Supporting Informed Choice for families of deaf children

2008 National EHDI Conference, New Orleans

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Context

- Newborn Hearing Screening universally implemented in England

- Growing government focus on Rights and Choice

- Wide regional variation in service provision and quality
Context

• Concerns over bias and incomplete information given to families

• Differing service philosophies restricting choice (particularly of communication mode)

• Early Support initiative (www.earlysupport.org.uk)
What is ‘Informed Choice’?

- Information?
- Choice?
- Knowledge?

- Understanding?
- Experience?
Aims of the project

• To undertake research which deepens understanding in the context of deaf children and families

• To produce guidance for professionals – theory and practical support

• To produce empowering guidance for parents to help them make the best choices for their children and for themselves
Process

• Literature review

• Consultation

• Product development

• Trialling
Literature review

• Very little in deaf education

• Wider scope, for example:
  – Smoking
  – Cancer
  – Childbirth
Evidence from sites

- 3 Areas
  - Different geography (urban and rural), structures, demographics
- Multiagency partnership consultations
- Parent consultations
  - Exploring issues and areas of concern
  - Identifying Drivers and Barriers
- Strategic consultations
Professional Handbook

- How to use
- Underpinning issues
- What parents and professionals told us
- Practical examples
- Resources
- Principles
Parent Booklet

• What does Informed Choice mean
• Case studies: underpinning issues in parent terms
• What to expect from services who offer an Informed Choice approach
• Key questions to ask
Professional version: underpinning issues

• Information, knowledge and understanding

• Availability

• Access to availability

• Parents vary in their ability to make informed choices

• Informed choice in families’ terms
Professional version: underpinning issues

- Does Informed Choice mean we offer the same to everyone?
- Are all issues open to Informed Choice?
- Individual choices and the effects on others’ choices
- Parents as experts
- Informed Choice is an active process
Professional version: underpinning issues

• Equality of resourcing

• Operational constraints

• Resources strategy and philosophy

• Training

• Attitudes and values
Parent version: underpinning issues

• Every family is different
• I know my family and child best
• I need more than information to make a choice
• Do I really have a choice in every situation?
• It seems like the professionals think one choice is better
• I don’t feel comfortable and confident about making choices
Parent version: underpinning issues

• It’s OK to change my mind
• It’s not readily available, but I still want to know about it
• Not everything I’ve been told about is available
• It’s available, but can I use it?
• Would learning a new skill help me to make choices for my child?
Topic areas

- Appointments
- Audiology
- Communication
- Family to family support
- Information
- Multi-agency working
- Service structure and organisation
- Training
- Transport
EHDI practitioners supporting Informed Choice for families: Different families, different needs
EHDI practitioners supporting Informed Choice for families

• Attitudes and Values (explicit and implicit)
  - Operate at all levels of professional activity
  - Professionals need to be honest and aware of own beliefs and opinions
  - Professionals need to take into account the values, beliefs and priorities of parents

• Respect, value and reciprocal sharing

• Risks, benefits and consequences
“Informed Choice means that families can make knowledgeable decisions, which reflect their own cultures, values and views. This should be based on full access to comprehensive, unbiased and evidence based information, about the full range of options”
Definition

An Informed Choice approach to service provision is one in which:

- Service providers adopt open and flexible policies that effectively endorse a range of possibilities
- Services and professionals make no value judgements about one option over another and this stance is reflected in their strategic decision making and resourcing
- Families are supported to reach decisions in ways that are sensitive to their individual strengths, resources, needs and experience
- An informed choice is not seen as a one off decision but as an ongoing process
Further information


  www.investigacion-psicopedagogica.org/revista/


Thank you

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