

# Supporting Informed Choice for families of deaf children

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## Context

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- Newborn Hearing Screening universally implemented in England
- Growing government focus on Rights and Choice
- Wide regional variation in service provision and quality



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## Context

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- 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](http://www.earlysupport.org.uk))

**Early Support**  
Helping every child succeed



## What is 'Informed Choice'?

- Information?
- Choice?
- Knowledge?
  
- Understanding?
- Experience?





## Aims of the project

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- 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



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## Process

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- Literature review
- Consultation
- Product development
- Trialling



## Literature review

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- Very little in deaf education
- Wider scope, for example:
  - Smoking
  - Cancer
  - Childbirth



## Evidence from sites

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- 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



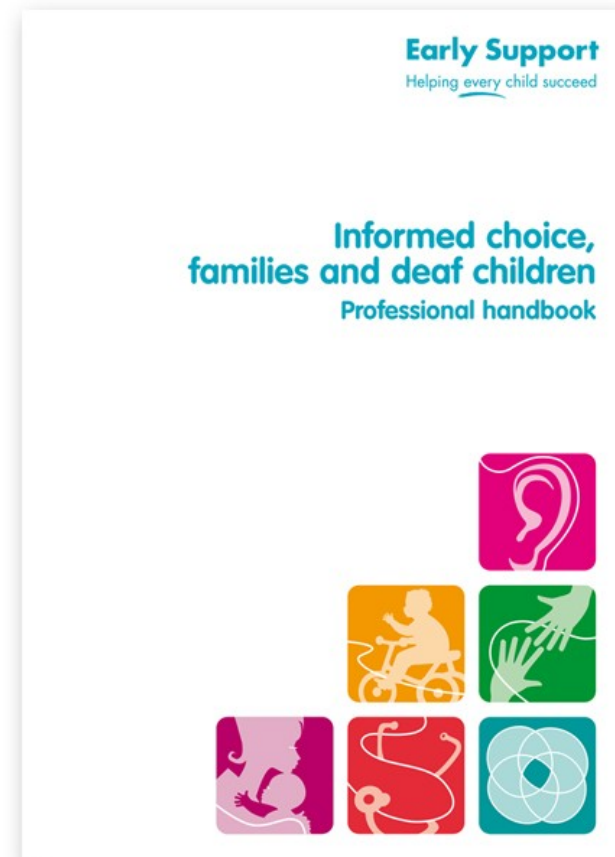


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## Professional Handbook

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



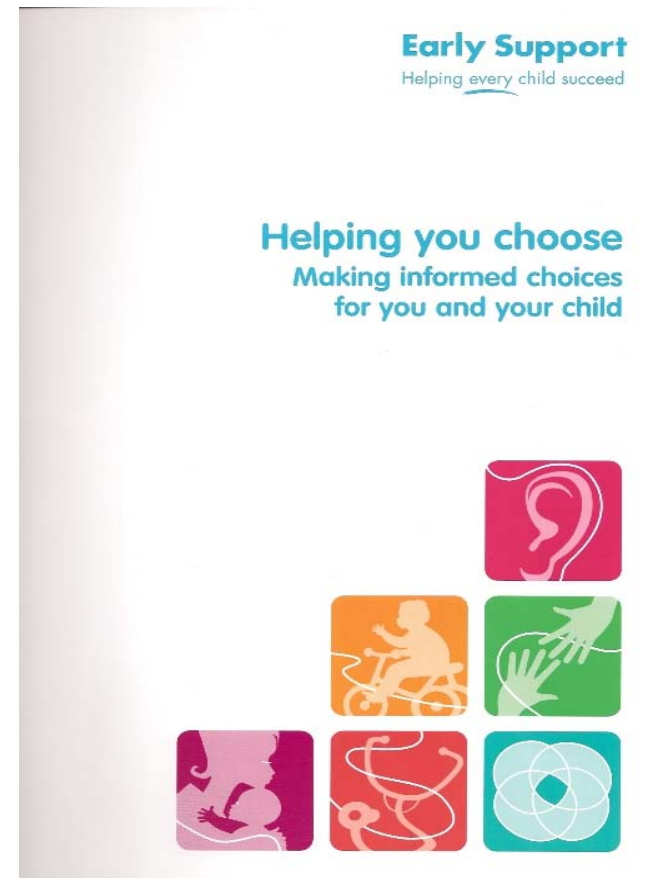


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## Parent Booklet

- 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**

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- **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?



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## Topic areas

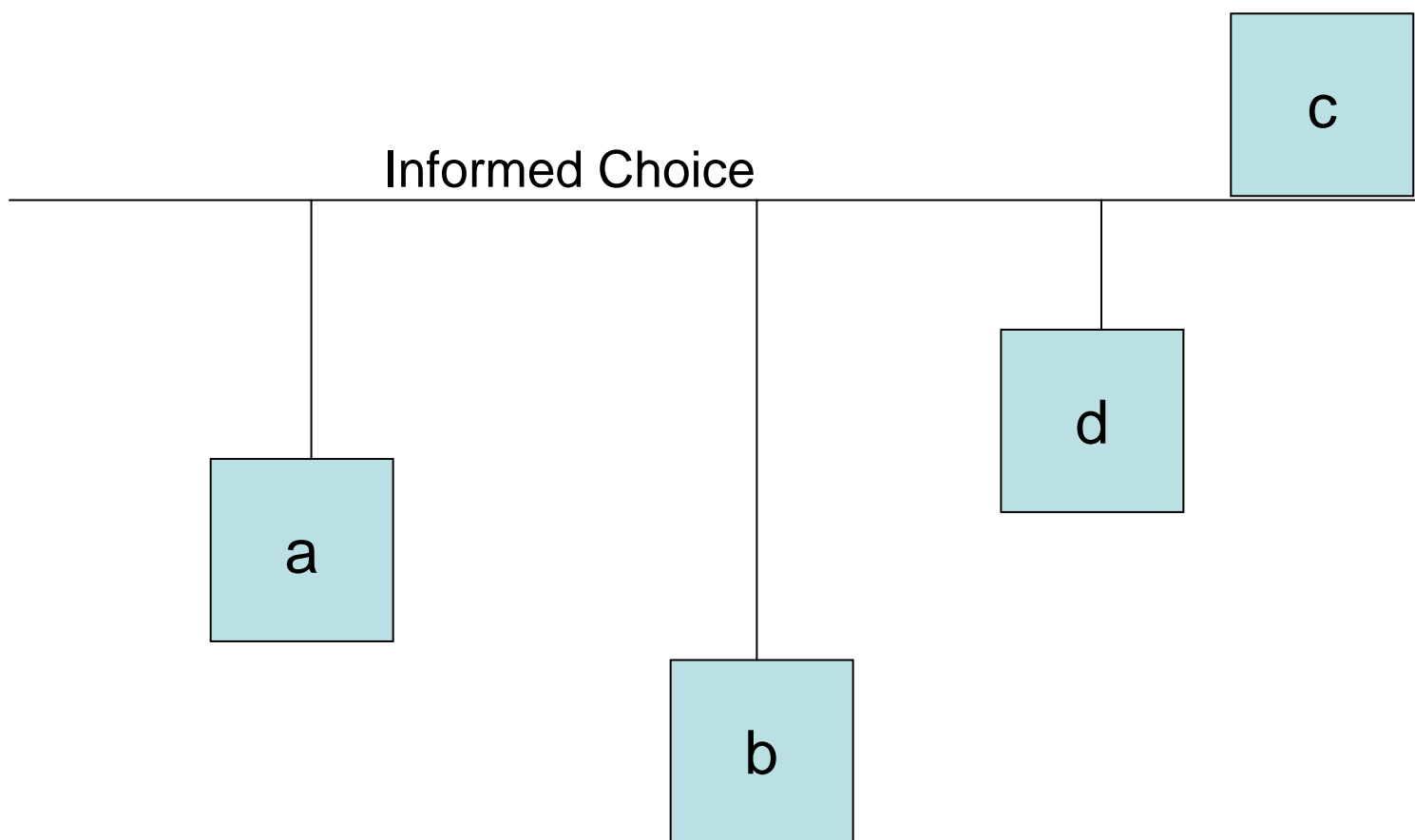
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- Appointments
- Audiology
- Communication
- Family to family support
- Information
- Multi-agency working
- Service structure and organisation
- Training
- Transport





## **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



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### **Definition**

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“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”



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## Definition

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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



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## Further information

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# Thank you

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