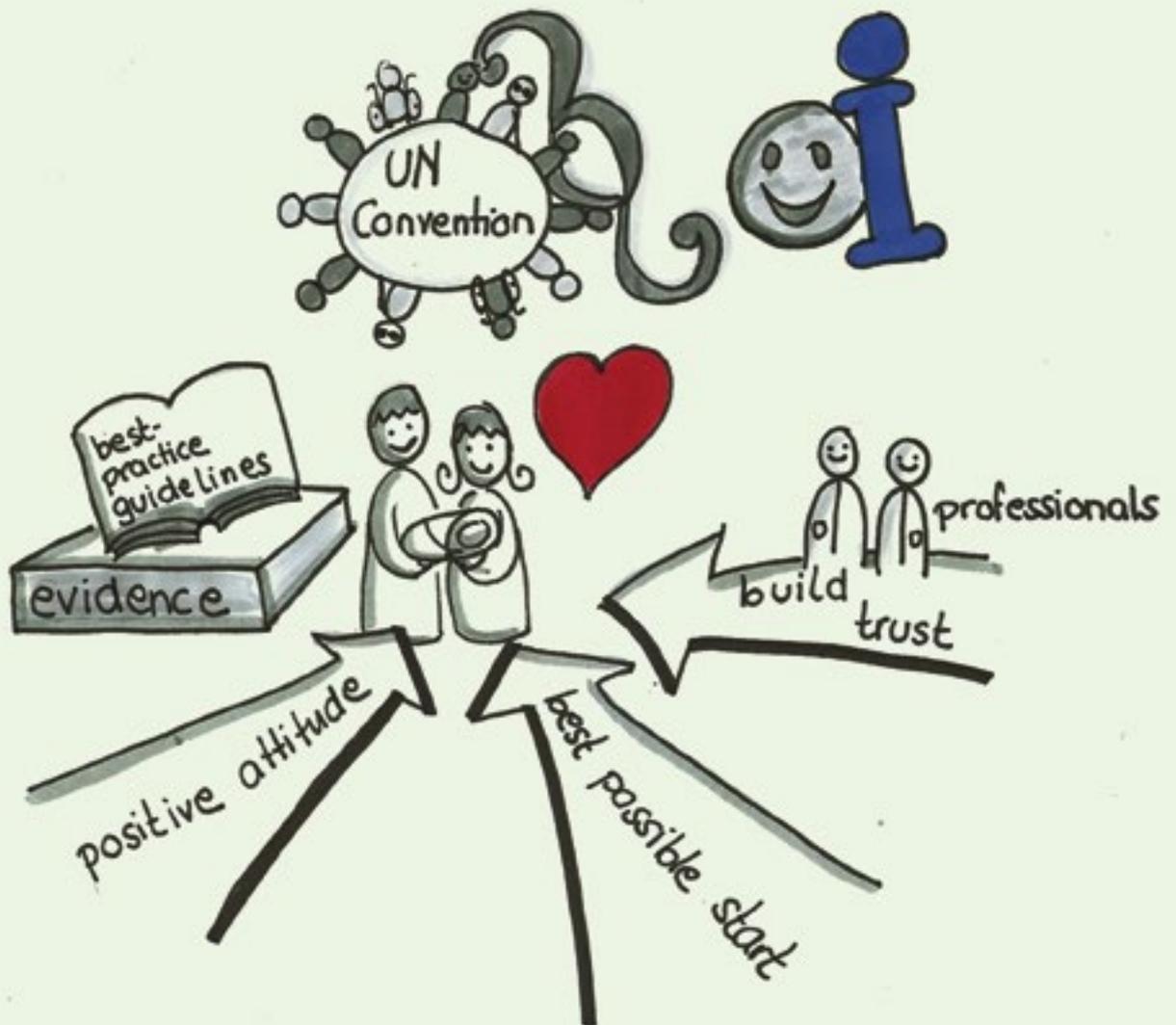
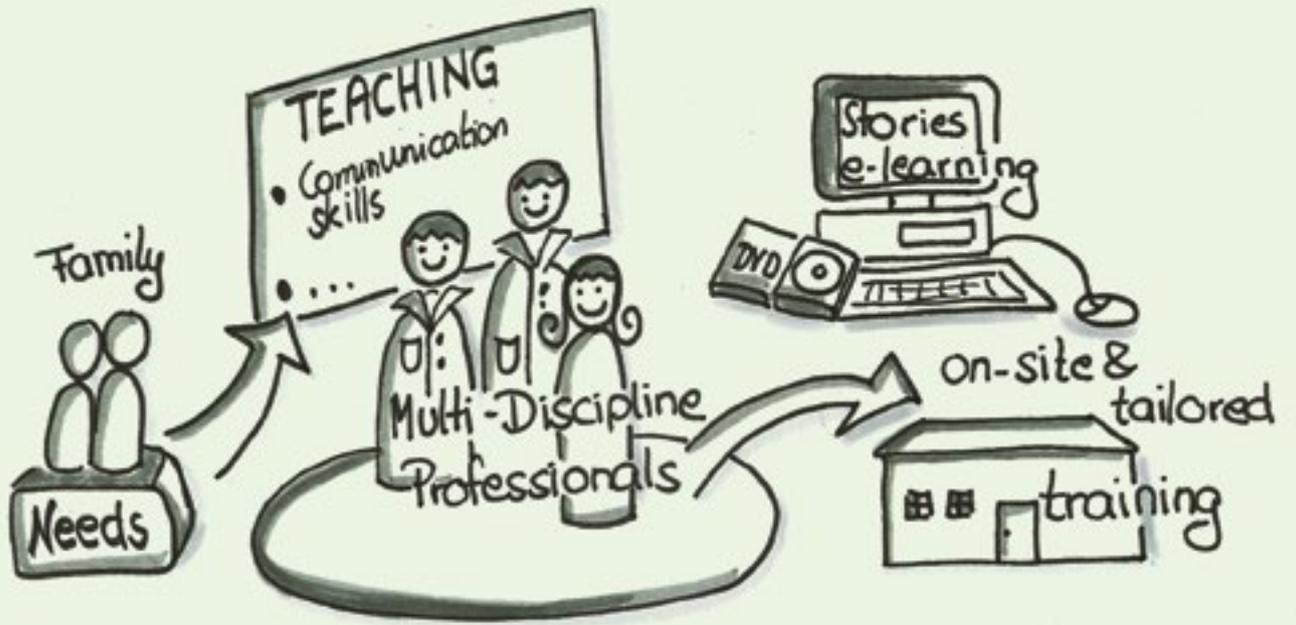
Ready for further dissemination

The guidelines are available for further dissemination in any country for which they are deemed useful and there has already been significant interaction with organisations in Finland, Austria and Germany in relation to these best practice guidelines. There is no charge for use of any of the materials as it is the intention of the National Federation of Voluntary Bodies to share this evidence-based guidance as widely as possible in order to promote supportive experiences for families everywhere.

Going forward, it is expected that professionals who inform families about their child's disability will have access to evidence-based best practice guidelines, and that families will have the most supportive possible experience. This will establish strong parent-professional trust, which will in turn support engagement with early intervention supports.



How doctors, nurses and staff are trained





ABOUT THE ORGANISATION:

National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation) is a national umbrella organization for voluntary/non-statutory agencies providing direct services to people with intellectual disabilities in Ireland. The organization and its 60 members account for more than 85 percent of this country's direct service provision to people with an intellectual disability.

The National Federation has developed initiatives to ensure that staff and volunteers in their services are equipped to meet the many challenges ahead, initiatives to promote the inclusion of people with an intellectual disability in their own communities, and key policy development initiatives. Another key function is the sharing of information among member organizations.

The National Federation is proactive in developing and contributing to policy initiatives that have a positive impact on the lives of children and adults with an intellectual disability. Working closely with various subcommittees, the organization develops policy positions on a wide range of topics for consideration by and approval of its Board. It also contributes and responds to initiatives developed by statutory authorities, including government representatives, the health service industry, and an extensive range of advisory and expert groups.

The National Federation of Voluntary Bodies also contributes to the development of various EU directives and to the implementation of the Council of Europe's Disability Action Plan.

BROAD DISSEMINATION:

Online courses available for download

The Royal College of Physicians of Ireland has adopted the National Federation's online training course – developed through the research of the Informing Families pilot implementation programme – nationally for all paediatric trainees. The course is similarly under current consideration for formal adoption by the Institute of Obstetrics following positive feedback from the Executive Council of the Institute in 2015. Funding has been provided for the national implementation of the guidelines by the Department of Health. The funding required is for a project coordinator to facilitate the roll-out of regional "training of trainers" courses and to provide printed copies of the guidelines and copies of the DVD "Words You Never Forget" to professionals. The project website provides information to families in the early stages following their child's diagnosis. This information has been translated into seven languages with financial support from the Health Services Executive.

Find more: www.informingfamilies.ie/about-the-project/support-and-training-materials.257.html



National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability Ireland

Ms. Alison Harnett

Tel. +353 91 792316

www.fedvol.ie

www.informingfamilies.ie

ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

EASPD Secretary General: Luk Zelderloo

Essl Foundation Programme Manager: Michael Fembek

Author: Wilfried Kainz

Project coordinator: Sabrina Ferraina

Graphic Design: Christoph Almasy

Graphic Facilitation: Petra Plicka

Editing: John Tessitore

This in-depth analysis can be downloaded for free at

www.zeroproject.org and www.easpd.eu

For information or copies, contact: office@zeroproject.org

Essl Foundation, Aufeldgasse 17-23, 3400 Klosterneuburg, Austria

© Essl Foundation and EASPD, April 2016. All rights reserved.