



Informing Families

OF THEIR CHILD'S DISABILITY

Beginning the journey:
Best practice when informing
families of their child's disability

*Alison Harnett, National Federation of
Voluntary Bodies*

Informing Families of their Child's Disability - Importance of Disclosure Process

For families:

- has an impact on levels of distress and anxiety
- has a bearing on the attachment process
- can influence parent-professional relationship thereafter.

(Cunningham, C 1994)

For professionals:

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

(Harnett, A 2007)

Overview

- Programme of research to develop guidelines
 - Literature review
 - 22 focus groups with parents and professional disciplines
 - National questionnaire survey of 584 parents and 1588 professionals
 - Leading to Consultation & Research Report, Guidelines and *'Words You Never Forget'* DVD
- National Best Practice Guidelines for Informing Families of their Child's Disability launched Dec 2007
- Cork Implementation Pilot Project 2008 - 2009

Project Scope

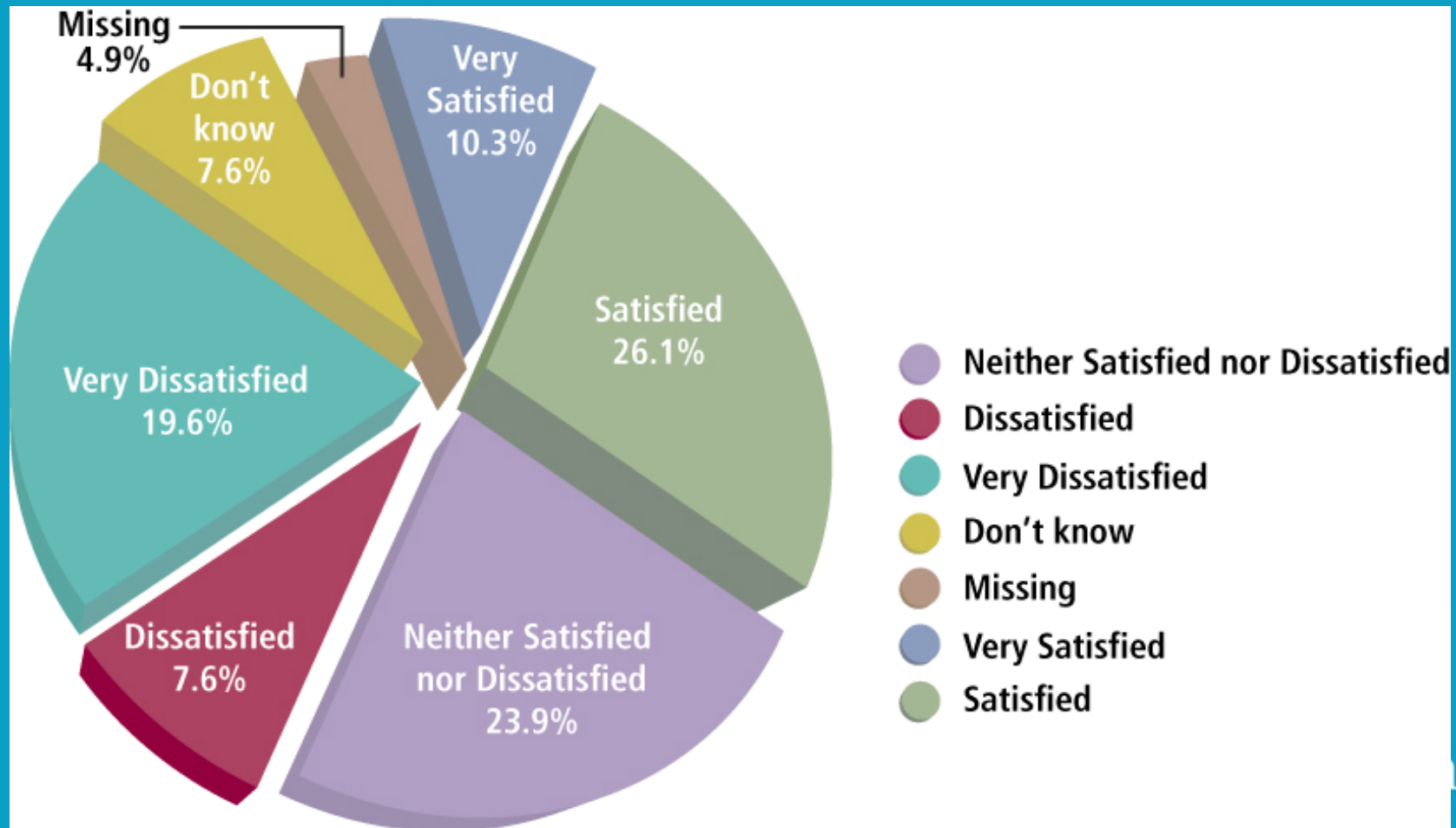
- Physical, Sensory, Intellectual Disability and Autistic Spectrum Disorders
- Ante-natal, at birth, evolving diagnosis
- Hospital, Community, Disability Services
- Professionals in 27 disciplines

Research Findings

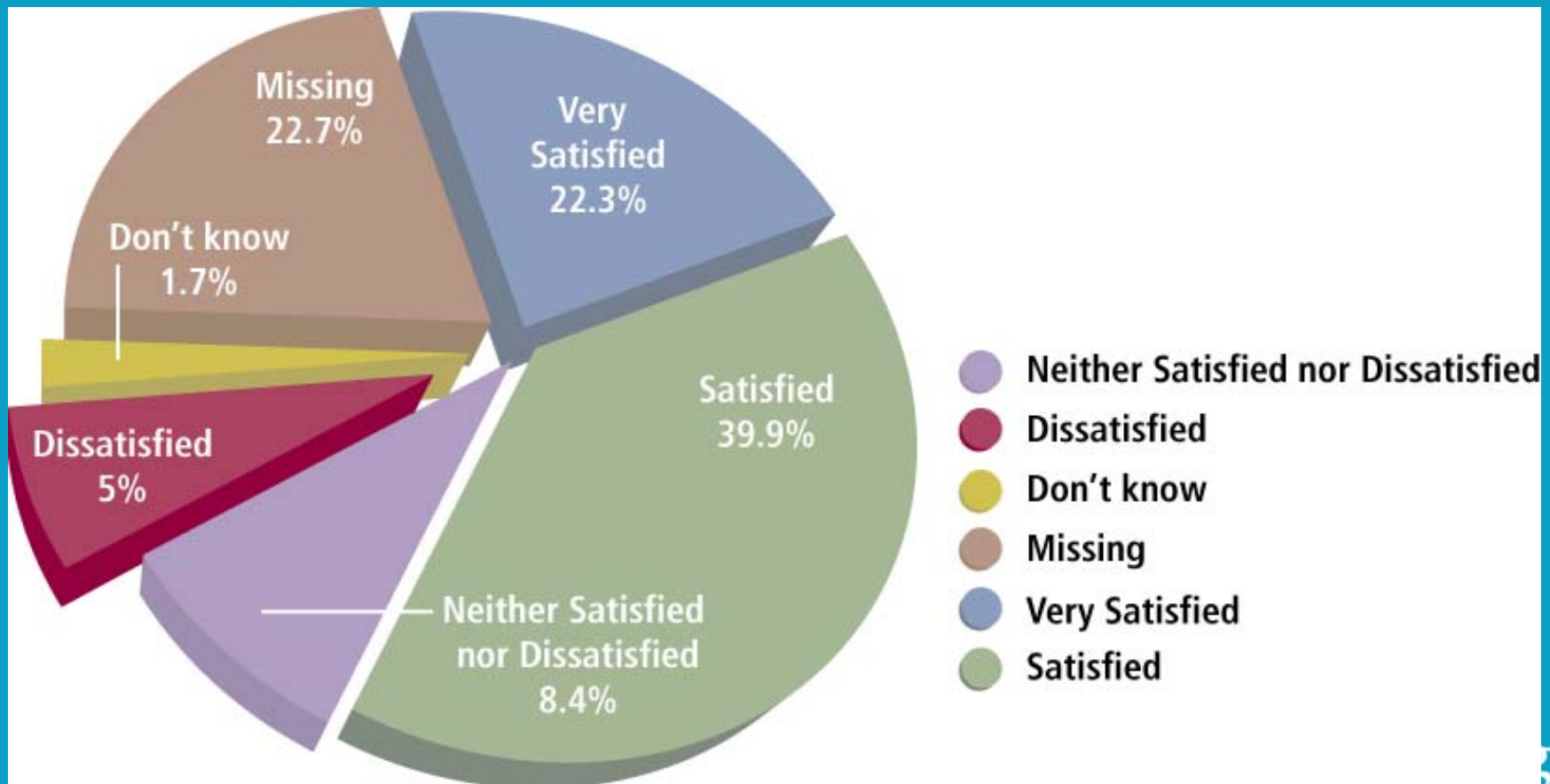


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Parental Satisfaction with Disclosure



Professional Satisfaction with Disclosure



Satisfaction with disclosure

- Gap between levels of 'Satisfied' + 'Very Satisfied' reported by parents (36.4%) vs. professionals (62.2%)
- Levels of parental satisfaction with disclosure reported in line with those found in the international literature.
- Basis for good practice already in place in Ireland
- There are, however, also parents who expressed significant levels of dissatisfaction
- And professionals who expressed an urgent need for further support and training to assist in the application of best practice.

Wide range of disciplines involved

- Disclosure is a *process* rather than a one-off event
- It can involve staff members from acute, community, disability service settings
- Who have varying levels of experience
- From nursing, medical and allied health professional disciplines



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1	Discipline	n=Times listed in Parent Questionnaires	Percentage of overall instances
2	Paediatrician	124	39.12
3	Psychologist	33	10.41
4	Neurologist	25	7.89
5	Nurse (Neonatal & Paediatric	12	3.79
6	Obstetrician/Gynaecologis	11	3.47
7			
8	Midwife	9	2.84
9	Trainee Paediatrics/Obstetrics	8	2.52
10	Audiologist	8	2.52
11	Speech and Language Therapist	7	2.21
12	Geneticist/Genetic Counsellor	7	2.21
13	Ophthalmologists and Optometrists	6	1.89
14	Phsyiotherapist	6	1.89
15			
16	GP	4	1.26
17	Public Health Nurse	4	1.26
18	Psychiatrist	4	1.26
19	Occupational Therapist	4	1.26
20	Social Worker	4	1.26
21			
22	Neonatologist	3	0.95
23	Parent	3	0.95
24	Liaison Person	3	0.95
25	Cardiologist	3	0.95
26			
27	ENT Consultant	2	0.63
28			
29	Area Medical Officer	1	0.32
30	Community Nurse (RNID)	1	0.32
31	Endocrinologist	1	0.32

Content of the Best Practice Guidelines



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Guiding Principles

- Child and Family Centred
- Demonstrate Respect for Child and Family
- Sensitive and Empathetic Communication
- Appropriate, Accurate Information
- Positive, Realistic Messages, with Hope
- Team Approach and Planning
- Focused and Supported Implementation of Best Practice

Full Guidelines can be downloaded from

www.informingfamilies.ie



Recommendations - Areas

1. Physical and Social Setting
2. Communication
3. Information and Support
4. Culture and Language
5. Organisation and Planning Requirements
6. Training, Education and Support for Professionals
7. Dissemination

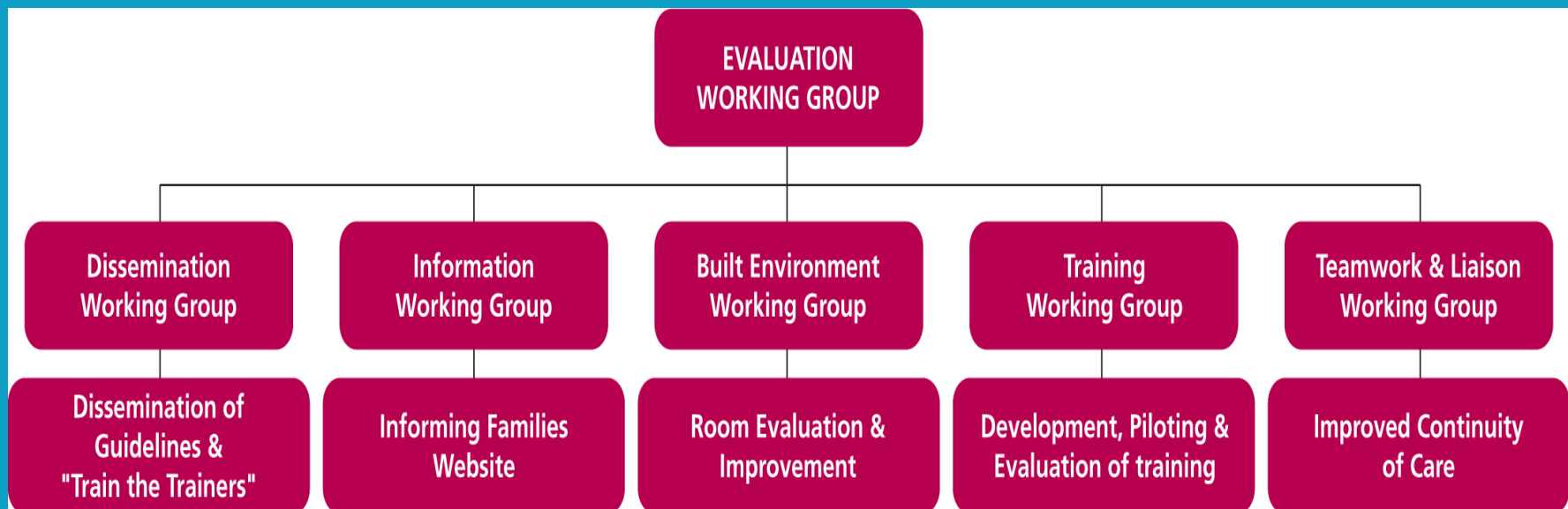
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Hospitals	Community Services	Disability Services	Universities
Cork University Hospital	HSE Primary Community and Continuing Care in the Cork Region:	Brothers of Charity Southern Services	University College Cork
Cork University Maternity Hospital	North Lee	Co-Action West Cork	University College Dublin
Mercy Hospital	South Lee	COPE Foundation	
Mallow General Hospital	North Cork	Cork Deaf Association	
	West Cork	Enable Ireland Southern Services	
	GP's in Cork Region	Inclusion Ireland	
		National Council for the Blind of Ireland	
		St. Joseph's Foundation Charleville	

Steering Committee & Working Groups

- Acute, community and disability service settings in the Cork region.
- Chaired by a parent of two children with disabilities
- Professionals from medical, nursing and allied health disciplines
- Management support a key step

Working Groups



Deficits identified in national research

- Inappropriate communication
- Overly negative messages
- Lack of privacy, inappropriate locations
- Insufficient or out-of-date information
- Lack of liaison/continuity of care
- Lack of training and support for professionals



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Dissemination



Needs

- 79% of professionals in Ireland unaware of guidance
- 1/3 unaware in UK study of implementation

Implementation & Solutions

- Management support
- Database of stakeholders
- Tracking of dissemination
- Presentations at national conferences and study days
- Train the trainers workshop: 30 champions for change disseminating in their disciplines and geographical locations
- All-users email & open training session
- Reports, articles, presentations

**Informing Families of their Child's Disability
Cork Implementation Project**
Please return this sheet to Audrey Moran by May 31st 2008.

Evidence-based best practice guidelines have been developed in partnership with parents and a wide range of medical, nursing and allied health professionals to guide those who inform families that their child has a disability, or support them immediately thereafter. The Guidelines are being piloted in the Cork region, to inform national roll-out. In order to ensure that the Guidelines reach all professionals who might need them, the Informing Families Project team are tracking dissemination. Please ask your team to fill in below to confirm when each have received the guidelines and to indicate if they have seen the accompanying video training aid, 'Wards You Never Forget'.

If you require any further information on the Guidelines please see:
www.fedvol.ie

Staff member	Team/Unit/Ward	Access to Guidelines	DVD Watched
noilette	Delivery Suite	✓	
Maire Conroy	Delivery Suite	✓	
Eimear Quinlan	Delivery Suite	✓	
Ann Cross	Delivery Suite	✓	
Simon	Delivery Suite	✓	
Nicole Conkley	Delivery Suite	✓	✓
Nicola Woodcock	Delivery Suite	✓	
Dea Heath	D.I.S.	✓	✓
Paula Murphy	Delivery Suite	✓	✓
Paula de Robert	Delivery Suite	✓	✓
Elise Hyatt	Delivery Suite	✓	
Siobhán Egan	Delivery Suite	✓	
Loz Manning	Delivery Suite	✓	
Caroline	Delivery Suite	✓	✓
Jo Lynch	Delivery Suite	✓	
Marian McCarthy	Delivery Suite	✓	
Sarah Cassidy	D.I.S. & D.S.	✓	
Michelle	Delivery Suite	✓	
Michelle	Delivery Suite	✓	✓
Ann Finn	Delivery Suite	✓	
Carolee Cui	Delivery Suite	✓	

Signed: Line Manager *Carolee Cui* Date: 10/9/08

Please return your completed form to:
Alison Harnett, c/o Partnership Office Floor 3, Áras Síainte, Wilton road, Cork

Training



- **2-hour classroom-based pilot training developed**
- **Training delivered**
 - 80 4th year medical students
 - Neonatal & Paediatric NCHD's
 - 130 Nursing & Midwifery students UCC
 - 34 members of multi-disciplinary Early Intervention Teams
- **Evaluation**
 - Increase in knowledge
 - Increase in comfort
 - Increase in confidence
- **E-Learning Module**

Information

Needs assessment

- 63.6% of parents received no written information
- 40.8% of parents did not feel they had understood child's diagnosis



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Telling Others about your child's disability



Brothers and sisters

As a parent, you are best placed to decide how much information is appropriate to give your children. Much depends on their age, their level of understanding and their curiosity. Don't be afraid to involve your children as soon as possible. It's OK to show them you hurt if that is the case – they may well realise that already. Tell them in an honest and open way. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions. Follow your children's lead in deciding what else to tell them.

You may want to cover things like...

- It's not your fault that your brother/sister has a disability
- It just happened by chance.
- Children with a disability may find it harder to learn new things. They will want to join in and do the things you like doing but they might take longer learning how to do it and they may not be good at it.
- You can't catch a disability.
- It's very important to have brothers and sisters
- We love you very much and we love your brother/sister too.

“ Your children will follow your lead. If you treat disability as just one aspect of your child's life, their siblings will too. ”

- Website of appropriate and up-to-date information for parents developed: www.informingfamilies.ie
- Information for professionals to print and provide to parents, or for parents to access directly



Information for Families

This section of our website provides general information for families on topics such as Entitlements and Benefits and Early Information.

This information is useful for families whose child has been given a diagnosis, and for those who have a concern about a possible diagnosis.



[View Information for Families](#)

Information for Professionals

[Email A Friend](#)

This section provides information that professionals can print for families at the time of diagnosis of a child's additional needs, disability or developmental concern. It also contains helpful information to directly support you in your communication with families.



[View Information for Professionals](#)

What's New

Informing Families Cork Implementation Project wins Taoiseach's Award

Feb-26-2010

Informing Families Cork Implementation Project is amongst 20 from across the range of public services that will receive the Taoiseach's Public Service Excellence Awards on 31 March 2010 in Dublin Castle.

Find out about the latest updates on the project and upcoming training sessions

(01 Feb 2010)

Visit this section to find out what's happening in the Informing Families Project, the latest news and training sessions taking place around the country.

Informing Families Best Practice Guidelines - Training for Nurses in UCC

(03 Nov 2009)

Training will take place on 10 March 2010 for approximately 130 students from second year nursing and midwifery, and for post-graduate Public Health Nurses in University College Cork.

[RSS Feed](#) [RSS Help](#) [More News](#)

About our Project

The *Informing Families Project* developed best practice guidelines for informing families of their child's disability, and supporting families receiving this news. The guidelines were developed through consultation and research with families and professionals. In this section of the website you can:

- > Download the [best practice guidelines](#)
- > Watch our film *'Words You Never Forget'*
- > Access useful [support & training materials](#)
- > Take our [e-learning training module](#)
- > See the [findings from the national research](#)
- > Find out [How this website works](#)



Built Environment

Needs assessment through the national study

- privacy key area for improvement
- negative impact of being told without privacy is considerable

Pilot implementation & solutions

- Organisations identified locations where families typically receive news
- Suitability of available facilities assessed using the guidelines
- Improvements made to take account of the best practice guidelines and optimise the spaces where families receive difficult news
- Photographs taken by staff members to record changes



Optimising and enhancing environments



**'Seomra 7' Cork University
Hospital Before refurbishment**



**'Seomra 7' Cork University
Hospital After refurbishment**

However! Changes can be made without incurring significant financial expense

- Ensure no interruptions – remove staff lockers & use 'occupied' sign
- Agree at staff meetings how a room should be booked/utilised to optimise privacy
- Provide tea, coffee, water and tissues in the room as a standard measure
- Schedule relevant appointments at the end of the day


Teamwork & Liaison

Needs assessment


- issues of continuity of care

Implementation & solutions

- Interdisciplinary workshop
(*acute, community & disability service settings*)
- ‘Safe Cross Code’ protocol
- Meetings with Early Services & Hospital
- Checklist for ante-natal diagnosis
- Discharge summary for parents
- Links with national shared documentation project
- Tertiary checklist in development



Informing families of their child's disability



the safe cross code
Stop, Look and Listen: Know the Code!

- 1 "Look for a safe place"**
 - Ensure privacy.
 - Be family-centred - have significant others present for support as parents wish, with another team member present for ongoing support after the initial consultation.
 - Have contact details and phone numbers ready to provide to parents.
- 2 "Don't hurry, stop and wait"**
 - Sit down together and collect your thoughts and emotions before starting to speak.
 - Introduce everyone present and their role in the child's support. Always address and refer to the child by name.
 - Allow uninterrupted time, have someone cover pager/phone calls during this time.
- 3 "Look all around and listen" – "Before you tell – ask"**
 - Assess family's perceptions of the situation. Pace all information to the individual family needs.
 - Use simple, straightforward, understandable language. Explain all medical/technical terminology used and avoid jargon.
 - Impart information slowly and clearly. Check that the information has been understood.
 - Acknowledge that several consultations may be required.
- 4 "Let all the traffic pass"**
 - Ensure communication is sensitive and empathetic.
 - Acknowledge the family member's emotions and respond to them.
 - Respect each family's dignity and reactions, being aware of cultural diversity.
- 5 "Walk straight across"**
 - Provide frank, open and honest information.
 - Acknowledge uncertainty and outline plans for ongoing assessment, care and supports.
 - Be realistic but retain hope.
 - Focus on the child rather than the disability.
- 6 "Keep watching and listening"**
 - Informing this family is the first step on the journey together supporting and caring for this child with disability.

Health Services National Partnership Forum  For further information visit www.informingfamilies.ie NATIONAL FEDERATION OF VOLUNTARY BODIES Priority Union of People with Intellectual Disability

Evaluation of Teamwork & Liaison Workshop

“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



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The work of the Cork Implementation Project was characterised by **partnership** working to put child & family at the centre of service provision.

- **Interdisciplinary partnership**
- **Parent-professional partnership**
- Careful use of resources was a feature of this project

Partnership working across hospital, community and disability services to place children and families at the centre of service provision

