



Informing Families

OF THEIR CHILD'S DISABILITY

'Words You Never Forget'

*CIS Obstetric Forum
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Introduction

- *'Words You Never Forget'* – positive and negative experiences of disclosure
- Best Practice Guidelines – development and content
- Challenges for implementation
- Where to from here?



Development of the Guidelines

- National Federation of Voluntary Bodies with support from the Health Services National Partnership Forum
- Evidence-based best practice guidelines launched in December 2007
- Endorsement from parents, professionals, HSE, Dept of Health and Children, and international experts, e.g. Harvard Medical School

Informing Families Project Aims

Development of National Best Practice Guidelines for informing families of their child's disability at the first stage of communicating a diagnosis or concern

- To encourage improved outcomes for children and families at the time of diagnosis of disability, through the implementation of best practice
- To provide improved support, guidance, education and training for professionals in this important and sensitive task
- To encourage Partnership working through development and implementation of best practice guidelines

National Steering Committee

- Chaired by Dr. John Hillery
- Parents
- Department of Health and Children
- HSE
- Unions and Professional Bodies of Disciplines involved in informing families
- Royal College of Physicians
- Health Services National Partnership Forum
- National Federation of Voluntary Bodies
- UCD - Specialist statistical advice



Consultation & Research Programme

1. Literature Review

2. Focus Groups

- 7 with parents
- 15 with professional disciplines

3. National Questionnaire Survey

- 584 parents (31.5% response rate)
- 1588 professionals in 27 disciplines
(response rate varies per discipline)

4. Report, Guidelines and DVD



Project Scope

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

Importance of Disclosure Process

International research indicates that the way in which families are given the news of their child's disability:

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

Importance of Disclosure Process

For professionals the process of giving families the news that their child has a disability, or supporting the family immediately thereafter:

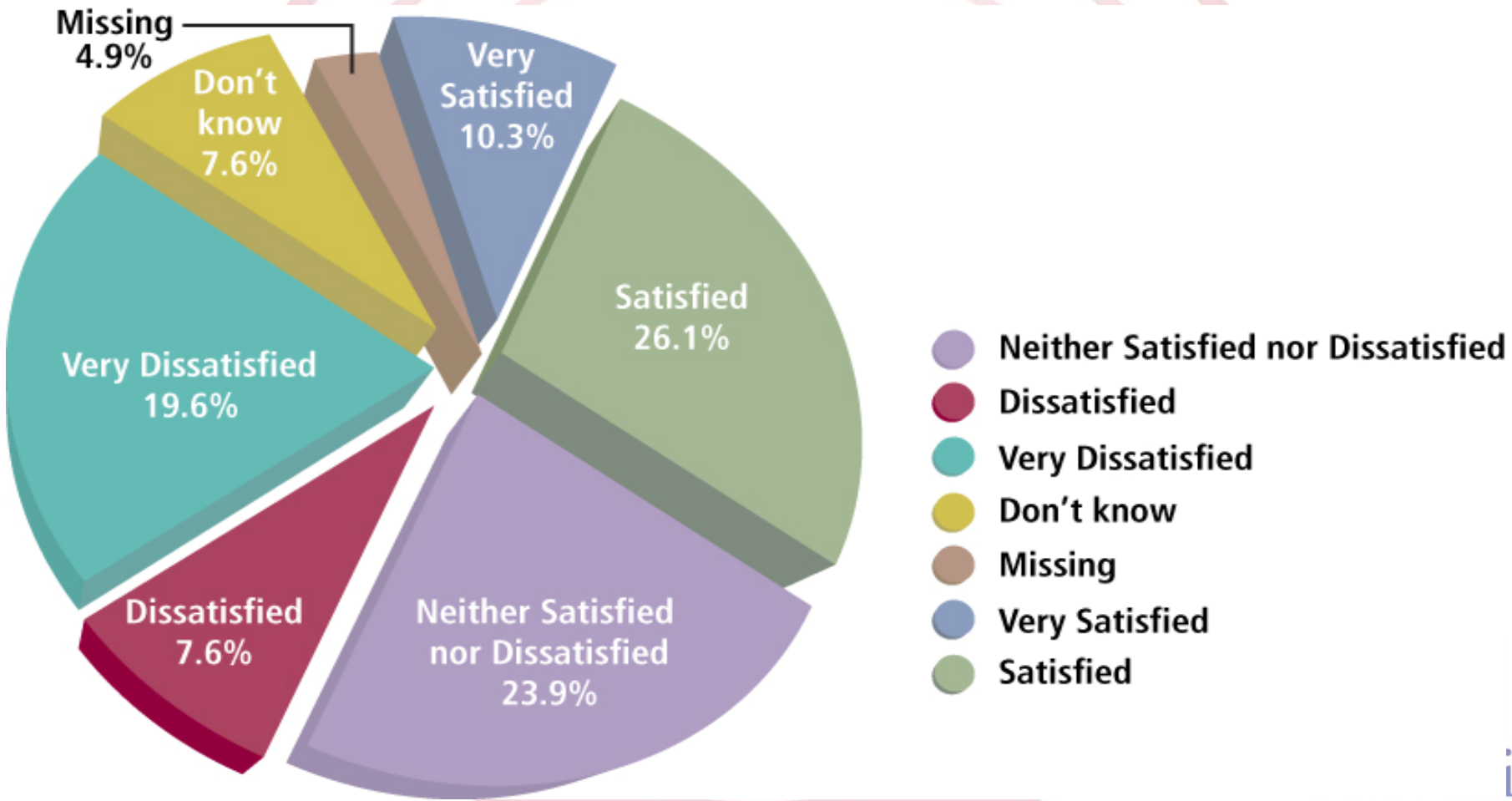
- is an emotional and challenging experience,
- requiring training and support
- and clear policies to guide practice on the front line

Rationale for Best Practice Guidelines

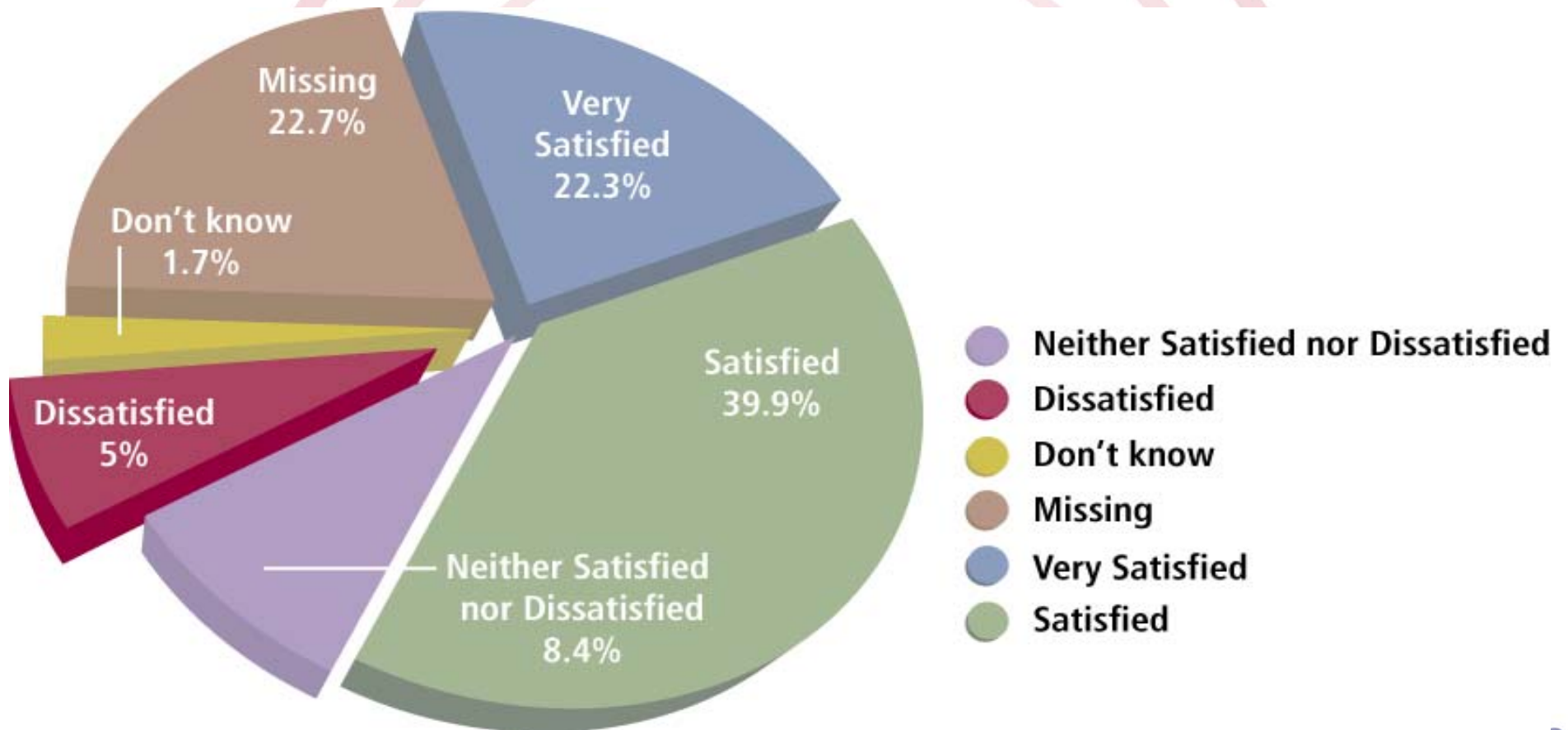
- Policy Documents over the past 17 years make specific recommendations for best practice
- Dissatisfaction with disclosure is not inevitable
 - UK Study - Ideal Service 100% Satisfaction
 - Parents clearly distinguish diagnosis from the disclosure
- Literature shows current lack of local guidelines in place
- Reduced litigation (Baird et al 2000)



Parental Satisfaction with Disclosure



Professional Satisfaction with Disclosure



Research Findings (1)

- 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.

Research Findings (2)

- When there are deficits in practice the consequences for parental distress can be significant
- When professionals do not feel adequately trained or supported, it increases the stressful nature of this emotionally challenging task
- Strong rationale for implementing guidelines that aim to ensure a more consistent approach to supporting parents and professionals

Research Findings (3)

- Deficits exist in the **information** currently provided to parents
- Deficits in **continuity of care** – a **named liaison person** required
- **Sensitive and empathetic communication** in many cases, needs to be on a consistent basis
- Need for the diagnosis to be delivered with **realistic, positive and hopeful messages.**
- Need for **appropriate, private physical environments** in which to provide the diagnosis
- High level of professional interest in **training and support** for in this area



“And it’s not just a sentence. Every word is important because you are hanging on to everything they say and you will remember every word they say, it sticks in your mind. They really need to plan their sentences and their words because this is going to stay with you for the rest of your life.”

Parent,

Informing Families Project Focus Groups



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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



Recommendations - Areas

- Physical and Social Setting
- Communication
- Information and Support
- Culture and Language
- Organisation and Planning Requirements
- Training, Education and Support for Professionals
- Dissemination



Implementation of best practice – rationale

- Poor disclosure practice can:
 - Impact on the welfare of the child when inadequate information leads to delays in accessing support (Hatton et al 2003)
 - Increase the risk of litigation (Fallowfield and Jenkins, 2004)
- Dissatisfaction with disclosure is **not** inevitable and good practice increases parental satisfaction with how they are told of their child's disability (Cunningham, 1994)

Challenges for implementation

- Informing Families research found deficits in key areas:
 - Information Provision
 - Privacy During Disclosure
 - Communication Skills
 - Continuity of Care



Challenges for implementation

- 1/3 of key staff members in UK unaware of Guidelines (Fallowfield & Jenkins, 2004)
- Dissemination alone is not sufficient for *implementation* to take place



Progress in Implementation

- Cork Implementation Project
- Four levels of practice identified at which implementation is required
 - Individual practitioner level (implications for my own practice?)
 - Team level (liaison between team members, or with other teams in my organisation)
 - Regional level (liaison between acute and community teams)
 - National level (regional referral to tertiary centres)



Progress in Implementation

- Supports being developed:
 - Information Resource – English and translated information for supply to parents
 - Protocols for practice and liaison in acute setting
 - Protocols for liaising with community services at the time of discharge
 - Training materials



Where to from here?

- Q. What is required to implement the Guidelines at all four levels of practice:
 - Individual practice?
 - At the team level?
 - At regional level?
 - With tertiary centres?



Contact

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Health Services
National Partnership Forum

NATIONAL FEDERATION OF VOLUNTARY BODIES

Providing Services to People with Intellectual Disability



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