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### A New Perspective on the Outcomes of Children with Cleft Lip and Palate: Application of the ICF-CY

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**A New Perspective on the Outcomes of Children with Cleft Lip and Palate:  
Application of the ICF-CY**

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***12th Australasian  
Cleft Lip and Palate Association  
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# A New Perspective on the Outcomes of Children with Cleft Lip and Palate: Application of the ICF-CY.

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US

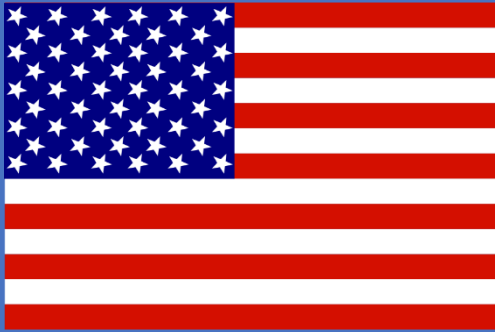
[louwb1@etsu.edu](mailto:louwb1@etsu.edu)

A word cloud featuring various names and terms in different colors and orientations. The most prominent word is 'Galang' in large green letters. Other notable words include 'Good Gaba' in green and yellow, 'Binbee' in green, 'weeyee' in yellow, 'yaadha' in blue, 'Mullee' in red, 'Pambarra' in yellow, 'morning' in red, 'D'Buthbee' in red, 'numgirr' in red, 'Bugal' in blue, 'gari' in red, 'Winba' in green, 'Gamba' in red, 'Weeimba' in red, 'Lung' in blue, 'niani' in yellow, 'dulara' in blue, 'meng' in light green, 'karri' in light green, 'gilee' in blue, 'Galangoor' in blue, 'duru' in yellow, 'G'day' in red, 'oomba' in green, 'daru' in green, 'Budjeri' in green, and 'gari' in red.

# Disclosure

- Financial Disclosure:
  - I gratefully acknowledge being invited and sponsored by the ACLAPA. I am a salaried faculty member of East Tennessee State University.
- Non-financial Disclosure:
  - I am a co-translator of the SPAA-C and FOCUS- 34 into Afrikaans; Research Mentor of the translation of the ICS into Brazilian Portuguese; Subject Matter Expert in developing ASHA's Practice Portal on Cleft Lip and Palate and the page on Functional Goal Writing Using the ICF for Cleft Lip and Palate.

# My journey !

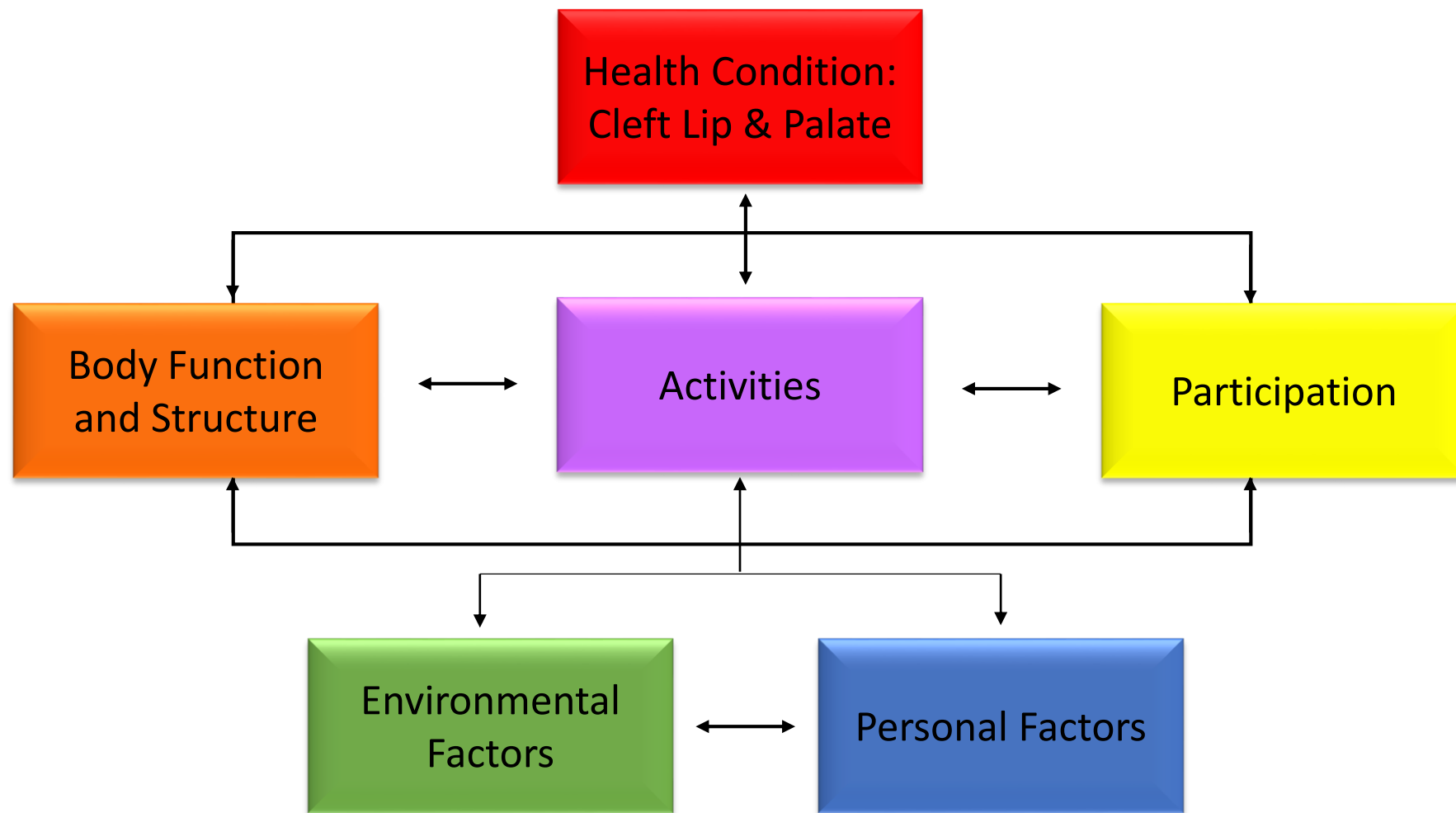


# Learner outcomes

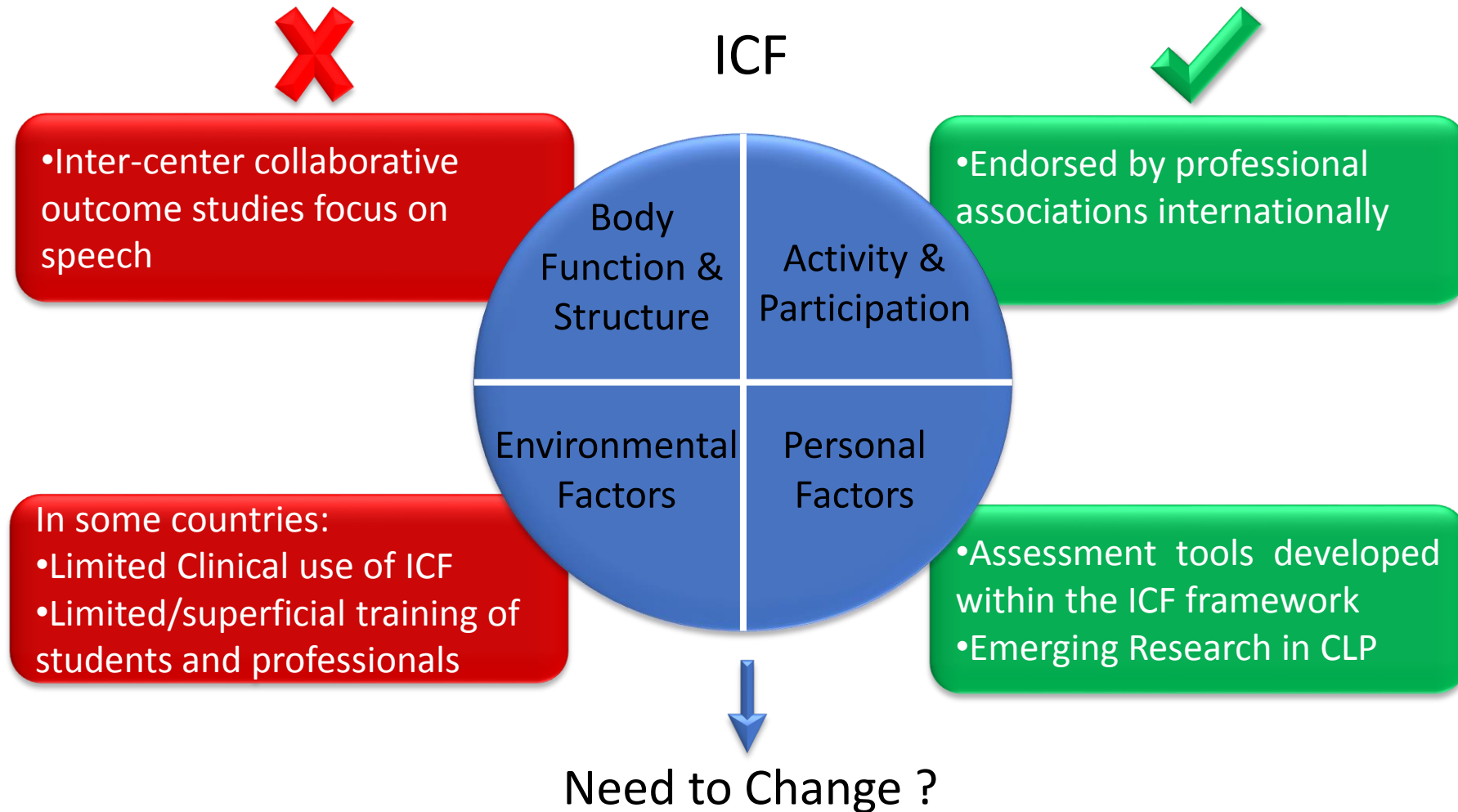
- Acknowledge the application value of the ICF to individuals with CLP.
- Integrate the ICF framework into the assessment of individuals with CLP.
- Formulate intervention goals that go beyond speech production skills to include functional communication outcomes in a variety of life situations.
- Include improvement and changes in communication participation in everyday functioning in assessment and progress reports.



# ICF Framework (WHO 2001,2007,2009)



# Conundrum: To use the ICF in CLP or not?



# ICF and Cleft Lip and Palate

- ❖ Early start but slow progression of applying the ICF to CLP in comparison to the fields of e.g. Speech Sound Disorders, Dysfluency, Aphasia etc.
- ❖ Despite the far researching potential of the ICF framework to assessment, intervention, education, and research in CLP, the integration of the ICF in CLP is still evolving.
- ❖ The ICF is expanding to include Quality of Life (QoL) and Health related QoL (HRQoL), which has implications for viewing cleft-associated speech problems as affecting social relationships, education, employment each of which is an index of QoL (Vallino & Louw, 2017).

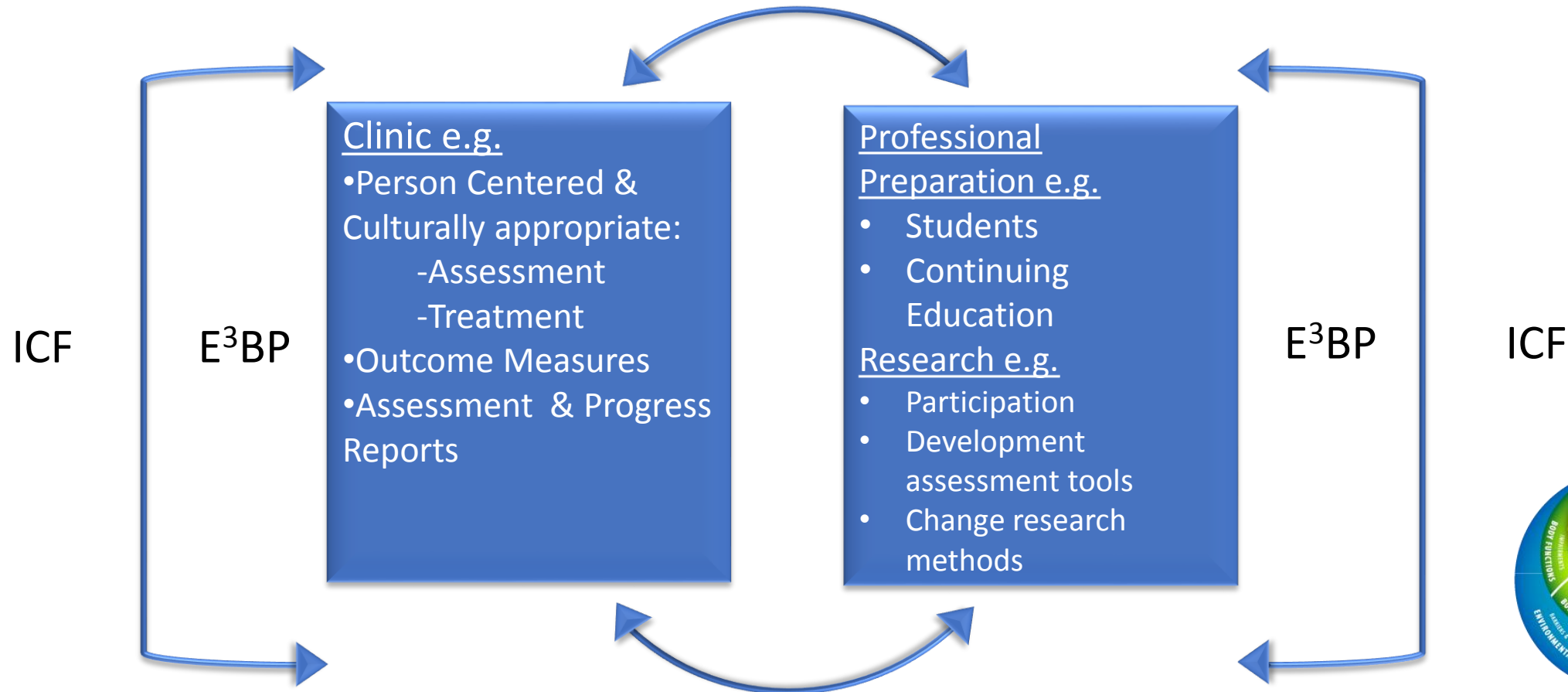
# Examples of publications on the ICF and Cleft Lip and Palate

| Authors            | Date    | Evidence ICF and CLP   |
|--------------------|---------|--|
| McLeod & Bleile    | 2004    | Applied the ICF to speech and language assessment to inform goal setting with an e.g. of CLP                     |
| Neumann            | 2011    | Applied SPAA-C to German children with CLP   |
| Havstam et al.     | 2011    | Provide an ICF perspective of communication attitude and speech in children with CLP                             |
| Neumann & Romonath | 2012    | Identified ICF-CY codes relevant for use with children with CLP in interprofessional approach                    |
| Dzioba et al.      | 2013    | Tutorial on applying the ICF-CY framework to children with VPI   |
| Vallino & Louw     | 2017    | Developed an EB service delivery model for transition of care for young adults with CLP within the ICF framework |
| Reddy et al.       | 2017    | Applied ICF framework to describe the impact of CLP on adults  |
| Cronin             | Current | Impact of CLP on toddler lives: experiences of toddlers with CLP and those of their families .                   |

# Examples of conference presentations on the ICF and Cleft Lip and Palate

| Authors         | Date             | Evidence ICF and CLP   |
|-----------------|------------------|--|
| Madison et al.  | 2010             | Case report of the application of the ICF to a client with cleft palate  |
| Meredith et al. | 2013             | Narrative review of the application of the ICF-CY to children with CLP   |
| Ewing et al     | 2014             | Proposed holistic model of assessment for children with CLP within ICF-CY framework  |
| Graham et al.   | 2015             | Use of the ICF-CY framework in academic preparation in CLP for SLPs in the US  |
| Louw et al.     | 2016             | Use of the ICF-CY framework in SLP's assessment practices with children with CLP in the US                                   |
| Vallino & Louw  | 2016, 2017, 2018 | Use of the ICF framework for the development of an EB service delivery model on transition of care for young adults with CLP |
| Gopal & Louw    | 2017             | Use of the ICF framework to describe the experiences of adults living with CLP   |
| Louw            | 2017             | Research update: Overview of the ICF-CY applied to CLP   |

# Time to Change to using the ICF framework in CLP!



# Person centered care (PCC) approach to CLP

## PCC

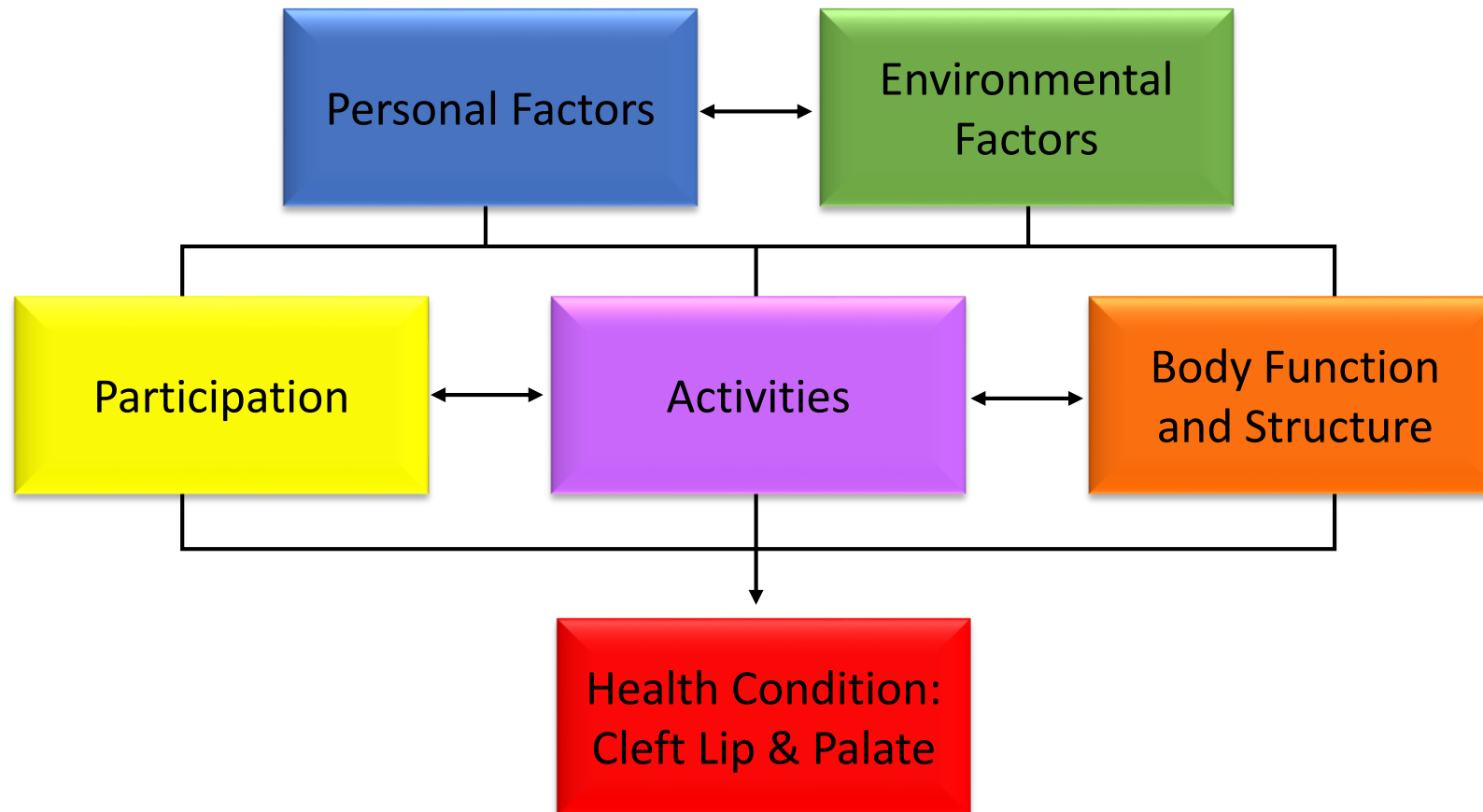
- *“Care that is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions” (IoM, 2001).*
- Biopsychosocial (ICF) model: client is viewed a *whole person* and not on CLP=holistic approach.
- Collaborative approach, partnership with families and clients.
- Leads to improved functional outcomes (Wolmack,2015).

## Application

- Reframing questions to families e.g. *Tell me about your child* vs. What concerns you about your child’s speech?
- Use of different ways to elicit information e.g. Ecomaps, Genograms.
- Shared decision making
  - Pinnacle of PCC (Barry & Edgman-Levitan,2012) *“Nothing about me without me”*.
- Goals:
  - Include functional goals in treatment
  - Ultimately- improve child’s ability to communicate in natural settings.

# Person-Centered Approach to ICF

(Nguyen, 2015)





# Cleft Lip and Cleft Palate



## What are person-centered functional goals?

- Goals identified by the client, in partnership with the clinician and family, that allow participation in meaningful activities and roles

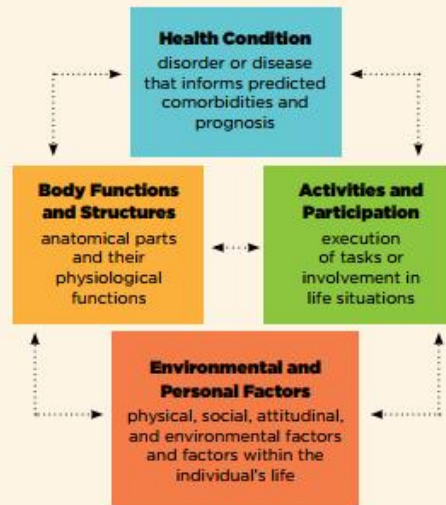
## Why target person-centered functional goals?

- To maximize outcomes that lead to functional improvements that are important to the individual
- To optimize the individual's potential to participate in meaningful activities
- To facilitate a partnership that ensures the individual and family have a voice in the care received and outcomes achieved
- To demonstrate to the payers the value of skilled services

## What is the ICF, and how does it help?

The International Classification of Functioning, Disability and Health (ICF)—developed by the World Health Organization (WHO)—is a framework to address functioning and disability related to a health condition within the context of the individual's activities and participation in everyday life.

## ICF: International Classification of Functioning, Disability and Health



### Case study: Maria

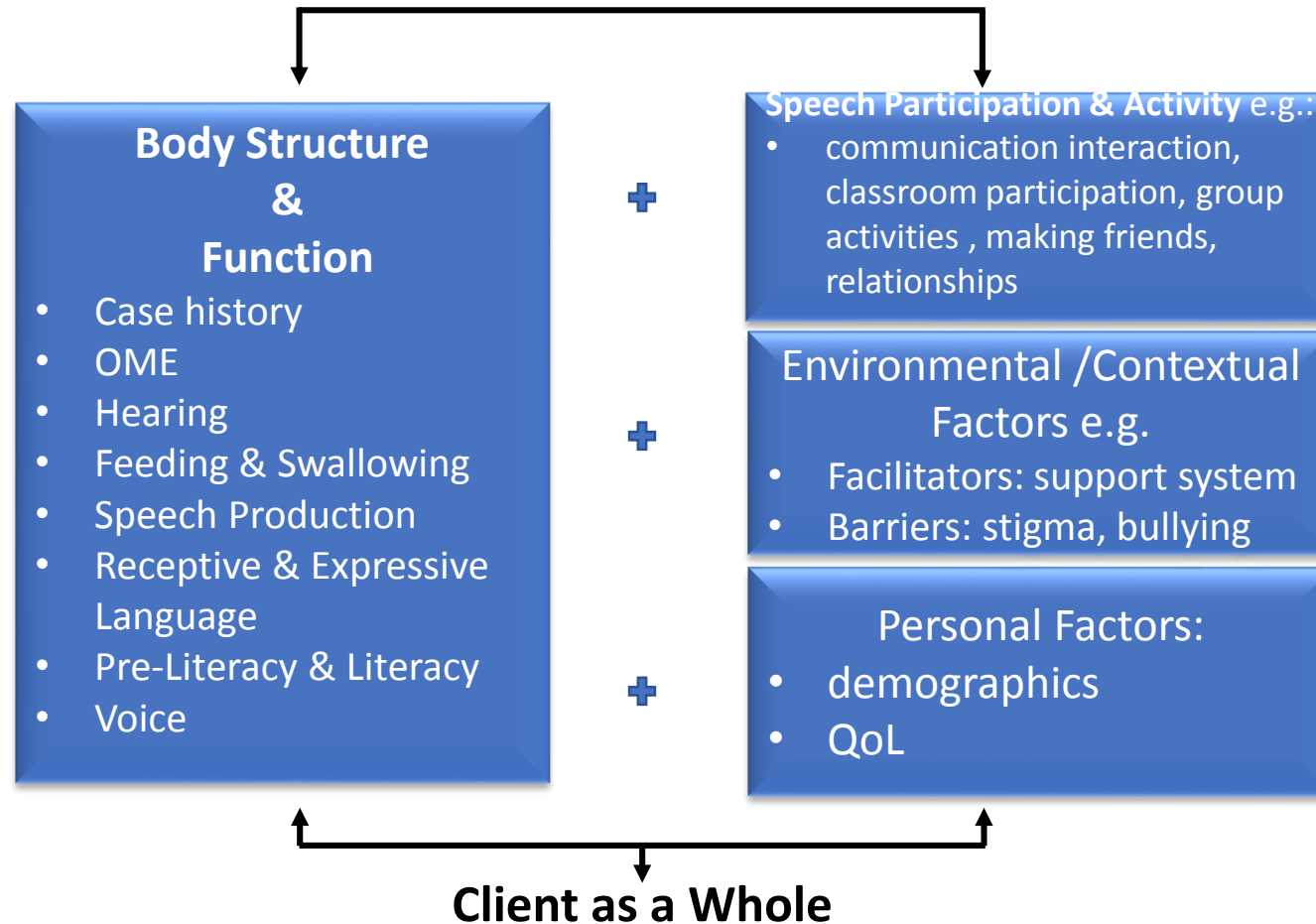
#### Health Condition: Repaired Unilateral Cleft Lip and Palate With Adequate VP Closure

| Assessment Data  | Body Functions and Structures  | Activities and Participation   | Environmental and Personal Factors  |
|--|--|--|---|
| <p><b>Unilateral Cleft Lip and Cleft Palate</b></p> <ul style="list-style-type: none"> <li>• Repaired at 3 and 12 months of age, respectively</li> <li>• Adequate VP closure</li> </ul> <p><b>Spoken Language (CELF-P-2)*</b></p> <ul style="list-style-type: none"> <li>• Average to above-average expressive &amp; receptive language</li> </ul> <p><b>Hearing (Status monitored regularly)</b></p> <ul style="list-style-type: none"> <li>• Within normal limits despite history of otitis media</li> </ul> <p><b>Articulation and Phonology (Perceptual speech assessment)<sup>†</sup> (GFTA-3)<sup>‡</sup></b></p> <ul style="list-style-type: none"> <li>• Compensatory articulation errors (glottal stop for /p, b, t, d/; posterior nasal fricative for /s, z/)</li> </ul> | <ul style="list-style-type: none"> <li>• Difficulty being understood by unfamiliar listeners (ICS)<sup>§</sup></li> <li>• Reduced participation in classroom activities (e.g., circle time and story time) (SPAA-C)<sup>¶</sup></li> <li>• Reluctance to join in play with classmates and to communicate verbally with unfamiliar listeners (FOCUS)<sup>‡</sup></li> </ul>   | <ul style="list-style-type: none"> <li>• Maria is 4 years old.</li> <li>• She is in preschool and has access to speech services.</li> <li>• She wants to improve her speech so others can understand her.</li> <li>• Maria has a strong desire to interact socially with her peers. (ASQ-3)<sup>¶</sup></li> <li>• Classmates are accepting and try to include Maria in play activities.</li> <li>• Family, friends, and teachers are very supportive. (SPAA-C)<sup>¶</sup></li> </ul> |   |
| Clinical Reasoning   | <p>What impairments most affect function in the current setting, based on clinician assessment and individual/family report?</p>   | <p>What activities are most important to the individual in the current setting?</p>  | <p>What personal/environmental characteristics help or hinder participation in activities or situations in the current setting?</p> |
| Goal Setting   | <p><b>Maria's Functional Goals</b></p> <p><b>Long-Term Goal:</b><br/>Maria will join in activities with peers and be understood when talking with friends and teachers in preschool and with unfamiliar listeners in everyday social contexts.</p> <p><b>Short-Term Goals:</b></p> <ul style="list-style-type: none"> <li>• Maria will produce /p, b, t, d/ with correct placement in all word positions to eliminate glottal stops 90% of the time in structured sentences during individual therapy.</li> <li>• Maria will produce /s, z/ with correct placement in all word positions to eliminate posterior nasal fricatives 90% of the time in structured sentences during individual therapy.</li> <li>• When invited by peers during free-play activities in the classroom, Maria will participate in conversation in at least 4 out of 5 opportunities per week as noted by the SLP and teachers.</li> </ul> |  |   |

\*Clinical Evaluation of Language Fundamentals—Preschool—Second Edition (CELF-P-2; Semel, Wiig, & Secord, 2004). †Perceptual speech assessment: Informal battery, including assessment of speech sound production, resonance, and airflow. ‡Goldman-Fristoe Test of Articulation—Third Edition (GFTA-3; Goldman & Fristoe, 2015). §Intelligibility in Context Scale (ICS; McLeod, Harrison, & McCormack, 2012). ¶Speech Participation and Activity Assessment—Children (SPAA-C; McLeod, 2003). ‡Focus on the Outcomes of Communication Under Six (FOCUS; Thomas-Stoneil, Robertson, Walker, Oddson, Washington, & Rosenbaum, 2012). ¶Ages and Stages Questionnaire—Third Edition (ASQ-3; Squires & Bricker, 2009).

# Reframing & Expanding Assessment

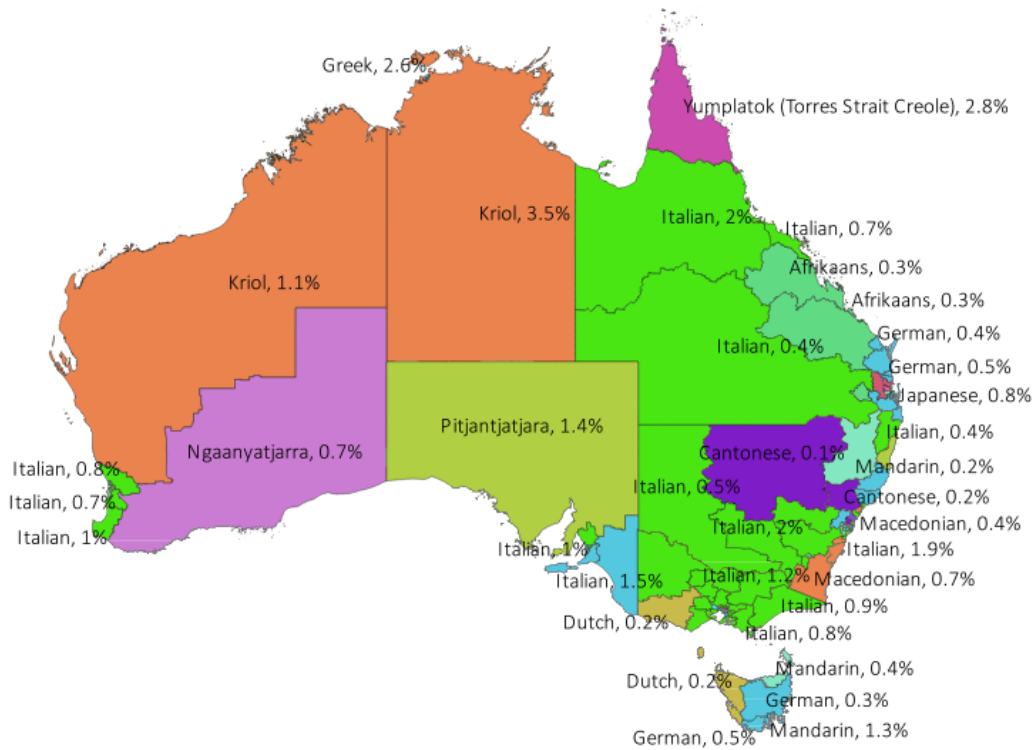
## ICF & ICF-CY



# Expanding CLP Assessment Battery: e.g. of ICF-CY and QoL Resources

| Clinical Tool   | Author   | Web link / Reference   |
|---|--|--|
| Intelligibility in Context Scale (ICS)                      | McLeod, Harrison, & McCormack (2012)                                   | <a href="http://www.csu.edu.au/_data/assets/pdf_file/0010/399970/ICS-English.pdf">http://www.csu.edu.au/_data/assets/pdf_file/0010/399970/ICS-English.pdf</a><br><br><a href="http://www.csu.edu.au/research/multilingual-speech/ics">http://www.csu.edu.au/research/multilingual-speech/ics</a> |
| Focus on the Outcomes of Communication under Six (FOCUS-34) | Thomas-Stonell, N., Oddson, B., Robertson, B. & Rosenbaum, P.L. (2010) | <a href="http://www.focusoutcomemeasurement.ca">http://www.focusoutcomemeasurement.ca</a><br>Manuals:<br><a href="https://flintbox.com/public/project/30968">https://flintbox.com/public/project/30968</a>   |
| Speech Participation and Activity in Children (SPAA-C)      | McLeod, S. (2003)  | <a href="http://www.csu.edu.au/research/multilingual-speech/spaa-c">http://www.csu.edu.au/research/multilingual-speech/spaa-c</a>  |
| VPI effects on Life Outcome (VELO)                          | Skirko, J.R., Weaver, E.M., Kinter, S. & Sie, K.C. (2012)              | <i>Arch Otolaryngol Head Neck Surg</i> , 2012,138(10:929-935.)   |
| Parental Appraisal of Cleft Questionnaire (PACQ)            | Shuttlewood, E., Dalton, L. & Cooper, M. (2014)                        | Cleft Palate-CranioFacial Journal, 2014,51(2): 207-221   |
| Child Oral Health Quality of Life Questionnaire (COHQOL)    | Agou, Malhotra, Tompson, Prakash, & Locker, (2008)                     | Journal of Public Health Dentistry, <a href="https://doi-org.iris.etsu.edu:3443/10.1111/j.1752-7325.2008.00093.x">https://doi-org.iris.etsu.edu:3443/10.1111/j.1752-7325.2008.00093.x</a>  |

# Culture and the ICF : Personal and Environmental factors



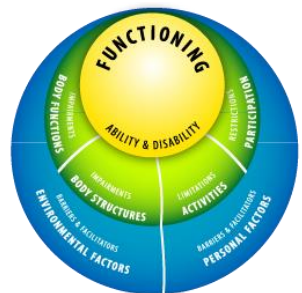
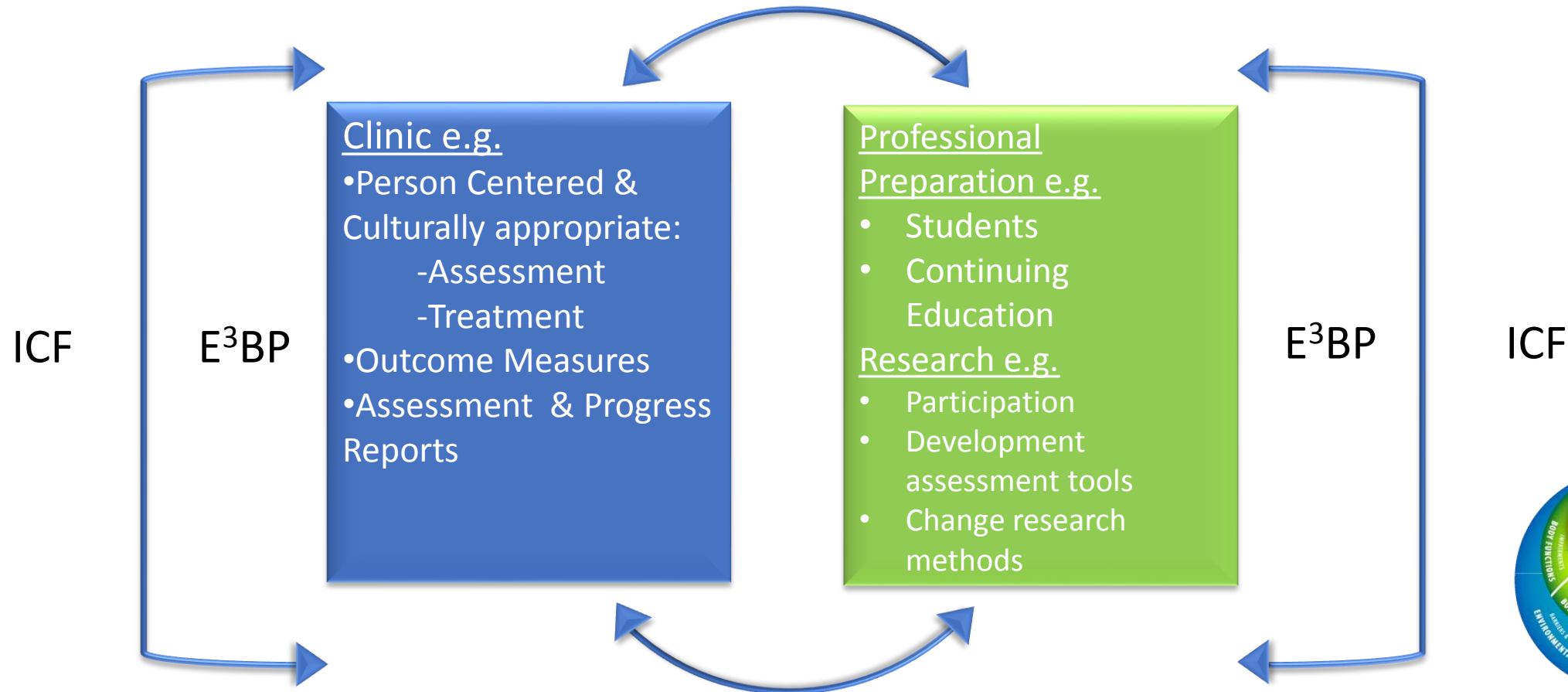
- 21% of Australians speak a language other than English (Australian Bureau of Statistics, 2016).
- View home language as a family strength (Peredo, 2016)
- General cultural considerations in CLP: access to health care; practices and beliefs; causal attribution, level of acculturation; community supports (Cordero, 2018)
- Six Principles of Culturally Competent Practice (Verdon, McLeod & Wong, 2015): e.g. culturally appropriate tools and resources; culturally appropriate and mutually motivating goals
- PCC key to cultural competence : based on respect, sensitivity, composure, partnership, honesty, astuteness, curiosity and tolerance. PCC and cultural competence share core elements and can to the improvement of the quality of service provided (Epner & Baile, 2012).

# ICF Framework and Report writing

- Assessment and progress reports need to reflect integration of the ICF framework to demonstrate the biopsychosocial approach and PCC followed in clinical practice.
- E.g. Report on the client's:
  - Activity/Capacity level (skill ) AND Participation (performance) level
    - formal & standardized test scores + speech and language skills in the life situations (e.g. mealtime, play, classroom).
  - Contextual factors:
    - Describe contextual factors that can serve as barriers or facilitators
    - Explain variability in child's performance
  - Include participation goals (social based)
    - E.g. by the end of the school term J will initiate conversation with peers, and asking a question or making a comment about a relevant topic, 80% of the time as observed by staff
- Progress measures should include gains in meeting participation goals.



# Time to Change to using the ICF framework in CLP!



# Professional Preparation and Continued Education

*“It is expected that an entry-level speech pathologist in Australia will be familiar with the ICF framework and competently apply the social health principles of individual functioning and well-being to their speech pathology practice”*

(Speech Pathology Australia, Competency- Based Occupational Standards for SLPs, 2011, p.6).



- *Student training:* Use the ICF framework to e.g.
  - Present Cleft Palate course content organized according to the ICF framework.
  - Use ICF framework to build an assessment protocol and intervention goals within the ICF framework (Graham, Palmer & Louw, 2015).
- *Continuing Education:* need to consider how we provide training on a new practice as a crucial aspect of implementation (Dust & Trivette, 2009).
  - Add a *coaching element* to traditional CE activities to improve carryover of knowledge and skills to everyday practice (Braun, Dunn & Tomcheck, 2017).
  - Use of *Commitment to Change Statements* to evaluate CE allows SLPs to integrate newly acquired knowledge and skills with prior knowledge and skills, which, in turn, affects clinical performance positively (Bornman & Louw, in preparation).

# Research needs on CLP within the ICF framework

- ICF is a research tool (WHO, 2007)
  - Provides a broad framework to guide choice and range of tools to collect, analyze and interpret data
  - Allows identification of functioning and contextual factors that influence individual with CLP participation in society.
- Stock et al.(2018) pose 4 suggestions re a conceptual and methodological *shift* in Craniofacial research e.g.:
  - (1) *Overarching conceptual frameworks are needed to guide research to key concepts and interposing factors to be explored and developed (ICF could be selected)*
  - (3) *A need for the increase level of patient involvement in research exists. (PCC)*
- Dearth of research on ICF and CLP: multiple opportunities out there!
- Research needs e.g. :
  - Assessment tools and measures.
  - Participation-based outcomes to determine meaningful life changes.
  - Change in research methods e.g. qualitative research with thematic analysis; Mixed-Methods Research.



# In conclusion: Are you ready for change?



- Change to integrating the ICF framework to CLP by:
  - Focusing on the BIG picture
  - Committing to evaluation of all components of ICF
  - Better understanding dynamic interaction between CLP and contextual factors
  - Creating functional goals
  - Changing perceptions and approaches of team members and others!
  - *Improving outcomes of clients*

# Discussion

**Questions**

&

**Answers**





*Thank You!*

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