

Welcome to the Informing Families Project Newsletter



My daughter Julie has a physical disability and my son Diarmuid has an intellectual disability. They are both now adults, so take it from me you will cope and you will be happy again. It just takes some time to adjust to this new path ahead. I often wonder why I cried so much in those first few weeks. I now have many occasions to cry with happiness and pride in their achievements.

Katherine O'Leary, Parent and Chairperson of the Informing Families Cork Project

This newsletter has been written to share with you some recent exciting developments that are taking place through the Informing Families Project, including the national roll-out of the *Best Practice Guidelines for Informing Families of their Child's Disability*, and the renewed dissemination of the www.informingfamilies.ie website.



A quick re-cap on the Informing Families project to date

Development of the Guidelines

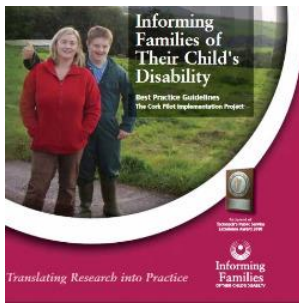
The *National Best Practice Guidelines for Informing Families of their Child's Disability* were developed by the [National Federation of Voluntary Bodies](http://www.nfvb.ie) in response to feedback from a number of families of children with disabilities that they had not been informed of their child's disability in a way that was sensitive and fully supportive. Professionals had also indicated that the communication of this sensitive news requires training, guidance and support - and so the National Federation set out on a journey of gathering evidence to inform best practice guidelines.



The Guidelines were first launched in 2007, following a significant national research project undertaken with families and with professionals who work with the families of children with disabilities. The Guidelines are supported by a robust evidence base which included 22 focus groups and a national survey of families and professionals. The results showed overwhelming agreement between parents and professionals on the practices required and on the need for training and support in this area.

The research also showed that there was good reason to implement the guidelines: whilst practice in Ireland was largely in line with international findings – there was evidence of good practice in place in many cases, some gaps still remained:

- Deficits were reported in information provision;
- There were instances of inappropriate communication;
- A tendency towards disproportionately negative messages was reported;
- Many families experienced a lack of privacy in terms of where they received the news;
- There was a lack of continuity of care;
- Professionals indicated their need for increased support and training.
- International evidence also demonstrates that the risk of litigation is significantly higher when communication is poor



Piloting of the Guidelines in the Cork Region

From 2008 to 2010 the Informing Families Project set out to translate research into practice through a two year pilot implementation of the guidelines in the Cork Region, across hospital, community and disability services. The purpose of the pilot project was to gain knowledge to inform national roll-out. The report of the Cork Pilot Project provides a range of practical tips and tools for implementing the Guidelines.

[Click here to download the report of the Cork Pilot Project.](#)

The pilot project was successfully implemented and was a recipient of the Taoiseach's Public Service Excellence Award 2010. A peer reviewed paper on the evaluation of the training which took place was published – please see reference below:

Harnett, A; Bettendorf, E; Tierney E; Guerin, S; O'Rourke M; and Hourihane, J. (2013) *Evidence-based training of health professionals to inform families about disability*. Archives of Disease in Childhood. 98(6):413-418

Development and translation of the website

In 2010 the Informing Families Project collaborated with the HSE's Social Inclusion Unit to address one of the key deficits identified through the national research – the difficulty for both parents and professionals in finding high quality general information materials that are relevant in the early stages after hearing of a child's diagnosis of a disability, or when a concern is raised that a child may have a disability. The result of this collaboration was the development of the Informing Families Website, www.informingfamilies.ie.

The information directed towards families on the website has been translated into 7 languages, bringing the total including English to eight; (English, Gaeilge, Polish, Russian, Romanian, Lithuanian, French and Brazilian Portuguese).

It is hoped that the provision of this content in professionally translated versions will support families of children with disabilities living in Ireland whose first language is not English, and professionals who wish to provide information to these families.

2017 - National Implementation of the Informing Families Guidelines

The National Federation is collaborating with the HSE in the implementation of the evidence-based *Best Practice Guidelines for Informing Families of their Child's Disability*, developed earlier by the Federation, over the course of 2017. Funding was secured through the Department of Health's National Lottery Scheme, and work on the implementation has begun to take place in a range of settings.

We are working in close partnership with Dr. Ciaran Browne, General Manager Acute Services HSE, to execute the national implementation plan. This includes looking across maternity, paediatric and early service settings in hospital, community and disability services to ensure that the training and awareness raising reaches those who undertake the sensitive and emotional task of informing a family of their child's disability.

The implementation of the Guidelines aims to support professionals who undertake this communication and to equip them with the tools that will support them in using good practice – to ultimately ensure that families receive the news in the best way possible.

Working with Dr. Ciaran Browne and HSE Communications, an email was sent in March 2017 to 100,000 HSE staff to alert them to the materials and resources available through the Informing Families Project and to let them know about training opportunities that will be coming up. A two page article was also published in the HSE’s Health Matters magazine, disseminating further information on the national roll-out plans.

Below you will find a few of the actions that have already begun to progress the national implementation of the Informing Families Guidelines.



Alison Harnett, Informing Families Project Coordinator & Dr Ciaran Browne, HSE

Training at the National Maternity Hospital



Dr. Deirdre Sweetman, Valerie Kinsella, Clinical Midwife Manager (National Maternity Hospital) and parents Nadine Campion and Katherine O’Leary at training session in NMH

As part of the roll-out strategy, training took place for 75 staff members at the National Maternity Hospital on 28 March 2017, with a wide range of staff disciplines attending. The training was well received, with a number of consultant doctors tweeting their support for the implementation of the Guidelines in the following days.

Follow up with the National Maternity Hospital will continue as plans are made to introduce the e-learning module and disseminate the Guidelines and resources hospital-wide.

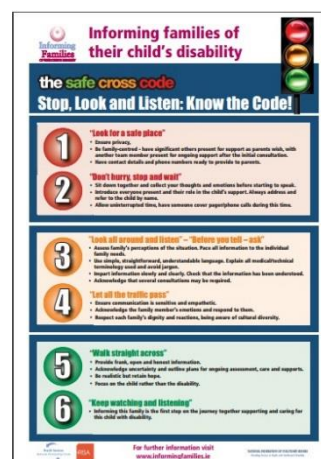
Rotunda Perinatal Palliative Care Conference

Staff at the Rotunda Hospital in Dublin invited the Informing Families project to make a presentation at their Perinatal Palliative Care conference, which took place on the 15th February. Ms. Niamh McGauley, National Federation, made the presentation at this event, which brought together a wide range of professionals involved in maternity care from across the country.

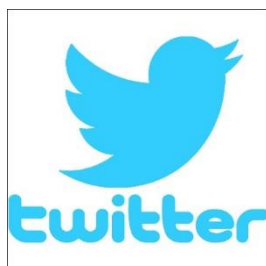
Resources available

If you would like to access the evidence-based guidance for informing families of a child's disability, a range of resources and supports are available as follows:

- National Best Practice Guidelines for Informing Families of their Child's Disability
- 'Words You Never Forget' 24 minute DVD
- A 1 hour e-learning module certified by HSE, and currently in use by a range of organisations and professions, including the SpR Paediatric programme with the RCPI – [Click this link to log on](#)
- Traffic Lights – Quick Reference Guide developed in collaboration with Dr. Brendan Murphy CUMH and the Cork Pilot Implementation Project
- Consultation and Research report (describing evidence-base for Guidelines)
- Training course and materials, being provided in a number of locations to establish the roll-out in 2017



Log on to the following link for full details: <http://www.informingfamilies.ie/about-the-project/support-and-training-materials.257.html>



Follow us on Twitter!

Informing Families has joined Twitter and is delighted to welcome a broad range of followers including families of children with disabilities; medical, nursing and allied health professionals; and service providers, to name a few. For the latest updates follow us at **@InformFamilies**. Please use the hashtag **#informingfamilies** if you would like to share information about the website or the best practice guidelines.