

# Informed Choice

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# An unknown/unfamiliar world



Friends????

Speech ?

Sign language ?

Nursery?

SCHOOL?



# Background

- This study was funded by the English government DfES
- This study was jointly undertaken by the University of Manchester and the National Deaf Children's Society
- Widespread concern about the so called “post code lottery” and lack of informed choices for parents of deaf children

# Parents of deaf children

- Typically were reported to have received information and advice that they later found to be biased or incomplete
- Found it hard to make choices when they did not know the implications of choices or alternatives

# Study design

## Part One

### No clear definition of Informed Choice

- Literature review [outside the field of deafness]
- 10 databases-927 hits all abstracts read and 152 selected representing the concepts and arguments associated with Informed Choice

# Study design

## Part 2: Consultation process involving parents and professionals

- To identify participants understanding of Informed Choice
- To generate specific examples of how this was/was not experienced
- To discuss barriers and facilitators of Informed Choice

# End products

- Literature review and data collection were used to develop guidance for Professionals and Parents on Informed Choice
- Identified underpinning issues of Informed Choice



# Underpinning issues

1. Knowledge and information
2. Availability
3. Access to availability
4. Does informed choice mean we offer the same to everyone?
5. Parents vary in their ability to make informed choices
6. Are all issues amenable to informed choice?
7. Personal preferences versus collective good / rights

## Underpinning Issues

- 8 Parents as experts
- 9 Informed choice is an active process not an end result
- 10 Attitudes and values
- 11 Equality of resourcing
- 12 Operational constraints
- 13 Resources strategy / philosophy
- 14 Training

# Knowledge and understanding

- Information alone does not provide Informed Choice
- Parents may be aware of the need to check aids daily but not own a stetoclip, not have spare batteries or a battery tester

# Availability

**Just because you have the information it doesn't mean it's available**

Even if something is available, there may be barriers to it actually being a possible or realistic choice from the family's point of view.

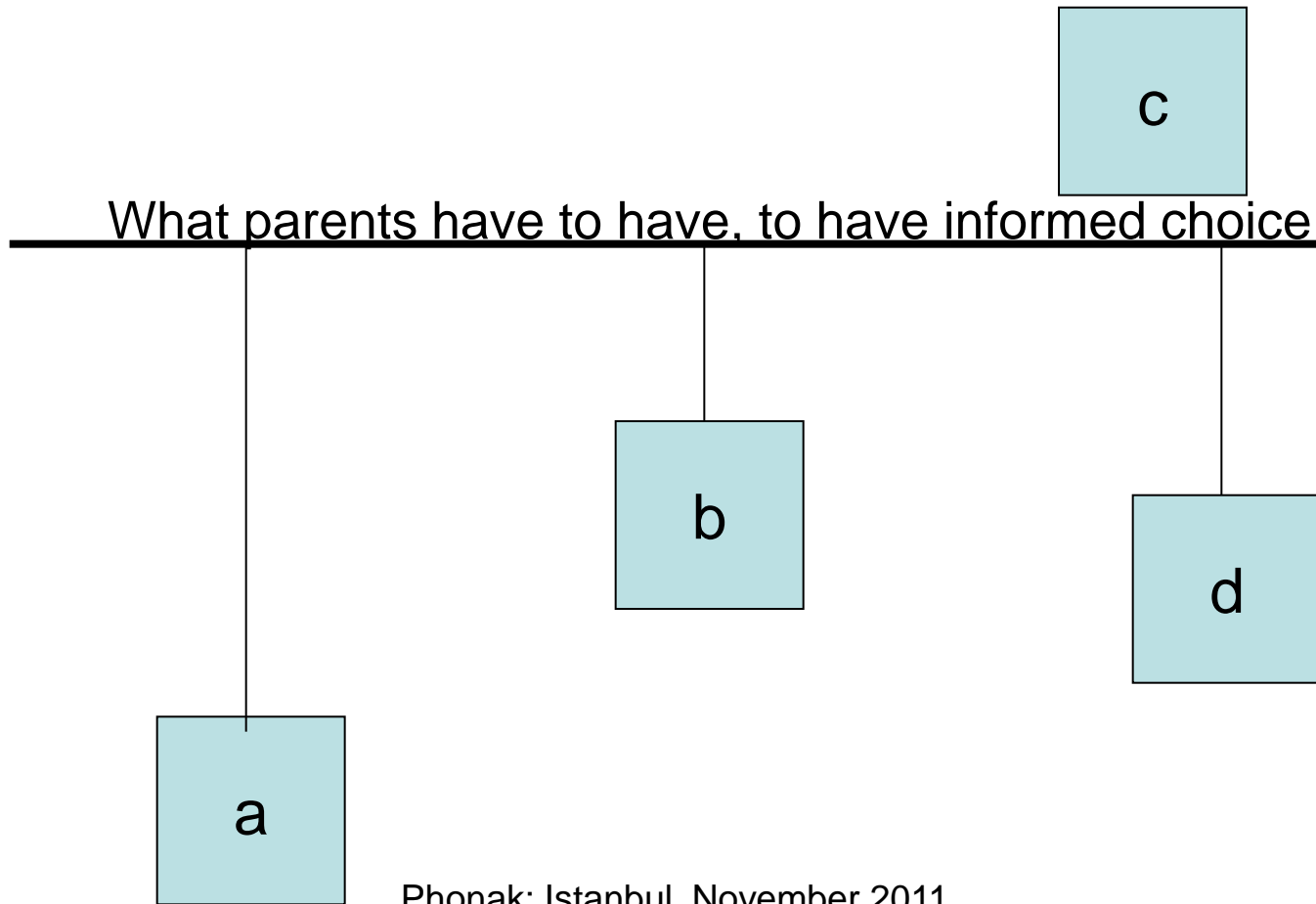
e.g. Barriers to using it may be distance, conflicting family demands, linguistic access.

# Access to availability

## **It's available but can I use it?**

- Parents may be able to make good use of an FM system at home but may not have the resources to access the equipment

# Does informed choice mean we offer the same to everyone?



# Are all issues open to Informed Choice

- Can a parent choose the time of appointment?
- Can they choose a paediatric fast track for earmoulds?
- Can they choose not to use the child's hearing aids?
- Can they choose coloured earmoulds?

# Families' definitions of informed choice

- Informed choice for me must take into account an individual family's priorities, culture, interests and values
- Are families aware of hearing aid programme and possibilities can they help to choose which are useful ?



# Families as experts

- Families may not feel experts in deafness and therefore look to professionals for information and to make decisions
- Families should be recognised as experts in their own child.
- Each family has its own ecology which should be respected even where this challenges basic beliefs of the support services.

# Attitudes and values

- Its not what you say it's the way that you say it
- Do Audiologists value the potential value of amplification for all deaf children including those with significant other disabilities?

# Equality of resourcing

- How resources can be organised to ensure individual families needs can be met / or a range of services can be offered to meet needs...
- This relates not only to physical resources but also human, cultural and social resources.

# Resources and strategy/philosophy

Attitudes and approach of service providers will actively enable some families to be at the centre of service provision

but may similarly constrain other families and keep them at the periphery.

# Parents specifically requested

- Privacy in being told about their child's deafness and the opportunity to have a family member or friend with them
- They wanted information about their child's hearing to be given in a sensitive way
- They wanted to have more time to understand their child's audiogram with the help of professionals

# Parents wanted...

- They wanted to know benefits and challenges of using and managing amplification with their child
- To know about Cochlear Implantation and Sign Language
- To have earmould impression taken at nursery or playgroup to avoid traipsing to hospital clinics

# Parents also wanted....

- Consistency so they met the same audiologist and had the same message
- An understanding of the roles and responsibilities of all those involved
- Professionals to be consistent in their approach to discussions on Auditory Neuropathy

# Informed Choice

- Informed Choice is not an endpoint but a process



# To find out more

- Young A. et al..Journal of Deaf Studies and Deaf Education, (2006) 11(3):322-336
- Young,A. et al..Electronic Journal of Research in Educational Psychology, (2005) Vol.3(3):253-273

With thanks to the research team

A Young, R. Hunt, G. Carr. A. Skipp, H.  
Tattersall, A.M. Hall