

Parents' views of the impact of early diagnosis on child development

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Today's talk

- Sharing data from interviews with 45 hearing parents of early identified deaf children
- Taken from the national evaluation of phase 1 of NHSP
- – A rare early window into the impact of early identification in the context of the family

Today's talk

- **Data segment:**
 - How do parents talk about knowing 'early' and its effects?
 - How do parents talk about language and communication?
- **Why should we be interested in this?**

'Old' issues do not of themselves change

- How (hearing) families make sense of what has happened
- How they form expectations and understanding
- How they explore and seek knowledge
- How they make decisions and why
- How they define, seek and use support
- BUT...

But...

- The conditions in which parents encounter deafness have changed
- And we know very little about the effects of those changed conditions on these 'old' concerns

‘Changed conditions’

- (i) Changed discovery mechanism –driven by routine medical procedure, not personal discovery
- (ii) Highly compressed timescale
- (iii) Identification happens at a much earlier stage in relationship formation
- (iv) Intervention happens quickly as part of the same process (and for longer)

Claims for effects

- With greater or lesser degrees of research evidence:
 - Grief is resolved quicker
 - Less family stress
 - Better bonding
 - Positive effects on quality of home developmental environment

NHSP Evaluation

- England
- DH funded (Phase 1 sites only)
- Six streams of work
- True case study – parents whose children were early identified as deaf

Research aims:

- To evaluate the impact of the screening process and its consequences for intervention from the perspective of parents
- To explore key personal, family and socio-demographic influences on that experience
- To enable parents to contribute to the identification and definition of what is good practice in newborn hearing screening.

A qualitative interview approach

- Elaborated narrative (not question and answer) based on 'story telling' model
- Loosely guided
- Areas to be covered: the discovery sequence; the screening process, the intervention experience, opinions for others

Why a qualitative interview study?

- More than asking service users their opinion....
- Method allows parents to make choices about what to include, how to express what is of importance
- Parents' set the definition and criteria for what counts as 'meaningful'
- Supported through how the data are analysed
- Allows for challenge to expert categories of interest

Sample

- Self selecting
- True case as defined by national protocol
- Excluded children with AN
- 27 interviews = 45 parents/caregivers
- 6 babies from NICU population
- 2 families with other deaf children
- 22% of infants had disabilities/illnesses at birth
- 10/27 families deaf child = first child

Sample cont.

- 5 families from minority ethnic background
- 3 families languages other than English used in the interviews [2 more used other languages at home]
- All parents/carers 'hearing' (but 2 with mild unilateral losses)
- **Age of child when interviews were conducted was between 8 and 51 weeks, average 25 weeks.**

- What parents thought about knowing so early that their child was deaf
 - [a specific question in the interview]
- How they talked about issues of developmental expectations and early language
 - [spontaneous and unguided discussion]

Overview of parents' attitudes to knowing early

- Very positive because picked up early
- Initial positive had been modified by perceived lack of action
- Positive but wondering if too early

Very Positive Group

- The overwhelming majority (23 out of 27 interviews)

“it can only be a good thing to find this out” [6,7,M]

- No obvious trend towards those parents we interviewed with younger children.
- No obvious trend depending on level of hearing loss or whether the child had disabilities.

Why positive?

- Reassuring:
 - knowing is helpful
 - things can be done
 - or parents can do things differently from early on

“Detect it then like getting in front with it”

[26,11,P]

Why positive?

Effects on grief/shock/loss

- None thought it took it away
- None thought it lessened it
- More like a trade off:
 - 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

“Clearly you go through the process of we well, almost grieving which is a gradual process, but that would happen at one point any way, when the child is two or three so there’s no way you could avoid it...things would be vastly different if he was three and it was happening now, but if it’s happening at such an early age, you’re not worrying too much about it. I’m sure things will turn out ok” [11,10,P]

- [24,4,P mother]: *“Breaking the news is going to be shitty at any stage isn’t really? It is a particularly vulnerable time for parents ‘cos of the tiredness and things like that, but that’s just one of those things...”*
- [24,4,P father]: *...If you’re diagnosed with cancer, you don’t go ‘oh it’s a shame it happened this week ‘cos it’s ruined this week’, you go ‘you need to know at some point, the sooner the better’”.*

Why positive?

- Avoids guilt
- Child can get used to hearing aids as normal
- Developmental advantages
 - Avoids missed opportunities
 - Can sort the problem out
 - Can give best start possible
 - Allows for positive expectations (hopeful)

Initial positive but then...

- Positive feelings eclipsed by perceived lack of action [5 interviews]
 - Families on a ‘timetable’ and they were behind
 - Services not supplied quickly enough or good enough
 - Child felt to be “losing ground”

- *“the whole thing about this newborn hearing is that you tackle it at an early stage and basically get the nerve ending, the auditory nerve to sort of work at an early stage and we haven’t achieved that yet because we’ve not obtained...that level in the digital ear we should have...at the moment he is not benefiting at all, so we’re still four months behind, we’re still four months behind, we haven’t benefited from this newborn hearing” [27,4,P]*

Positive why?

- Positive but could it have been done a bit later?
 - 3 families
 - 2 had unhappiness associated with services and processes
 - 1 – a child with moderate loss, still unclear whether will have a hearing aid

“I suppose if the child has got a hearing loss then the sooner you know about it and the sooner you can do something to help the better. But from our point of view it has been a nightmare really. I wish I hadn’t been told I wish I was just finding out now because I would have had nearly 8 months to just enjoy him, It has actually been 8 horrible months on and off. It hasn’t affected me bonding with him or anything but I have not enjoyed him, like I did [my other child. I wish I had never been told. I wish I was just finding out now...” [19,8,M]

Main points so far...

- For majority, early is good and positive
- Does not solve problems
- In some ways creates problems
- But advantages outweigh the difficulties

- New constructs of ‘catching it early’ and ‘needing to act quickly’ can create pressure and measures of losing ground

- Frustrations with services/processes affect appraisals of whether it’s good to know early

How did parents talk about developmental advantage?

- Expectations of normal development [10 families; 5M,2S,3P]
 - Reach normal milestones on time, or be very close to them
 - Manage successfully in mainstream school on a par with hearing peers
- Very strongly expressed, source of reassurance and confidence
- Firmly linked in parents minds with the connection between:
 - early ID – early hearing aids – spoken language development

“ As [ToD] says, the children who are picked up when they are 6 or 7 months old, you have to teach them to listen, whereas he’s actually just come along with it, he knows how to listen...so it’s just like all positive, and she said like because he is so young being picked up we expect him to be even more sort of normal...he’s not missed out on 10 months of noise, we haven’t got to make up for that.” (9,5,S)

How did parents talk about developmental advantage?

- Avoidance of previously expected problems with deaf children [8 families]
- Strongly predicated on: early ID plus hearing aids
- Largely retold ‘horror’ stories from professionals that had been used comparatively.

“We were told if it wasn’t diagnosed then perhaps she could go off in her own little world and maybe like baby babble or talk whatever you want to call it, would eventually fade away. So by [my daughter] having her hearing aid so early it has given her like that step up, if you like, so she has had that advantage of having them earlier so...she would be able to achieve and go in the right path roughly about the same age of a normal child anyway.” [22,14,S]

How did parents talk about developmental advantage?

- Possibilities of enhanced developmental environments early on [two interviews]
 - Modifying speech
 - Playing games differently
 - More sensitised to child's fears and anxieties
- One family in sibi provision experimenting with both languages
- One family already with deaf child (been through sibi)

How did parents talk about developmental advantage?

- Those who did not comment [eight families]
 - child with a lot of developmental needs – greater priority than deafness
 - deafness just seen as big disadvantage full stop
 - 2 feeling negative about the process
 - 3 who were generally positive but not detailed
 - one who made no relevant comment

How did parents talk about language early on?

- Overwhelmingly parents talked about spoken language development facilitated by early identification combined with hearing aids.
- As we've already reviewed, most did so in terms of matching normal developmental milestones.

How did parents talk about sign language early on?

- It's not appropriate: [eight interviews]
 - Child with motor difficulties
 - Early ID and hearing aids mean it's not relevant
 - Sign would mean the child had a problem, but the problem is being overcome
- It's a fall back [five interviews]
 - Useful to keep in reserve if speech does not develop/CI does not work
 - Back up when child is not using hearing aids
 - Useful early on but with limited shelf life

How did parents talk about sign language early on?

- Speech is society's way of communicating [three interviews]
 - Will need to talk to be accepted
 - Why would you want your child not to use the majority language?
- It's about giving the child a choice [two interviews]
- It's not one or the other [2 interviewees]
- Undecided and still thinking [2 interviews]

How did parents talk about sign language early on?

- **It's not one or the other** [2 interviews]
 - In society people do sign and speak
 - The more the better
- **Undecided and still thinking** [2 interviews]
 - Still weighing up options/want more advice
 - Looking for 'objective evidence'

Discussion

- Of the moment narratives – but/and things change with experience
- ‘Grief’ responses complex
 - Synchronicity of the positive with the feelings of loss/sadness
 - Relationships between grief and taking action (helpful modifier or avoider or??)
 - Early interventionists need to be alive to these new layers

Discussion

- Time
 - Perceptions of more
 - Perceptions of less
 - Dangers of pressure and timetable
 - Early intervention being sensitive to the effects of ‘early’ and perceptions of time in having reasonable and helpful expectations

Discussion

- How parents construct their child's deafness and influences on that
- Metaphors of illness, cure, catching it early
 - Understandable
 - Dangerous?
 - An effect of early id and associated processes?
 - Early Interventionists being aware of the power of their discourse in influencing constructs

Discussion

- Being 'normal'/promise of more 'normal' development
 - Predominantly yard stick is hearing-speaking-normal
 - What is normal development for a deaf child?
 - May be same end point but differently achieved
- A new narrative of normalisation that is failing to promote understanding of diversity of experiences ?
- How does early intervention promote the 'comfort' of non-deficit approaches as well as acknowledging the diversity of deaf experience?

Reminders

- Vital to be non-judgemental about this data/parent experience
- Much will undergo change for parents
- But important to become sensitised to these new issues and to track them forward.

- Young, A.M., Tattersall, H. (2007). Universal Newborn Hearing Screening and early identification of deafness: parents' responses to knowing early and their expectations of child communication development. Journal of Deaf Studies and Deaf Education, 12 (2), 209 - 220

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