



Measuring Parent Engagement and Quality
Assurance – living FCEI Principle 10
Queensland Hearing Loss Family Support Service

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How it all began... just to recap!

- In 2006 the Healthy Hearing Program engaged a consultant who undertook focus groups and phone interviews with families of children with permanent hearing loss.
- Resulted in the report 'Face to face: the experiences, decisions, issues, and needs of parents who have a child who is Deaf or has a hearing loss'.
- Parents appreciated the opportunity to participate in the consultation process and to input into future services for children who are Deaf or hard of hearing.
- The stage was set, and the QHLFSS came into being.

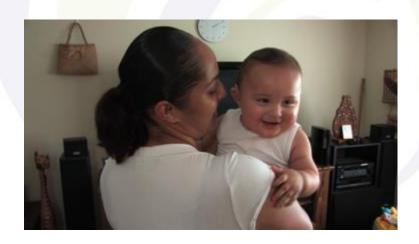


Where are we?



3 Family Centred Streams of Service Delivery

- 1. Direct services to families
- 2. Community development and capacity building
- 3. Research and development activities



Direct Services to Families

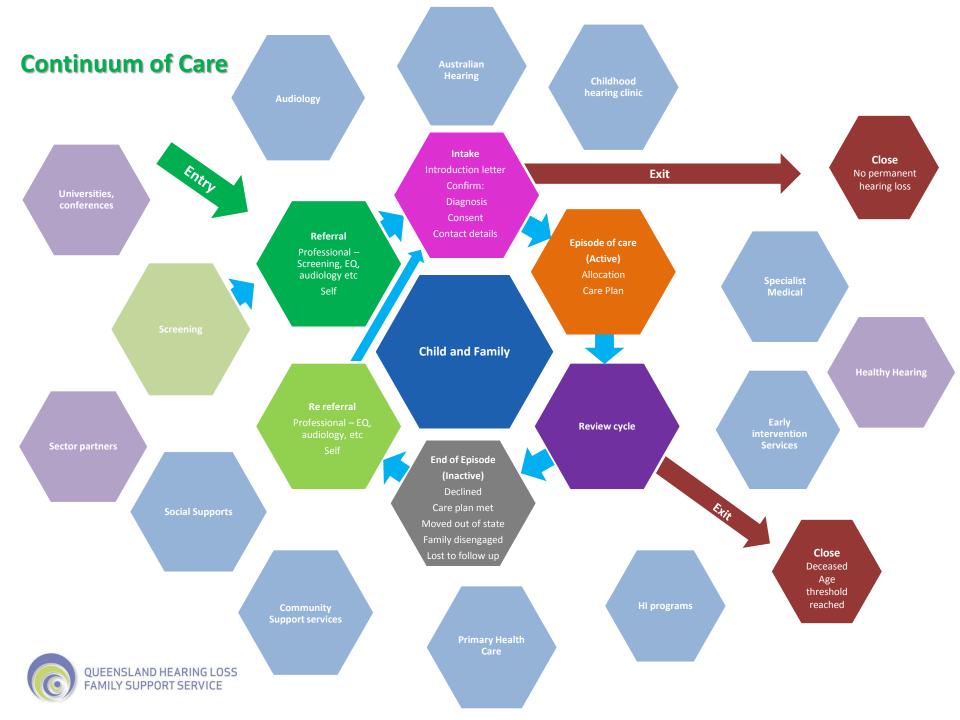
We see families face to face:

- At their home wherever it is!
- Video conference
- Clinics, hospitals, parks,
- Playgroups, coffee shops.

We also:

- Liaise and network with other services and can carry out joint home visits
- Teleconferences





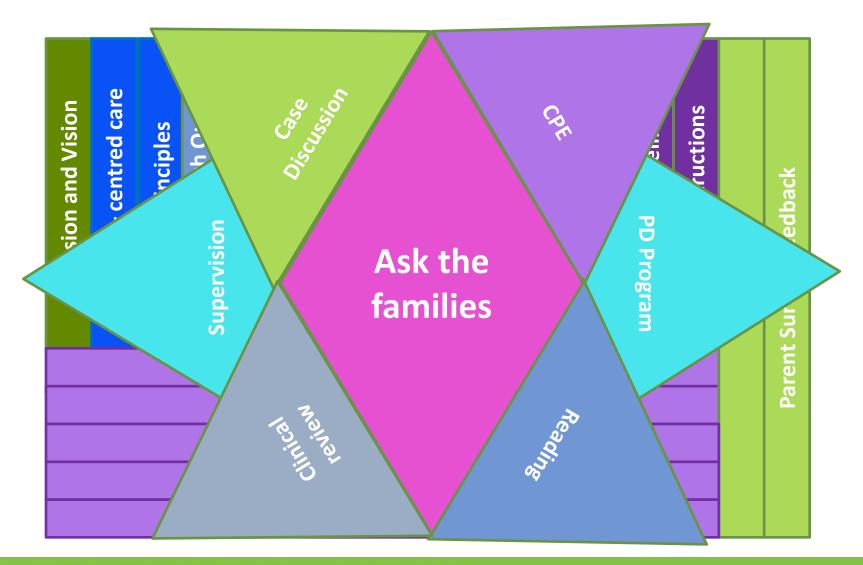
FCEI - 2012

Principle 10: Program Monitoring	Early Intervention Programs
FCEI programs evaluate provider adherence to best practices and include quality assurance monitors for all program elements.	Use quality assurance measures to monitor program components
	2. Provide a means for ensuring/measuring that service providers, programs, and systems are aligned with the principles listed in this consensus document.
	3. Include program-wide quality assurance measures, documenting child and family outcomes, knowledge and skills of the interventionists, and family benefit from services.
	4. Include parent feedback mechanisms beyond satisfaction measures (e.g., convening focus groups, documentation of changes in knowledge and skill, and monitoring involvement and program components that foster it).
	5. Use continuous assessment data and validate program practices through continual evaluation.

How do we do this?

Mission and Vision	Family – centred care	FCEI Principles	National Health Quality Standards	Newborn Hearing Screening Standards	Model of Service	Code of Conduct	Code of Ethics	APS	AASW	AHPRA	QH policy	C&YCH Guidelines	Work instructions	MPOC	Parent Survey/Feedback
Clinical review										aren					
Clinical Audit								P							
Performance and development plans															
Professional registration															
Accreditation															

How do we do it better?



Annual Clinical Audit

Random sample audited using a generic tool developed across 6 ACHS domains

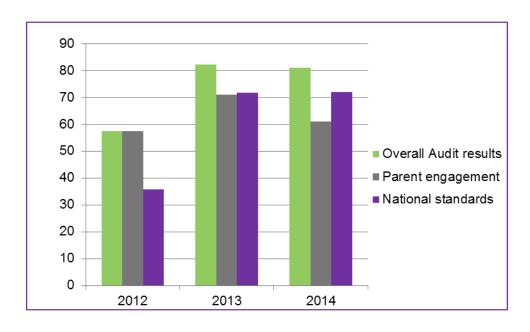
- Administrative Component
- General documentation
- Progress note documentation

- Clinical Assessment
- Care Planning
- Discharge Planning

Analysis also drilled down 2 further domains:

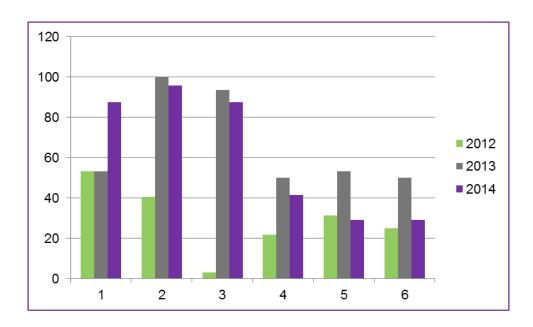
- Parent engagement
- National Newborn Hearing Screening Standards

Overall Progress to date



Percentage of audit that met standards

Parent engagement

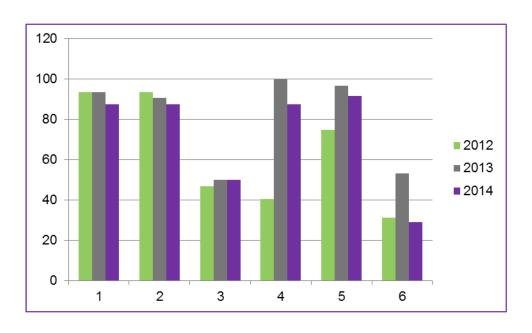


Percentage of audit items that met criteria

Parent engagement items

- 1.Consent
- 2. Care plans in Partnership
- 3. Care plans present
- 4. Discharge plans in Partnership
- 5. Information provided to parents at discharge
- 6. Discharge agreed by parents

Against the national standards



Percentage of audit items that met criteria

Audit items aligned with National Standards

- 1. Contact within 1 week of referral
- 2. Allocation within 4 weeks of diagnosis
- 3. Engagement in EI by 4 months
- 4. Care plan in place
- 5. Care plans reviewed every 3 months
- 6. Information provided to parents at discharge

There's still some work to do!

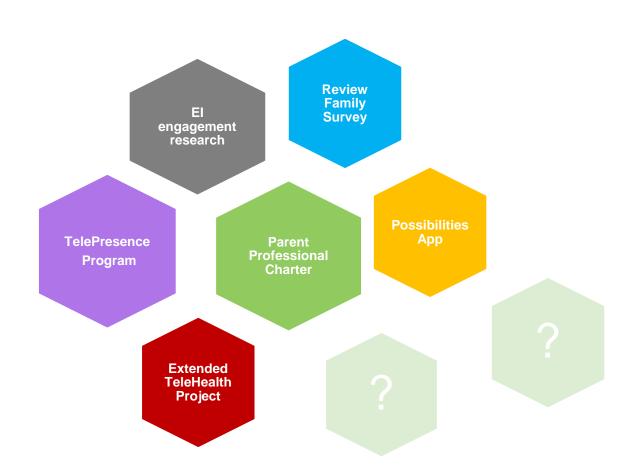
When we put this all together what did it mean?

- Highlighted the need for parent engagement and consultation:
 - through assessment and care planning, and
 - in service planning and development
- A clear assessment in consultation with the family drives the family's progress through the service
- Our goal is to enable families to reach a point where they are empowered and can self manage.

Parent engagement: What happens now?

Information	Consultation	Participation	Collaboration	Empowerment
Facilitating parent participation in sector activities, e.g. POD, Parent to Parent.	Parent Professional Charter	Parent participation in resource development and review.		
Facilitating parent engagement with each other through play groups, etc.	Parent representation on Community Stakeholder forums.	Parent representation on recruitment panels.	Parent involvement as central to case management meetings.	MPOC
Family Bulletin	Parent representation on community networks	Annual Family Survey	Parent involvement as central to care planning.	'Have your say'

What action did we take?



Parent Professional Charter*

- Initiative of Support and Advocacy Group a subcommittee of service stakeholder group representing Deaf Sector services, professional services and parents and consumers
- Aims to enable all stakeholders within the hearing loss sector to have access to the needs of families of children with hearing loss, and embrace principles of family centred practicerepresented by way of a Charter

^{*} Charter Project Leads S. Linn, M. Thorpe.

The Charter

- is unique in Australia for defining the expectations of parents about the services they receive by service providers and professionals in the Hearing Loss sector.
- is a living document that demonstrates sector partners commitment to the Global Coalition of Parents of Children who are Deaf and Hard of Hearing (GPOD) whose 2010 position statement which stated that ...

"the time has come for the visioning and implementation of systems that are more supportive for families and therefore better calculated to produce successful outcomes for children with hearing loss".

GPOD stated that one of the keys to achieving this goal is:

"formalised acknowledgement and incorporation of parent perspective into the development and monitoring of the systems that serve them."

Benefits of having a Charter

Parent Professional Charter

Context to development of policies and procedures

Promoting the needs of parents – choices, access, family centred care

Greater involvement of parents

Increased satisfaction of parents

Cross sectoral participation

Developing the Charter

Parent Professional Charter

Launch and distribution

Professional focus groups and endorsement

Identification and distillation of themes

Parent focus groups and written surveys

Avenues for feedback

Background research



Do you know what parents of children with hearing loss value?

The Parent Professional Charter describes things that are important to parents of children with hearing loss when working with professionals to ensure enhanced outcomes for the child.

- Professionalism
- Communication
- Being positive
- Responsiveness
- Sensitivity
- Direction

- Information
- Support
- Respect
- Choice
- Knowledge

View the full charter at www.health.qld.gov.au/ healthyhearing/docs/parentcharter.pdf

This project has been facilitated by the Qld Hearing Loss Family Support Service



So we have a Charter?

Planning ...Review...Feedback

- Meaningless without measurement
- Following through on commitment to families
- Redesign Family Survey
- Survey now based on Themes of Charter
- Are we doing what the families expect?
- 2014 implementation following pilot
- Culturally appropriate



Looking at the Family Survey

Initial Family survey

- Non-validated measure defined by the service
- Asked to give rating across 20 questions
- Targeted specific areas
- Opportunity for qualitative feedback

Issues:

- Low return rate
- Anonymity
- Limited accessibility to other languages



^{*} Reported at ANHS conference Perth, 2011, M. Thorpe

2014 Family Survey*

Methodology

- Email invitations with link to Survey Monkey for families with current email address (167)
- Hard copy sent via standard post (141)
- Where a family was NES then use of a interpreter (1)
- Personal contact with Indigenous families by ICDW (14)
- New survey to be annual and initially conducted in August 2014
- Cohort all parents/carers who received a service in 2013
- 53 families out of 293 successfully contacted

* 2014 Family Survey Leads S. Linn.

2014 Family Survey

Summary of Results

18% of families who received the survey chose to participate

The responses were mostly positive with 92% of responses being rated as either strongly agree or agree

These results suggest that most of the families who completed the survey agree that Family Support Facilitators are meeting their expectations in providing family centred care

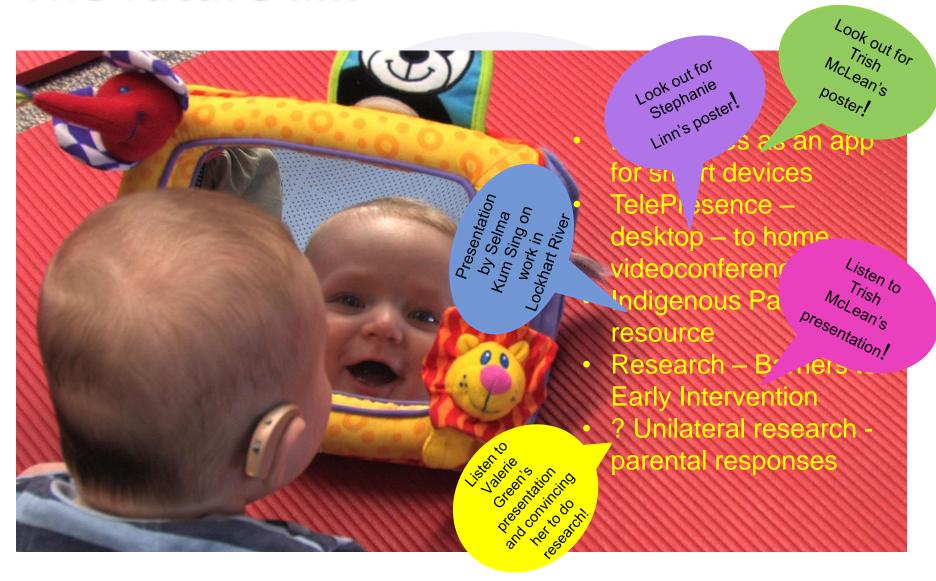
Although only 2% of responses were negative, for this/these families the experience was significant and we should reflect on the comments made in providing services in the future to families.

2014 Family Survey

Issues:

- Low response rate but higher numbers of returns
- 11% of posted surveys were returned "undeliverable"
- Back loading of data to Qchild
- Mobility of families addresses, email addresses phone numbers change
- Limited response by indigenous families highlights broader issues surrounding engagement of indigenous families to services

The future



A challenge for the future



FCEI Best Practices – International Consensus Statement

Finding a measure that brings together the unique parent defined elements of the Parent Charter and the FCEI International Consensus statement....

and meets organisational requirements – ACHS standards.....

and aligns with National NHS Framework

In one snappy user friendly non onerous audit tool Easy Peasy!

References

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Moeller, Mary Pat, et al. "Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement." *Journal of deaf studies and deaf education* 18.4 (2013): 429-445.

Outreach photos thanks to Valerie Green

Thank you for listening and remember ...

How to contact us!

Queensland Hearing Loss Family Support Service 1800 352 075

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http://www.health.qld.gov.au/healthyhearing/pages/family.asp