

**"Not everything that counts can be counted and not everything that can be counted counts" ....**

**Perceptions of quality in Newborn Hearing Screening Programmes.**

**Gwen Carr**

**7<sup>th</sup> Australasian Newborn Hearing Screening Conference,  
17 – 18<sup>th</sup> May 2013, Auckland New Zealand**



**nurture.... grow.... enrich**



**We've come a long way .....**

**Since 1946!).....**





## We've come a long way





## nurture.... grow.... enrich

**Difficult and challenging times?**

“The new enlightenment”

Sir Paul Nurse, President

The Royal Society

28/02/12





## **Sir Paul Nurse, 28.02.12**

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“...it is often in mixed up and chaotic circumstances that the most creative work is done. Remember Harry Lime in the Third Man who said, “In Italy for 30 years under the Borgias they had warfare, terror, murder and bloodshed, but they produced Michelangelo, Leonardo Da Vinci and the Renaissance. In Switzerland they had brotherly love – they had 500 years of democracy and peace, and what did that produce? . . .



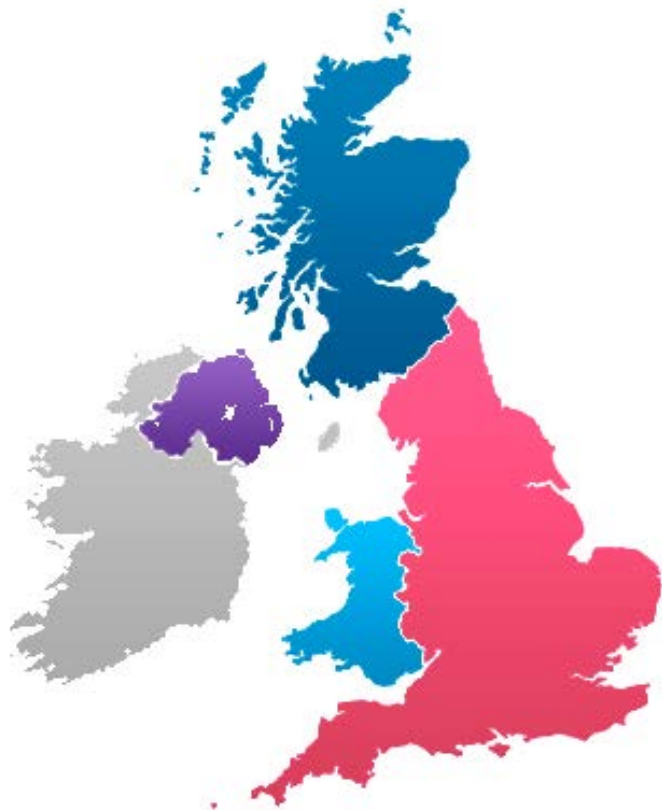
.....the cuckoo clock.”







## Some background stats



Programme fully implemented since 2006

5 millionth baby screened (May 2012) - now over 5.5 million

England population 53.1m; births (2011) 675,000

115 local screening programmes

Local screening programme incorporates the whole care pathway – screen to early intervention

33 nationally defined quality standards relating to activity across the care pathway

QA Programme started in 2006 – 4 cycles





## **UK Support Context**

- Hearing aids readily available and free at point of delivery
- Cochlear implant centres
- Health / Education / Social Care model of provision
- ToD (usually) as main deliverer of support in the home
- Provision (at least theoretically) of a range of communication options



## **The England NHSP....from the NHS to PHE**

- From 1<sup>st</sup> April 2013: Public Health England – a new government agency, “established to protect and improve the nation’s health and wellbeing and to reduce inequalities”
- All Screening Programmes sit within one of 8 directorates: “Health and Wellbeing”
- 8 non-cancer screening programmes re-organised into 3 groups (Adult AAA/DES; NHSP/NIPE/FASP; SCT/IDP/BS)
- Expanded cross-cutting functions and smaller core programme teams
- Opportunities and Challenges



## NHSP Vision

“Improving **outcomes** for every child through a **high quality screening** programme, **safe and effective assessments** and family centred **early intervention**”





## NHSP Strategic Aims

- To raise standards in service performance to achieve better outcomes in screening, assessment, diagnosis and habilitation.
- To ensure a robust evaluative culture of service provision locally, regionally and nationally.
- To promote and develop family friendly integrated services.
- To empower parents to make informed choices.
- To ensure an efficient and effective NHSP Programme Centre that delivers effective support for Local Programmes and delivers value for money.



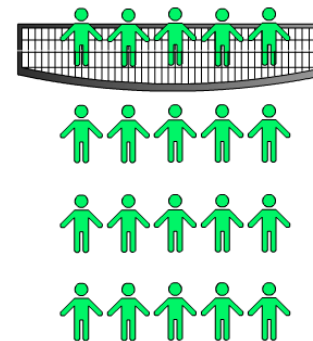
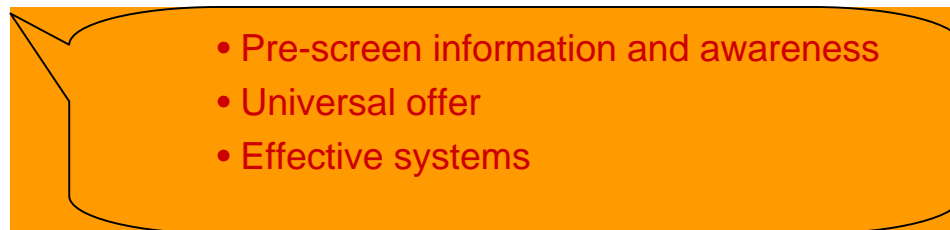
## NHSP Strategic Aims

- To ensure equality of access for all children and families thereby fulfilling the requirements of the programme to reduce health inequalities
- To work within PHE and with the NHS and Government framework to deliver an integrated approach to screening and follow-on services.
- To be recognised as a quality programme and to influence the development and delivery of high quality screening services, utilising the latest research, technology, best practice guidance and benchmarking.

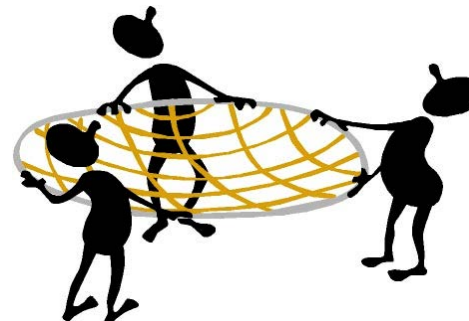
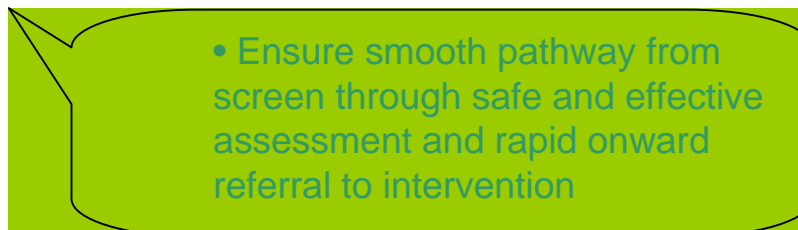


## A clear system and care pathways

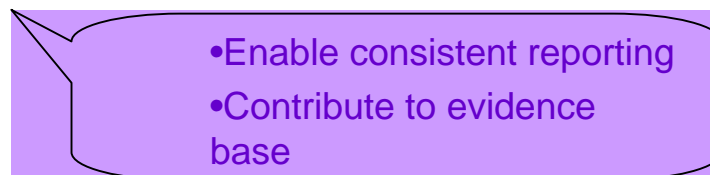
- Manage population through the process



- Provide failsafe mechanisms



- Monitor, evaluate & improve



# NHS Newborn Hearing Screening Programme

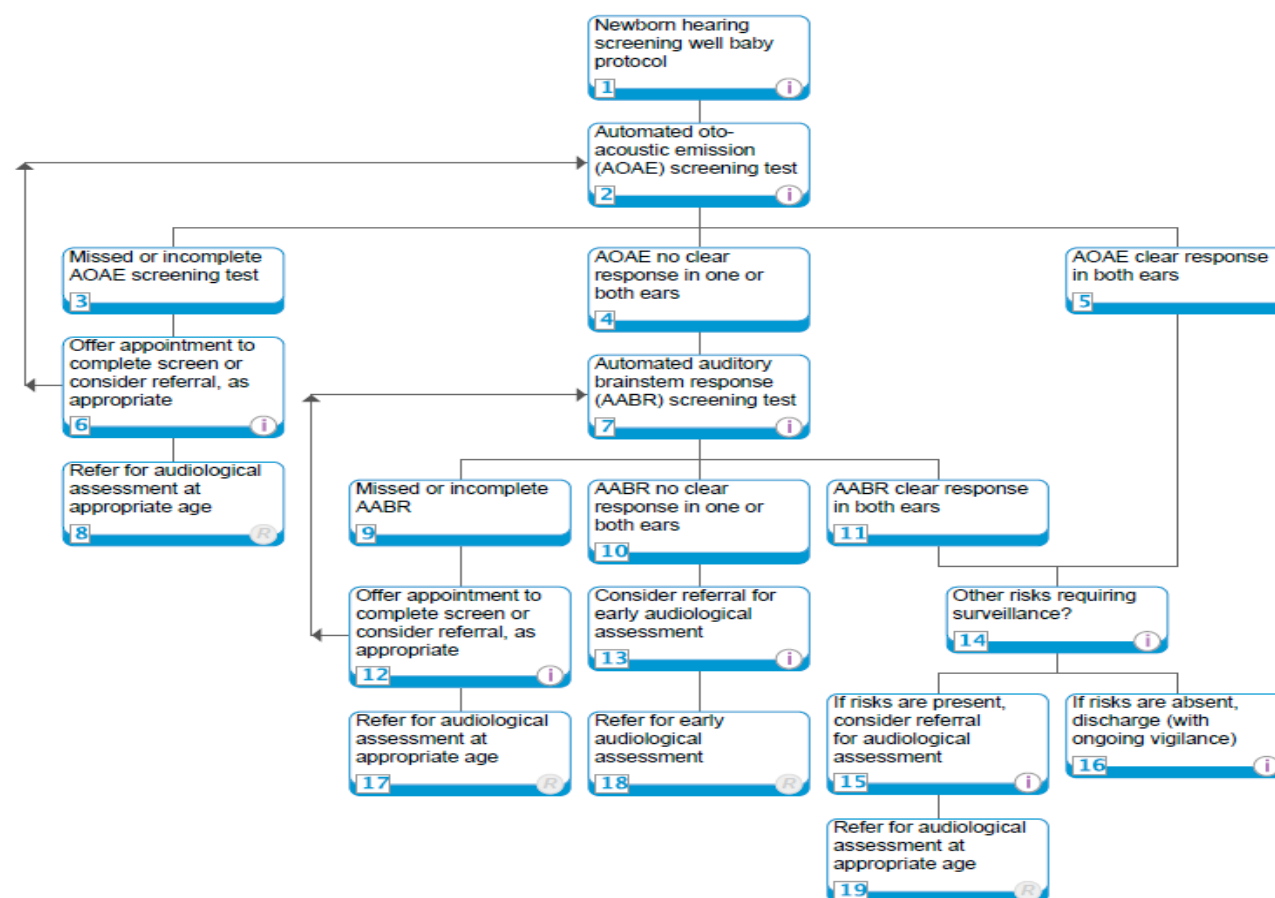


## Newborn hearing screening - well baby protocol

Paediatrics > Screening > Newborn hearing screening

map of medicine<sup>®</sup>  
Institute for Innovation  
and Improvement **NHS**

Information  
 Primary care  
 Secondary care





# NHS Newborn Hearing Screening Programme

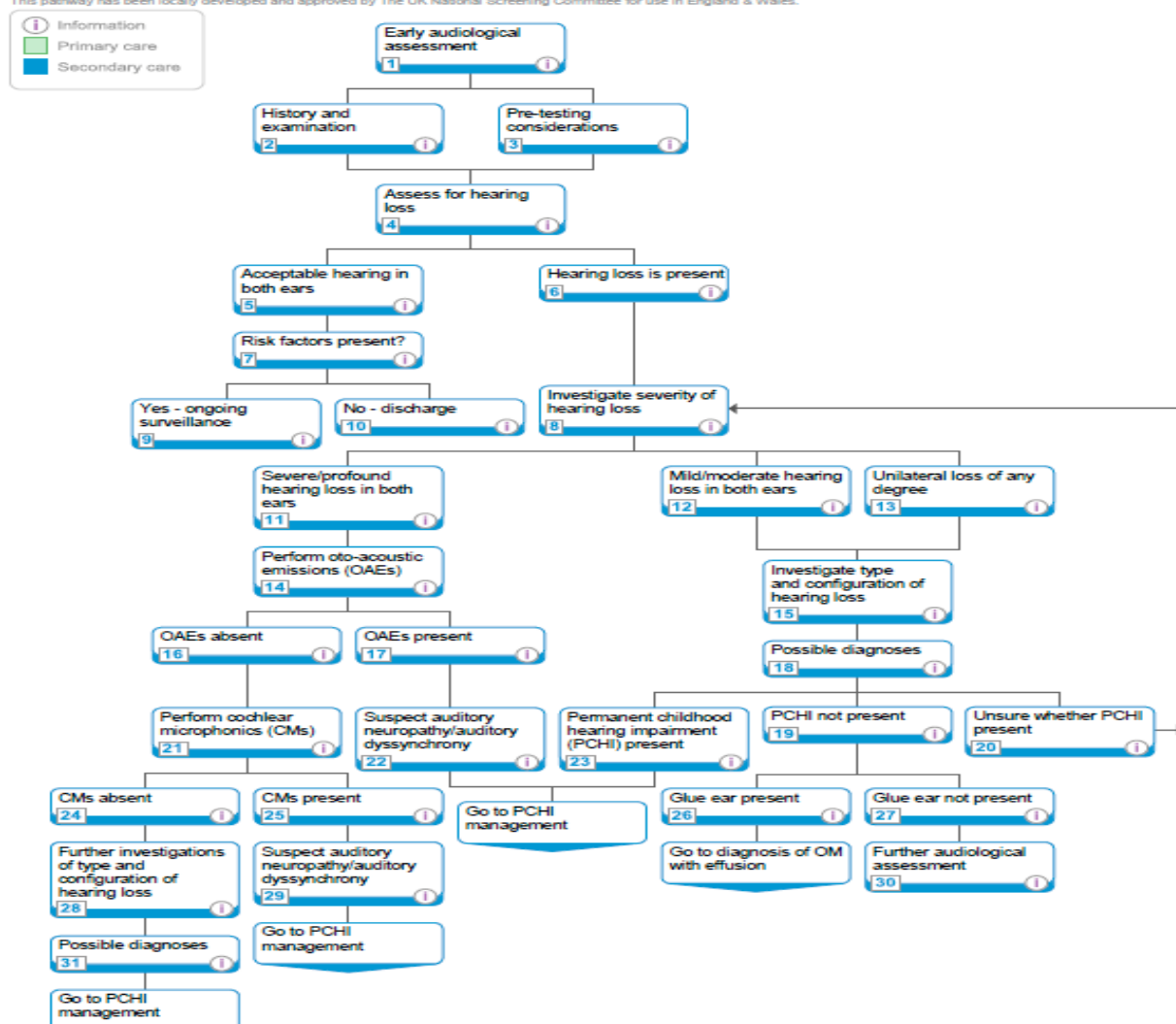


## Early audiological assessment



[http://healthguides.mapofmedicine.com/choices/map/early\\_audiological\\_assessment1.html](http://healthguides.mapofmedicine.com/choices/map/early_audiological_assessment1.html)

This pathway has been locally developed and approved by The UK National Screening Committee for use in England & Wales.





# Quality in Newborn Hearing Screening Programmes



**What is Quality?**



## Definitions of quality

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- “Nature, character, attribute, grade of goodness, excellence in skill and accomplishment”
- “The character of a proposition as affirmative or negative”
- Neutral quality markers
- Subjective markers - Perceptions of quality
- Outputs and outcomes



## Outputs and outcomes

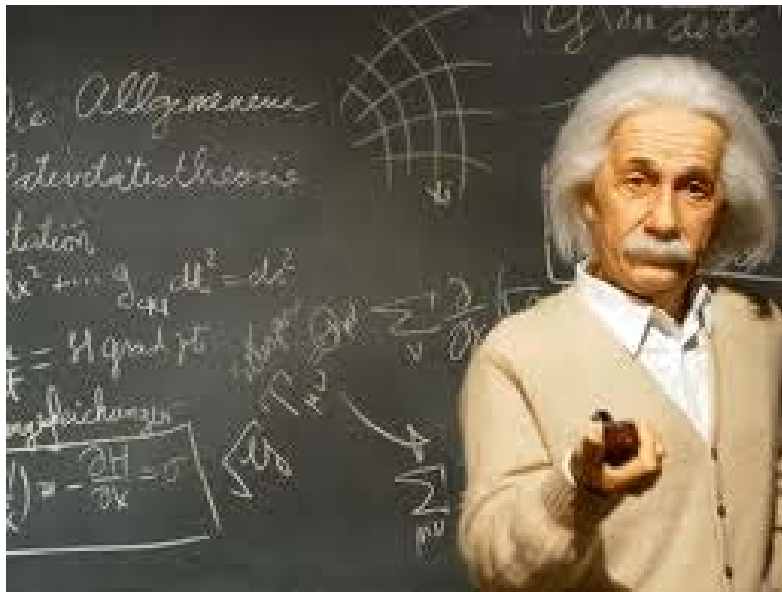
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- An output is the product or service that derives from a process (e.g. steps in a care pathway or a changed pattern of service delivery in response to early identification)
- An outcome is what is achieved (e.g. the developmental progress of a deaf child; the level of parental confidence)



## Outputs and outcomes

- In the delivery of a programme or service and in its monitoring and evaluation.....
- Outputs can too easily get regarded as outcomes
  - E.g. revising the model of early intervention to include a standard that says a family / child receives an assessment or input from any particular professional whether audiological, medical, social or educational is not an outcome.
- Keeping the distinction between outputs and outcomes is really important in planning and service development and in measuring quality.



"Not everything that counts can be counted and not everything that can be counted counts"



## What does our routine data (eSP) tell us?

- That for babies born upto Dec 2012:
- 5,724,506 baby records are on the system
- 5,631,502 screens have been offered (98.4% of births)
- 16,709,420 screening tests have been carried out
- 2.54% of babies are referred for audiological assessment
- 10,523 babies have been identified through the Programme (6675 bilateral; 3848 unilateral)
- Every week on average (Jan – Dec '12): 13,290 babies screened, 338 referred and 27 identified with PCHI





## What does our routine data (eSP) tell us?

- A baby's journey through the process
- That screen refer to assessment for well babies had gone down from an average of 29 days in 2006 to 16 days by 2011
- That the average age of amplification provision for well babies had gone from just under 6 months in 2006 to just over 8 weeks in 2011
- How services perform against (some of )...the national Programme Standards
- How well failsafes operate and helps us to manage risk and reduce incidents.



## **What does the routine data not tell us?**

The skills and competencies of the practitioners

How the professionals work together to deliver the pathway in an integrated way

Child developmental outcomes

Family experience

Family outcomes





## **Quality Assurance – from 2006 (4 cycles)**

- Audit Data – both routine collection (eSP) and as part of QA process.
- Peer review – verification of self assessment ; systems and professional competency focused.
- Cycle 4 – case study review
- Dissemination of learning, locally regionally and nationally to inform policy and practice



## **Areas of Focus and Governance**

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- Governance Structures and Strategic Partnerships
- Commissioned Services Meet the Needs of Children/Families
- Quality Improvement Culture in Place
- Services delivered in a Family Friendly manner



## **Quality Standard Targets Relating to:**

- Service access and availability of interpreters.
- Information sharing about screen.
- Notification of birth to screen.
- Universal offer of screen.
- Screen commencement.
- Screen completion.
- Decline rates.



## **Quality Standard Targets Relating to:**

- Timely confirmation of hearing loss
- Data entry onto eSP system.
- Timely explanation of results, support mechanisms etc.
- Timely referral to medical care / assessment.
- Timely referral and response for follow-up services.
- Co-ordination of family support / key professional contact.
- Hearing aid fitting.



## Quality Standard Targets Relating to:

- Support for developing communication within a framework of Informed Choice
- Provision of 'family care' support.
- Identification and response for complex needs.
- Existence and functioning of 'Children's Hearing Services Working Group' (CHSWG).





## Quality Workshop: Como 2010

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- Parents, Clinicians, Early Interventionists, Service Strategists / Public Health
- Shared and agreed vision and goals
- Some variation in definitions of outcomes
- DIFFERENCES IN PRIORITIES IN DEFINING QUALITY



## Parental Assessment of Service Quality

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- Parent satisfaction surveys
- Does satisfaction with a service mean that the service is a high quality service?



## **Parental Assessment of Service Quality**

**‘Positive Support’: A UK study  
about outcomes for young deaf children  
and their families**

**<sup>1</sup>Bamford J, <sup>1</sup>Carr G, <sup>1</sup>Davis A, <sup>1</sup>Gascon-Ramos M,  
<sup>1</sup>Keeble T, <sup>1</sup>Lea R, <sup>1</sup>McCracken W, <sup>1</sup>Pattison E,  
<sup>1</sup>Pickles A, <sup>2</sup>Woll B, <sup>2</sup>Woolfe T, <sup>1</sup>Young A.**

**1: University of Manchester / 2: University College London**



## My Views on Services (MVOS)

- New parent report questionnaire (Young, Gascon-Ramos, Campbell and Bamford, 2009)

Four elements:

- (i) a description of the structure of professional services evaluated according to *timeliness and availability*;
- (ii) the content of intervention evaluated according to *quantity, relevance and satisfaction*;
- (iii) the process of the intervention evaluated according to *extent and importance*;
- (iii) the overall impact of the intervention.



## Which professionals work with you?

1. Have you, as a parent, had any direct contact with specialised services in the past 6 months regarding your deaf child?

☐ Yes

☐ No

Who have you  
and your child  
had contact with?

If yes, how many hours  
of support per week,  
month or year do you  
and/or your child get  
from professionals?

Please,  
tick if you  
were  
offered  
this  
service

Please  
tick if  
offered  
BUT  
refused it  
at the  
time

Please,  
tick if you  
would like  
to have  
contact  
with this  
service

Please,  
tick if  
you feel  
it is/was  
hard to  
get this  
service

	<input type="checkbox"/> Yes	<input type="checkbox"/> No		h	week	month	year				
Audiologist	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ENT consultant	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Audiological physician	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetic counsellor	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health visitor	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Educational audiologist	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Teacher of the deaf	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speech and language therapist	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support worker who is deaf	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deaf role model	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Signing support	<input type="checkbox"/>	<input type="checkbox"/>	h	week	month	year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## To what extent are professional services...

Not at all	To a very small extent	To a small extent	To a moderate extent	To a fairly great extent	To a great extent	To a very great extent
1	2	3	4	5	6	7

## To what extent are professional services...

How important is this for you now?

To what extent are professional services...	To what extent are professional services...							How important is this for you now?			
	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
1. Flexible in arranging meetings that take into account your family's availability.	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
2. Adapting to your needs (e.g. reconsidering what they had planned to do with you on a particular meeting to meet your needs).	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
3. Trusting you as the 'expert' on your child.	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
4. Providing enough time to talk (so you don't feel rushed)	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
5. Working together with you in designing and deciding the support you want for your child and family.	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important
6. Taking into account your family's culture and lifestyle when working out support plans.	1	2	3	4	5	6	7	Not Important	Somewhat Important	Important	Very Important



## Has the support made a difference?

Overall, how much have professional services made a difference for:

	Not at all			Very much	
Your child	1	2	3	4	5
Your family (partner, siblings...)	1	2	3	4	5
Yourself as a person	1	2	3	4	5

Has this difference been positive for:

Your child	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Your family (partner, siblings...)	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Your self as a person	<input type="checkbox"/> Yes	<input type="checkbox"/> No





## Satisfaction and Quality

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- Positive Support concurrent with NHSP QA Cycle 2
- Parents expressing high levels of satisfaction on the MVOS.....
- QA showing levels of service not meeting quality standards
- How to reconcile?!
- Would parents feel differently looking back in light of outcomes for their child and family?



## Areas of most dissatisfaction

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- Professional Communication and information sharing.....(gatekeeping, bias, not being given informed choice etc)
- Lack of cohesion and coherence in professional services co-ordination.



## Quality in... Information and Communication





## Seamless Services

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- Families say that a major positive factor in their experience with professionals is when professionals work in a truly multi-disciplinary way, often referred to as 'seamless services'
- What do we mean by seamless services?







## Anything but seamless. . .

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“the procedures and the channels of communication between all these agencies, whether it’s the paediatricians or the audiologists, social services, physiotherapists, speech and language therapists – the channel of communication between them all varies between very poor to non-existent, and people look at one specific area and don’t link the box up. . . You wouldn’t criticise any individuals it’s just the structures that link them together – that’s the key thing. They do not talk to each other, and the paper chain must be hundreds of miles long. I am sure there must be a simpler way of people talking to each other”

[Complex Needs, Complex Challenges, NDCS 2011]



## Improving Outcomes

- Early identification is not enough.
- All gains/advantages predicated on early identification PLUS quality early intervention
- One without the other is pointless and arguably unethical?
- But early identification has changed how we think about early intervention





## **Improving outcomes**

- It's not just early intervention but **QUALITY** early intervention that makes a difference.
- How do we define, develop and assess quality in early intervention?



## Improving Outcomes

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- Are early identified deaf children doing better?
- Yes, but.....
- Are we looking at desired outcomes that are too narrow?  
(Language, speech, vocabulary, quality of life indicators which relate primarily to audition, etc etc)
- Are we forgetting to look at children's learning? (Kritzer, US; Nunes et al, UK)
- Pragmatics (Yoshinaga-Itano, 2012)



## Improving outcomes

- Is early intervention being sufficiently informed by research and especially longitudinal studies?
- Are research study findings feeding through sufficiently to inform early intervention practice?
- New learning from LENA studies about the importance of quantity of conversational interactions
- Evidence that child outcomes are improved when families are 'engaged with' services (Calderon, Moeller, Yoshinaga-Itano )
- But what do we mean by that?



## And what about Family Outcomes?

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- A new look at patient outcomes within the NHS
- Mid Staffordshire public enquiry
- Francis report
- Children Young People and Family Forum report
- CYP and family; Government's system wide response
- Redefining quality and outcomes
- Parents of deaf Children ahead of the game



## What Parents Say They Want

- GPOD Position Statement (2009)

<http://www.gpodhh.org/>

- ANZPOD Quality Standards for Newborn Hearing Screening Services Supporting Families

[www.users.on.net/~phisa/Standards%20final%200709.pdf](http://www.users.on.net/~phisa/Standards%20final%200709.pdf)

QUALITY STANDARDS  
FOR NEWBORN HEARING SCREENING SERVICES  
Supporting families



Compiled by ANZPOD - a coalition of parents of deaf children  
across Australia  
July 2009



## International consensus on FCEI



**fcei**  
Family Centred Early  
Intervention

2<sup>nd</sup> INTERNATIONAL CONFERENCE ON  
FAMILY-CENTRED EARLY INTERVENTION FOR  
CHILDREN WHO ARE DEAF OR HARD OF HEARING

**FORGING GLOBAL  
COLLABORATION**

11<sup>th</sup> - 13<sup>th</sup> June 2014  
Bad Ischl, Austria  
[www.fcei.at](http://www.fcei.at)



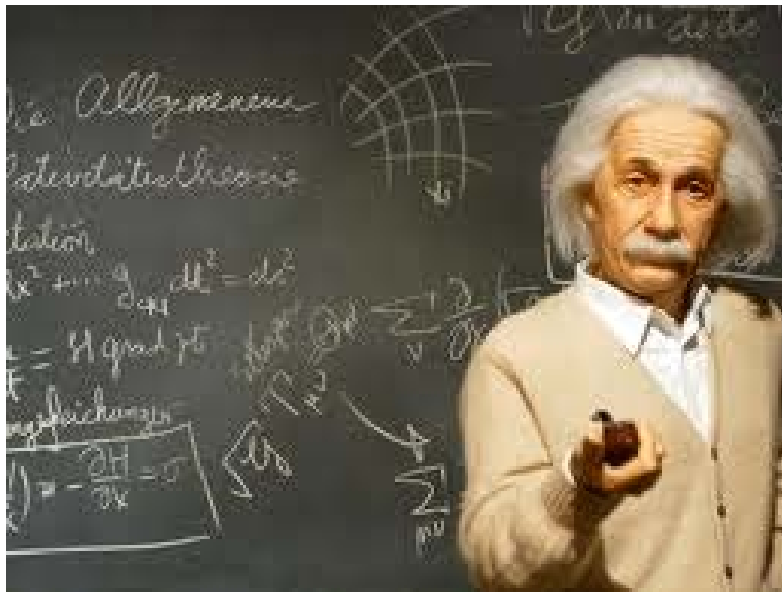
supported by



## **We've come a long way.....**

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- But it's not far enough!
- Maybe it's time for a rethink.....
- Definition of Outcomes?
- Models of service delivery?
- True partnerships at all levels with parents and families
- True partnership at all levels with 'Experts Through Experience' in both d/Deaf and cultural communities
- Celebrate our successes but never stop thinking it can get better still.....



"Not everything that counts can be counted and not everything that can be counted counts"

....we need to make what matters to families count!





## Thank You

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**Gwen Carr**

National Programmes Lead

NHS Newborn Hearing Screening,

Newborn & Infant Physical Examination

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