

Building strong parent/ professional partnerships in the era of early identification

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This presentation

- What characterises the 'era'?
- What do parents tell us?
- Wisdom – knowledge – information
- Communication in the context of partnership

Changed
discovery
mechanism

Earlier
engagement

New Era

Expectations
and outcomes

The 'world'
around

Changed
discovery
mechanism

- Routine 'medical' procedure
- Lessened role for parental suspicion and confirmation
- Very early in the relationship
- But not 'changed' from parents' perspective

Grief/shock/loss

- Not taken away or necessarily lessened
- Existed alongside strong sense of potential advantages of knowing early
 - Would have happened anyway, just earlier
 - More time to get used to it
 - Would not want to avoid it, because the advantages are so great for the child
 - Avoids guilt
 - Child used to hearing aids as 'normal'

But...

- ‘Grief’ responses complex
 - Synchronicity of the positive with the feelings of loss/sadness
 - Relationships between grief and taking action (helpful modifier, or avoider, or??)
- Does grief come later? [when the ‘solution focus’ changes with some developmental challenges?]

Earlier
engagement

- Challenges of working with younger children
- Engagement at earlier point in time
- Far less 'before' and 'after'
- Longer involvement

Time and action

- Catching trains...
- Perceptions of early identification
- Creating less time, a more urgent need for action, pressure to get going, frustration when others did not
- Creating more time, no need to rush, discovery enabled reflection, less worry, did not want to feel pressured

Expectations and outcomes

- 'normal' development
- No longer rescuing/
making up for lost
time
- High expectations
- Whose outcomes?

Understanding what it is to *be* deaf

- ‘Screen’ – illness narratives, ‘catching it early’, ‘cancer’
- ‘Normal’ – hearing, speaking, developmental milestones, mainstream education (same goal same pathway)
- Sign language – unnecessary, fall back, temporary. (viable choice in own right?)

'Being' deaf (Young & Temple, 2013)

- Diagnosis followed by habilitation?
- Recognition followed by consequences?
- A visual variety of the human race? (Bahan, 2011)
- A disability?
- All of the above?

- What works for deaf children with particular characteristics?

AND/BUT

- What works for which families in which contexts

- What is a successful outcome for the child?

AND/BUT

- How would the parent define success for their child?

The world around

- Advances in new hearing technologies
- Recognition and rights associated with signed languages
- Promotion of equality and respect for diversity
- ICT revolution

WHAT DO PARENTS TELL US?



Undergoing change Young, 2002.

- Family realities will undergo change as a result of the whole experience that comes with having a d/hh child.
- Not just new knowledge/information
- New ‘sphere of relevance’ (Schutz)
- Living with ‘imposed set of relevancies’ (Voysey)

You don't know what you don't know

- But is it like putting together a conventional jigsaw?
- Or is it like 'spilt milk'?



But some things stay the same...

- Families existed before the d/hh child
- Parents as individuals existed before the d/hh child
- Attitudes, values, previous experiences, culture, personality, social situation...
- The resource for making sense of the experience; coping strategies; basis for choice; shaping priorities; envisioning the future

- As individuals and as family systems we vary enormously in our capacity to admit change and to cope with change
- Having a d/hh child forces a spotlight on this capacity

"Having deaf children has emphasised my own difficulties with life (I am not good at asking questions, accessing information/ demanding things) and my children need me to be."

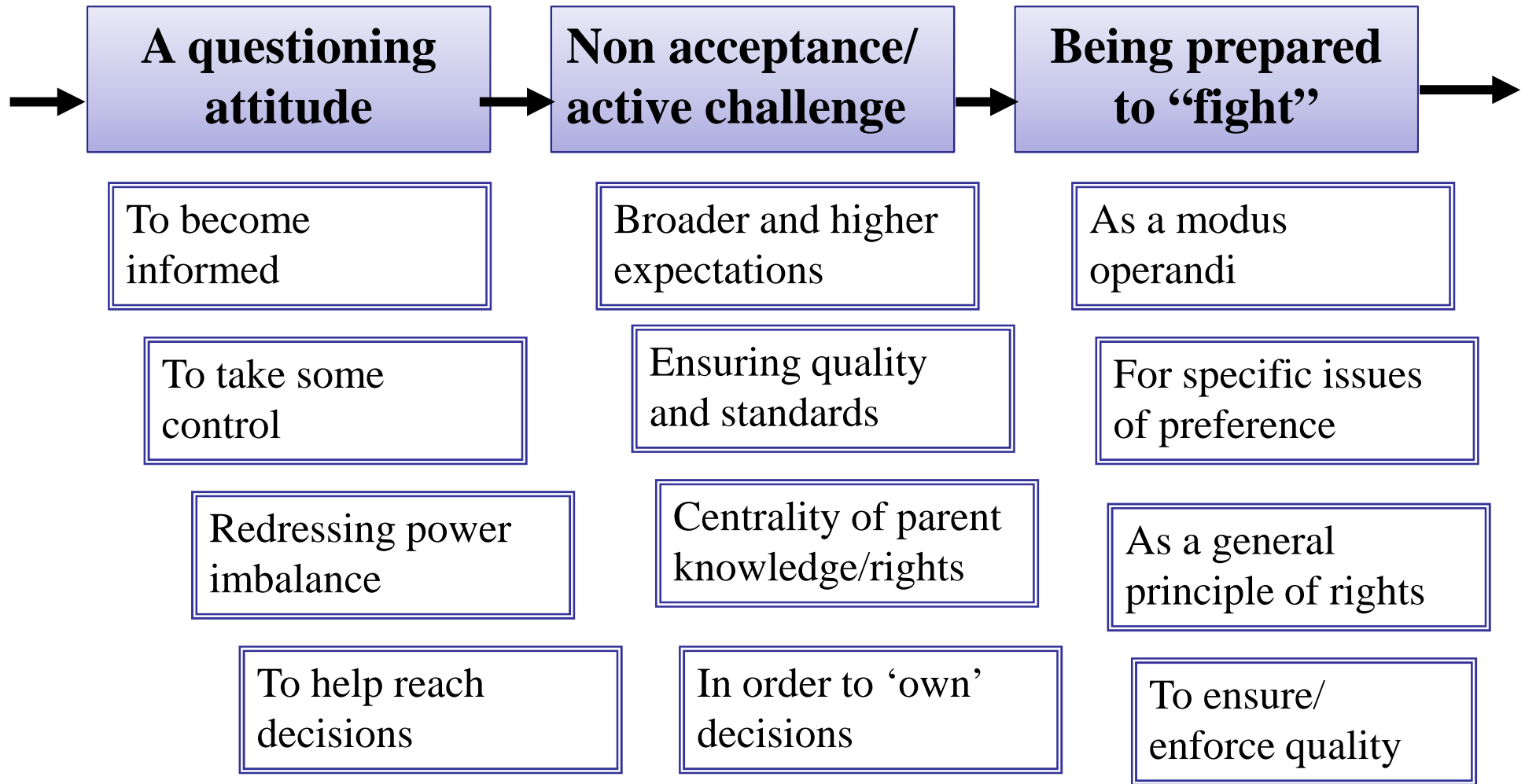
[Parent evidence in Young and Greally, 2003]

What do parents say they need to be????

- " If you were talking to new parents of deaf children, what are most important things you would like to share with them from your own experiences?"
- 900 parents wrote comments

[Young and Grealley, 2003]

The Assertiveness Continuum



“Trust your instincts”

INSTINCT

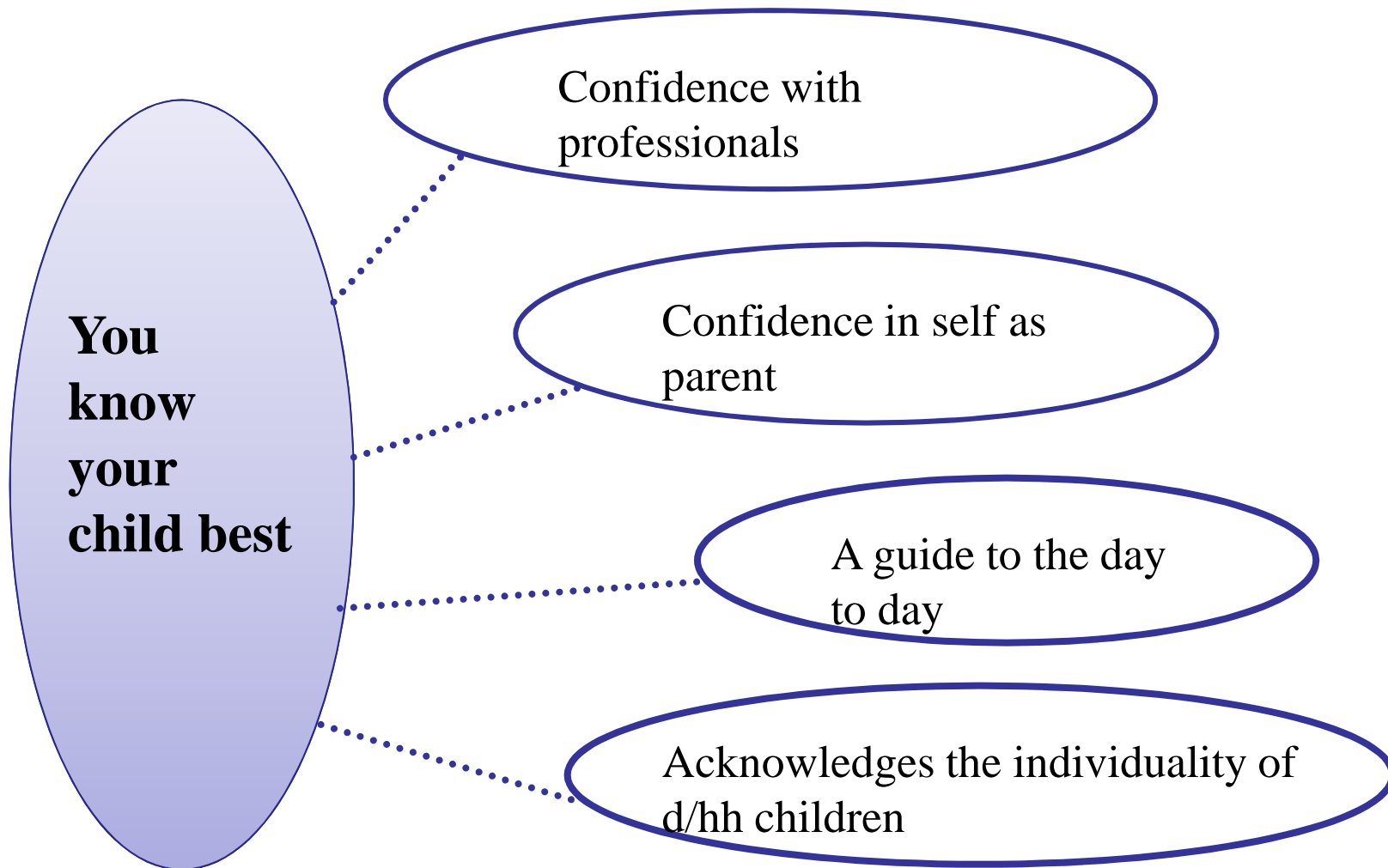
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graph LR; A((INSTINCT)) -.- B(As an aid to decision making); A -.- C(As a means of being comfortable with choices made); A -.- D(An appeal to self belief);
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As an aid to
decision making

As a means of being
comfortable with choices made

An appeal to self belief

“You know your child best”



Being and staying positive

**Adopting
and
maintaining
a positive
approach**

It should be the starting point

Enables attitudes and behaviours that work for parents and children

It's not wishful thinking - there's good reason to be positive

Because time is a 'healer'

Because time is a 'revealer'

This is the scaffolding...

Parents tell other 'new' parents that it is most helpful to be:

- Assertive
- Instinctual
- Confident in their own knowledge
- And always positive

Family realities

- But not everyone can be, not everyone starts off that way
- Capacities to admit change and to develop will vary enormously
- We need to be focussing on the promotion of the scaffolding
- Not everyone is a Wendy the Sheep...



WISDOM, KNOWLEDGE AND INFORMATION



EHDI brought information consequences

- Bias in information
- Strongly held beliefs
- ‘Post code lottery’
- Pressure to make choices
- Decisions make it harder to change your mind
- Where is the evidence?
- The ‘how’ of information

Balanced information is not enough

- “There’s a raging debate out there” – information is contextual and has meaning beyond itself
- Completeness/comprehensiveness is an issue
 - “We support informed choice, we are one of the choices”

Unbiased information – really?

- All information is biased because all communication is biased
 - Can't detach the message from the means
 - Can't uncouple understanding from the person
- But there is a difference between information that sets out to persuade and communication that sets out to inform

Information does not necessarily bring understanding

- Information has to become real
- Knowledge can come from experience
- We have preferred information styles
- “just say no or just say know”

Choice does not depend on information

- Choice is influenced by many other factors
- Choosing style
- Telegraphed messages
- Personality and experience

Information does not bring access

- Is it available and if it is not should I still know about it?
- Unrelated issues mediate access and choice
- Not a consumer model or is it a consumer model?

Time

- Information, knowledge and understanding grow and change with time
- Choice is a process to be revisited
- It is active and multiple not passive and one-off

Implications for partnership?

- Create the conditions in which making decisions and revisiting choices are possible
- Attend to the person, not the choice
- Equitable resourcing for equality of provision
- Provide experience not just information
- Promote knowledge and wisdom, not information



COMMUNICATION



ANSD

- Around 10% of early identified ‘deaf’ babies
- Characteristically:
 - “the presence of normal evoked otoacoustic emissions and/or cochlear microphonic (implying relatively normal outer hair cell function in the cochlea), with an absent or severely abnormal auditory brainstem response”

Heterogeneous

- Hearing thresholds from within normal range to profound loss
- Speech perception typically poorer than would be predicted by behavioural audiogram. Ranges from little difficulty to severe problems in quiet listening conditions; or only difficulties in noisy conditions
- Fluctuations can happen on a daily, weekly or longer basis
- ABR result might stay the same or recover partially or fully

Contextual considerations

- Largely special care baby population
- Role of sign language not really evidenced or explored
- Conflicting advice on the utility or harm or uncertainty about hearing aid benefit
- Debate over the timing and appropriateness of cochlear implantation
- Relatively rare condition from a hearing community point or quite frequent from a Deaf community point of view ?

Research aims

- How do parents construct and frame their experiences of having a child with Auditory Neuropathy Spectrum Disorder?
- What are their experiences of diagnosis and early intervention, both in terms of the care pathway and the personal impact in relation to their particular family?
- What advice or suggestions would they give for the improvement of this process for others?

Uus, Young & Day, 2012 a, b

Sample (all hearing)

- 21 families/interviews (involving 25 parents)
- Age of baby at interview (range: 4 months to 6 years. Average = 35 months)
- 7 had no persisting medical conditions
- 5 children had a CI, 1 was referred, 3 were considering
- 11 used some BSL, 2 used 'baby sign'
- 5 used no amplification

- Qualitative interview study
- Thematic analysis
- Only looking at the segments of data to do with explaining, understanding and parent/professional communication

Describing and making sense of ANSD

- Very big stressor – explaining ANSD to others – especially friends and family
- Contradictory evidence of others' experience of their child
- Doubts that the parents knew what they were doing
- Constantly having to re-visit the uncertainty of prognosis and implications
- Evolving a “public account”

Describing and making sense

- Having to **insist** there was a problem whilst at the same time hoping that the problem would resolve itself
- *“Family will look at him and say oh he’s not deaf there’s nothing wrong with him... but then you get.. to the point where I don’t want to go around being negative ‘cos obviously I don’t want him to be deaf “*

Describing and making sense

- Being offered language to explain was important
- Most appreciated analogies/ways of describing, were ones that helped parents to understand what their child's world experience was like
- Not just descriptions which explained what ANSD is

- *“a bit like when you’re playing a song and all the...all the parts of the song are all jumbled up and...to me that was the clearest...way of explaining...something like that”*
- *“imagine a speaker, everybody’s had a broken speaker at some stage where the wire doesn’t quite connect properly... and that’s the one I use and everyone says I get what you mean”*
- *“dyslexia of hearing”*
- *“when he’s having a hearing day...”*

Comparing with 'typical' deafness

- Big issue – professionals often used explanations that compared ANSD to 'typical' deafness
- But the comparison is not helpful if you don't have an understanding of the other context/condition
- Oranges and grapefruits

Uncertainty of prognosis

- Uncertainty of prognosis was a very big factor for all families
- Hard to make sense of why it is possible to be certain of a diagnosis AND professionals:
 - Not know what this implies for particular children
 - Not know a great deal about the condition themselves
 - Not offer clear guidance on how to ‘manage’ the condition

Uncertainty and professional discourse

- Parents surprised by the degree of uncertainty commonly expressed by professionals.
- They came across professionals who said:
 - ANSD is a ‘new’ or ‘vague’ diagnosis
 - That they didn’t know much about ANSD
 - That they were unsure how to manage ANSD
 - That they had never worked with an ANSD child
 - That knowledge was changing all the time
- Being honest about uncertainty was not necessarily helpful on its own.

- *“well it makes you feel a bit sort of erm...pointless really ‘cos you just think well I mustn’t matter because nobody seems to know anything about this...and it makes you feel like...it doesn’t matter about..that particular condition ‘cos nobody seems very concerned about it...’cos erm it doesn’t seem to be a big issue..for anybody or not many people “*

Parents preferred professionals who:

- Were honest about their lack of experience/ knowledge AND who committed to find out information and share it with the parents together
- Or who were knowledgeable AND able to discuss uncertainty and options within that uncertainty
- Were focussed on their individual child (not just the condition)

Parents preferred professionals who:

- Did not make their child feel like a guinea pig
- Were not overly enthusiastic because this was the first ANSD child they had
- Who facilitated parents choice of who they trusted/were they wanted to go for support

Parents preferred professionals who:

- Were not anxious/scared of being involved with a child with ANSD
- Who did not take a 'hands off' approach to decision making
- Who were genuinely interested in children with ANSD

Parent to Parent Support

- Hard to use parent support groups/ interventions with other parents
- Commonly experienced as stressful
- Different concerns/pathways
- Not adjusting to the same thing:
- *“It’s nothing to come to terms with ‘cos you don’t know what you are coming to terms with”*

Support

- Didn't feel legitimate, a 'fraud', 'gate-crashing';
- Didn't belong there – but if not there, then where?
- What is my child's identity?
- No other family stories available

- *“she was like bona fide deaf...you know..erm..she was allowed to say her daughter was deaf and I wasn’t.. didn’t feel that I was allowed to say my child was deaf erm.. because he could... hear....(laughs)”*
- *“oh no I sound like I’ve got Munchhausen syndrome now (laughs) because you’re trying to accept and you sort of...get quite proud I mean deaf’s you know being deaf they have a big culture and you sort of think oh well ok my son’s deaf and he’s going to belong to this this and this and then you think you can’t then take it away from him...by saying actually no he’s not so...that was difficult”*

What can we learn

- Knowing AND telling are important
- Cannot assume shared knowledge in communicating
- Honesty about uncertainty is not enough but uncertainty is very important
- Cannot assume common ground in parent to parent support

Some conclusions

- It is important for professionals to re-examine their knowledge and wisdom of pre-EHDI days but some will still hold true.
- Parents teach us the importance of being assertive, trusting your instinct, knowing your child 'best' and remaining always positive
- Information is not enough
- Helpful communication means paying close attention to the context(s) in which it occurs and from within which meanings will be defined