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Can I Say Something Now? Family-and-Child-Centered Care in Cleft Lip and Palate

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Can I Say Something Now? Family-and-Child-Centered Care in Cleft Lip and Palate

Copyright Statement

Can I say something now?
Family-and-Child-Centered Care in Cleft Lip and Palate

ISHA Conference

April 8-10, 2021

Brenda Louw, D. Phil. SLP

East Tennessee State University

- **Hello and thank you for joining us!**

- Use the chat box to ask questions.
- As a courtesy to others, please turn off your microphone and camera.

- To exit this session click the *Leave* button.

- CE Reporting Deadline is April 24: A link will be provided via email to request ASHA credit and report your session attendance. Please note you will be required to report your hours for the live event on April 8-10 separately from the recorded sessions available April 14-28.

- Recorded session viewing instructions will be provided next week.

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Disclosures

Financial relationships:

- Dr. Brenda Louw is employed full-time as a professor in SLP by East Tennessee State University, Johnson City, TN.
- Current funded projects :
    - Carnegie African Diaspora Fellowship Program
    - ETSU Equity and Inclusion Cultural Competency Grant
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Relevant Non-financial relationships

- Dr. Brenda Louw is the Editor of SIG 5 (Craniofacial and Velopharyngeal Disorders) *Perspectives; M*ember SIG 5 CC*;* Subject Matter Expert in developing ASHA's *Practice Portal on Cleft Lip and Palate*; and *Functional Goal Writing Using the ICF for Cleft Lip and Palate.* She is a member of ASHA Sigs 5, 17 and the ACPA.She also collaborated on translating the DOUCS, SPAA-C into Afrikaans, her first language.

Other:

- Formal permission (*Visual/Audio Release Form*) was granted by a family receiving services at the ETSU SLH clinic for use of visual images ,as well as permission to use health information of the children (*Authorization to Use and /or Disclose Protected Health Information –External Educational Conference)*

Acknowledgements

Students, Colleagues/friends
& Mentor

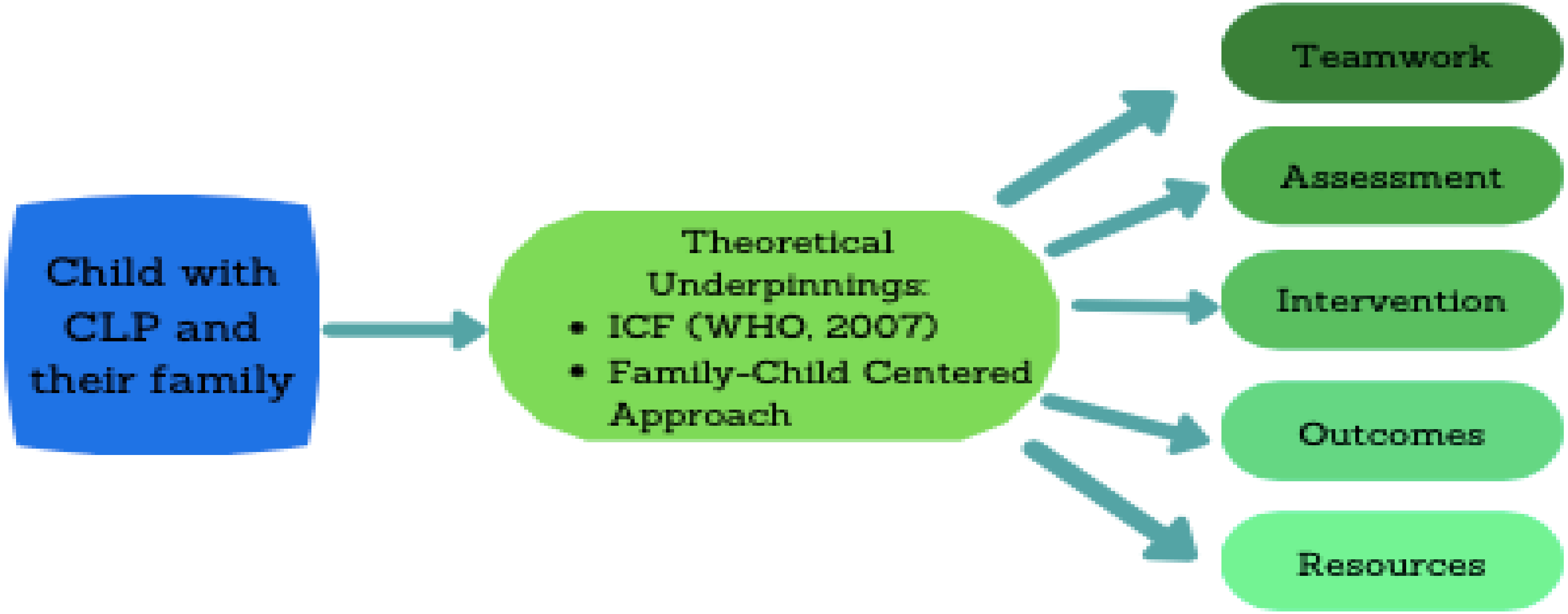
Morgan Geise (ISHA) for the invitation

Learner Outcomes

➢Participants will be able to:

- Explain the concept and advantages of the Family- and- Child-Centered-Care (FCCC) approach.
- Describe the components of the FCCC as applied to individuals with CLP and their families.
- Explain the EB strategies of FCCC be applied by the SLP and its positive effects.

Overview



Child with CLP and their family

Theoretical Underpinnings:

- ICF (WHO, 2007)
- Family-Child Centered Approach

Teamwork

Assessment

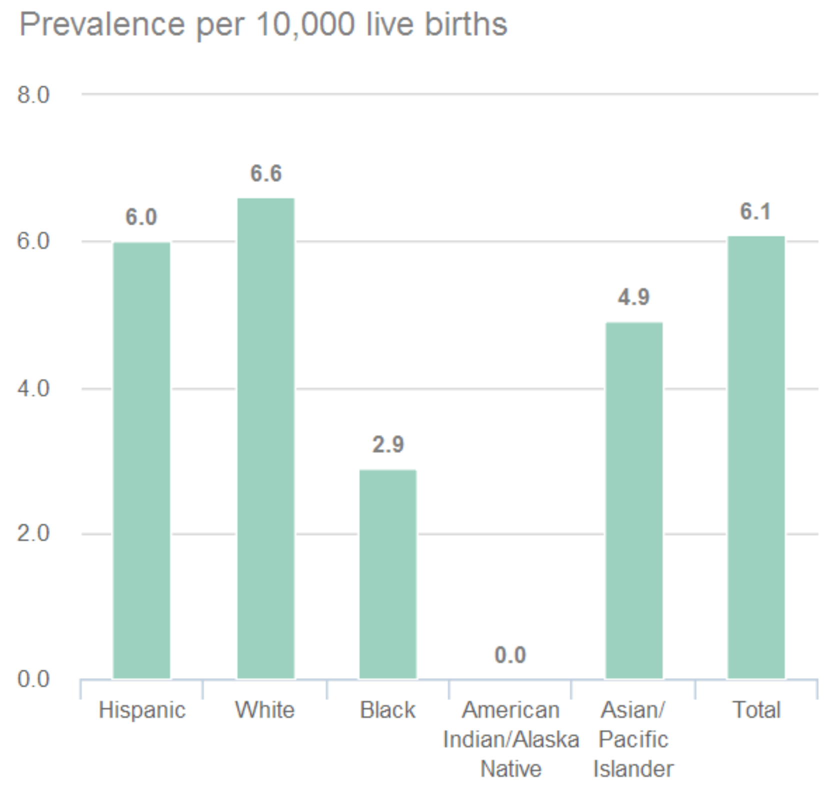
Intervention

Outcomes

Resources

CLEFT LIP WITH CLEFT PALATE BY RACE/ETHNICITY

Indiana, 2012-2016 Average



Source: National Birth Defects Prevention Network (NBDPN) Retrieved March 28, 2021, from www.marchofdimes.org/peristats.

And so a journey begins….

and continues with 2.....

Case study : The brothers

- Boy 1: scan at 20 weeks raised concerns re micrognathia, born with Pierre Robin Sequence(PRS)
- Moved to CLP team by helicopter 4 hours away
- 3 ½ years later Boy 2: ultrasound mandible not quite as recessive, informed 50/50 chance for PRS, born with PRS, moved to same team
- Currently genetic testing re Stickler Syndrome , if diagnosed earlier might not have wanted more children, now cannot imagine life without boy 2;diagnosis important re other medical conditions
- Boy 1: feeding issues, Positive Eating Program for sensory feeding issues, speech issues
- Boy 2: no feeding issues , speech issues
- Both distraction osteogenesis surgery in infancy – different surgeons; CP repaired 8 months and 13 months respectively
- Both hearing, vision tests 2x year , team visits 1x year
- Both weekly speech therapy and reports sent to team with annual visits; team and community SLPs collaborate
- Boy 1 : EI, Speech therapy, VPI
- Boy 1 :1st grade teacher difficulty understanding him- Mom does not want him to be discounted
- Boy 1: nasopharyngoscopy, discussion with team and boy, asked Mom “don’t you like the way I talk?”, Surgeon consulted parents re surgery and both want to help Boy 1 ‘VPD surgery in February
- Boy 2: stopped speech therapy during COVID , continuing in summer
- Mom comments: some providers connect better with the boys as “ a whole person” than others ; recommend SLPs ask-tell me about your child NOT what is the problem

CLP & Craniofacial Disorders:

- LOW prevalence
- HIGH impact

Impact on individuals with CL/P and CD e.g.:

- Feeding
- Hearing
- Speech & Language
- Dental
- Psychosocial functioning etc.

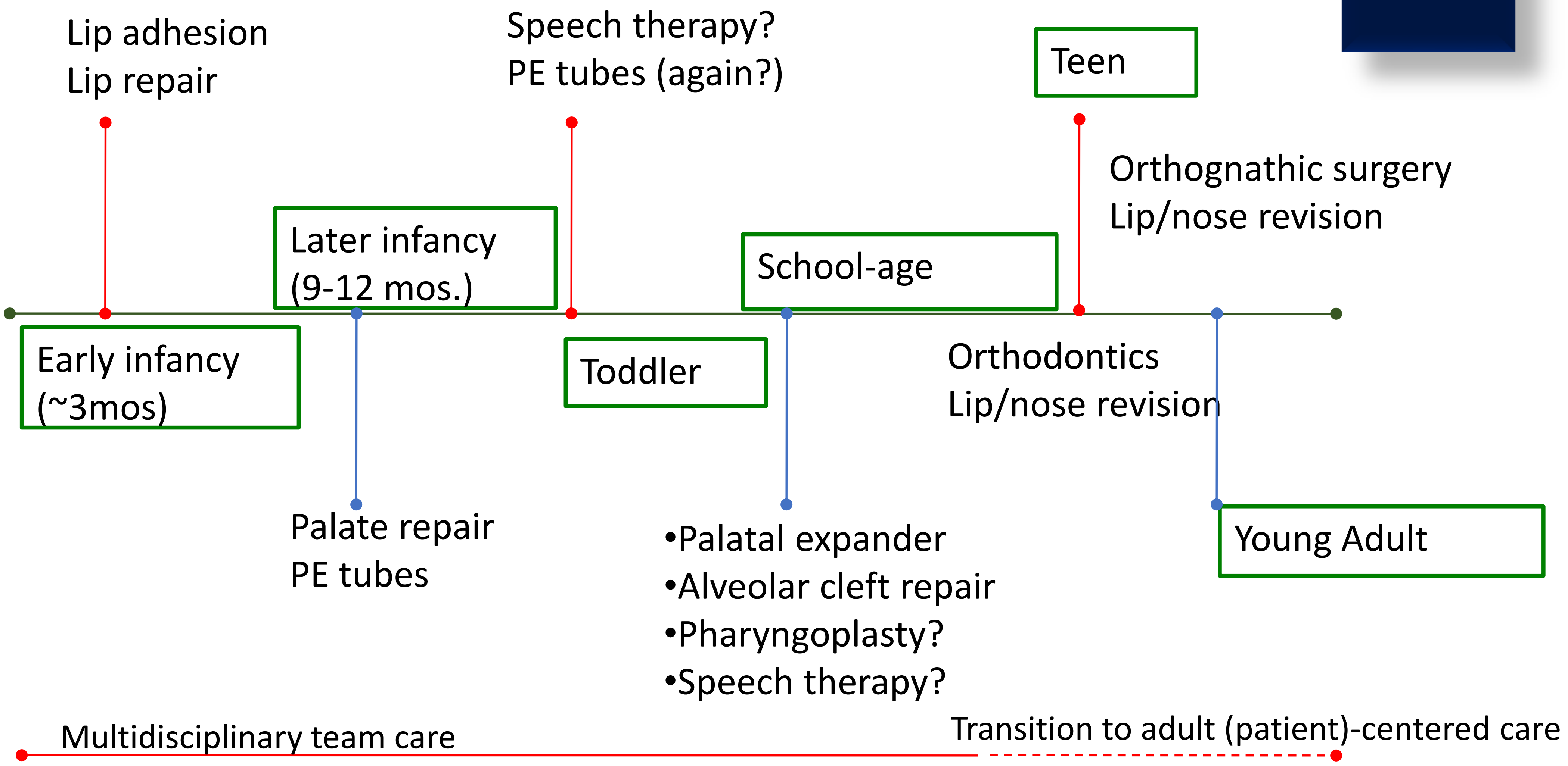
Family:

- Parents
- Siblings
- Grandparents
- Extended Family

Complex disorders necessitates:

- Holistic approach
- Partnership with team, family & client
- FCCC Approach

Timeline of Team Care of CL/P (Zajac & Vallino,2017)



Lip adhesion
Lip repair

Early infancy
(~3mos)

Later infancy
(9-12 mos.)

Palate repair
PE tubes

Speech therapy?
PE tubes (again?)

Toddler

School-age

- Palatal expander
- Alveolar cleft repair
- Pharyngoplasty?
- Speech therapy?

Teen

Orthognathic surgery
Lip/nose revision

Orthodontics
Lip/nose revision

Young Adult

Multidisciplinary team care

Transition to adult (patient)-centered care

Can I say something now? Importance of family and client voices

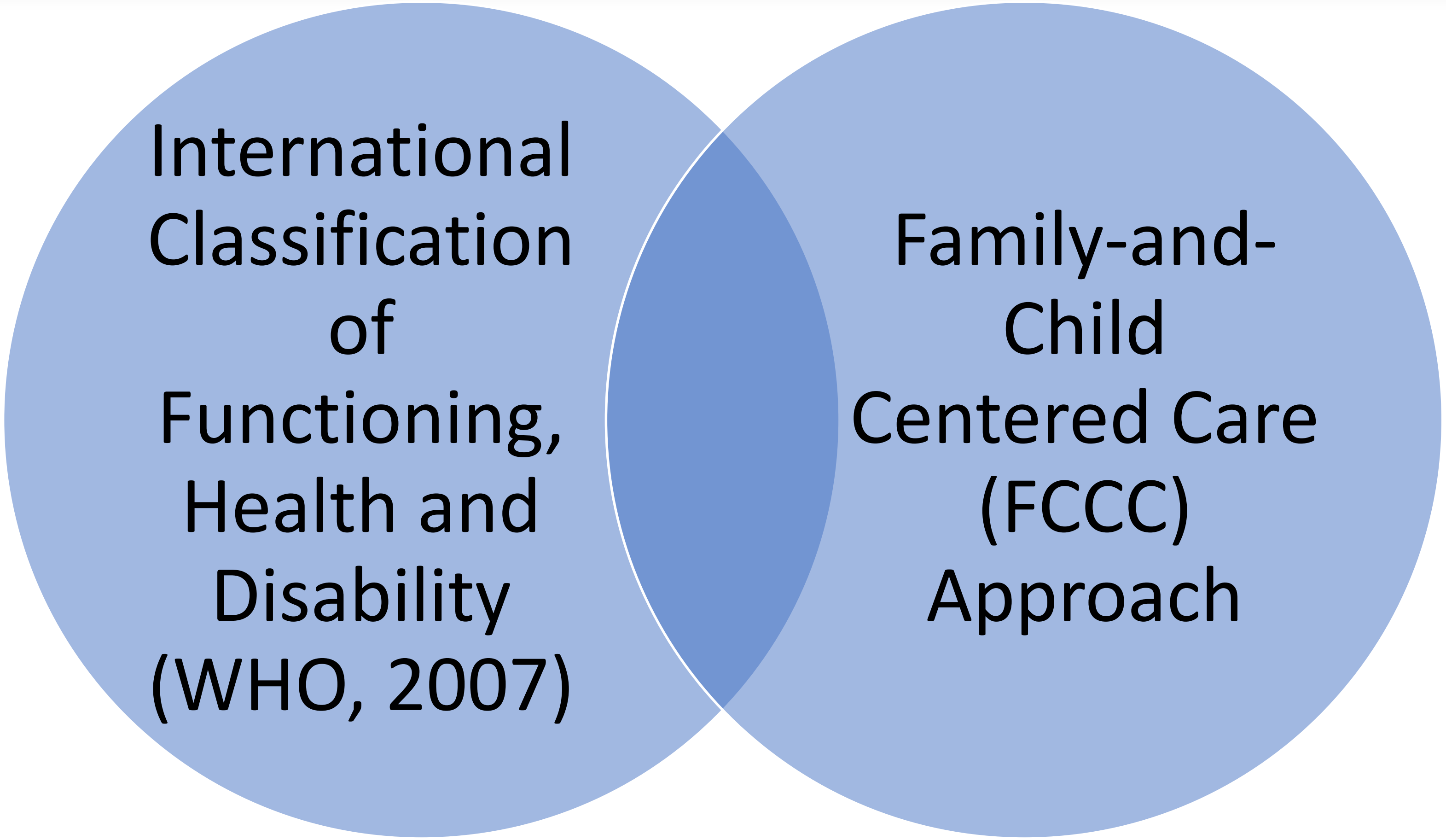
Practitioners need to acknowledge the social, emotional, developmental, and physical components of this disorder over the life span.

Patients and families play a vital role in ensuring the well-being of the family members.

First, it is the family who makes this decision and then it begins to involve both the patient and family, and then eventually the grown-up patient in the caregiving and decision-making. This is an evolution of care and it is always a partnership (Vallino, 2021).

Theoretical Underpinnings

Theoretical Underpinnings required to Hear the Voices of Clients and their Families



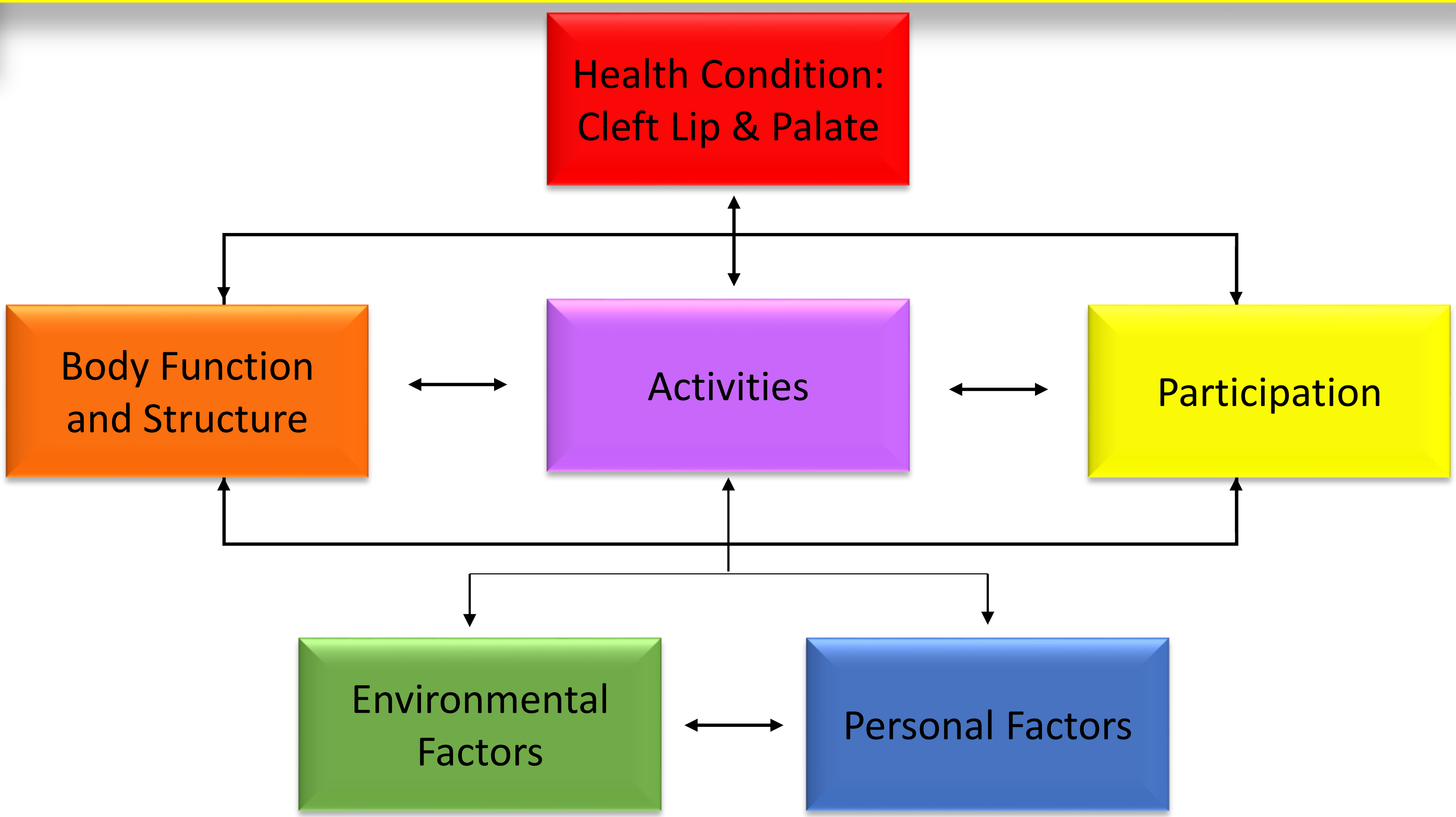
International Classification of Functioning, Health and Disability (WHO, 2007)

Family-and-Child Centered Care (FCCC) Approach

ICF (WHO,2001,2007,2009)

- The International Classification of Function, Disability and Health (ICY) (WHO, 2001)(provides a *biopsychosocial* framework for the *holistic* consideration of the impact of communication disorders such as cleft lip and palate (C/LP) on individuals.
- It is a *strength based* model, emphasizing functioning.
- Provides a *framework* for examining ways in which we think about and evaluate outcomes in SLP
- The individual's functioning and disability are viewed as being in *dynamic interaction* between *health conditions*(e.g. CL/P) and *contextual factors*
- ASHA endorses the use of the ICF and has adopted this framework for *person-centered care* in its policy documents (Vallino & Louw, 2018)

Traditional ICF Framework (WHO 2001,2007,2009)



Health Condition: Cleft Lip & Palate

Body Function and Structure

Activities

Participation

Environmental Factors

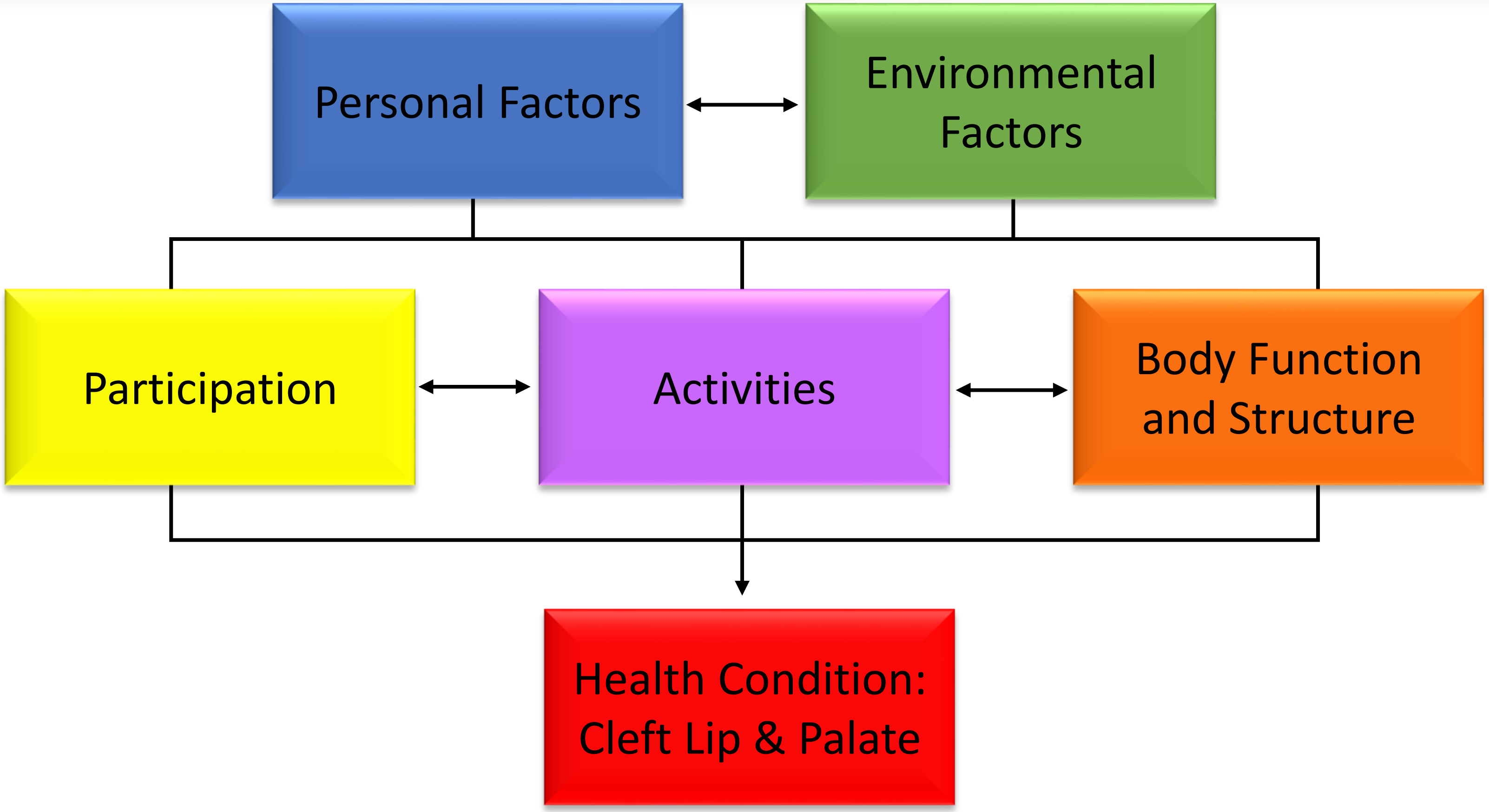
Personal Factors

ICF

International Classification of Functioning, Disability and Health

More Person-Centered Approach to ICF

(Nguyen, 2014)



Personal Factors

Environmental Factors

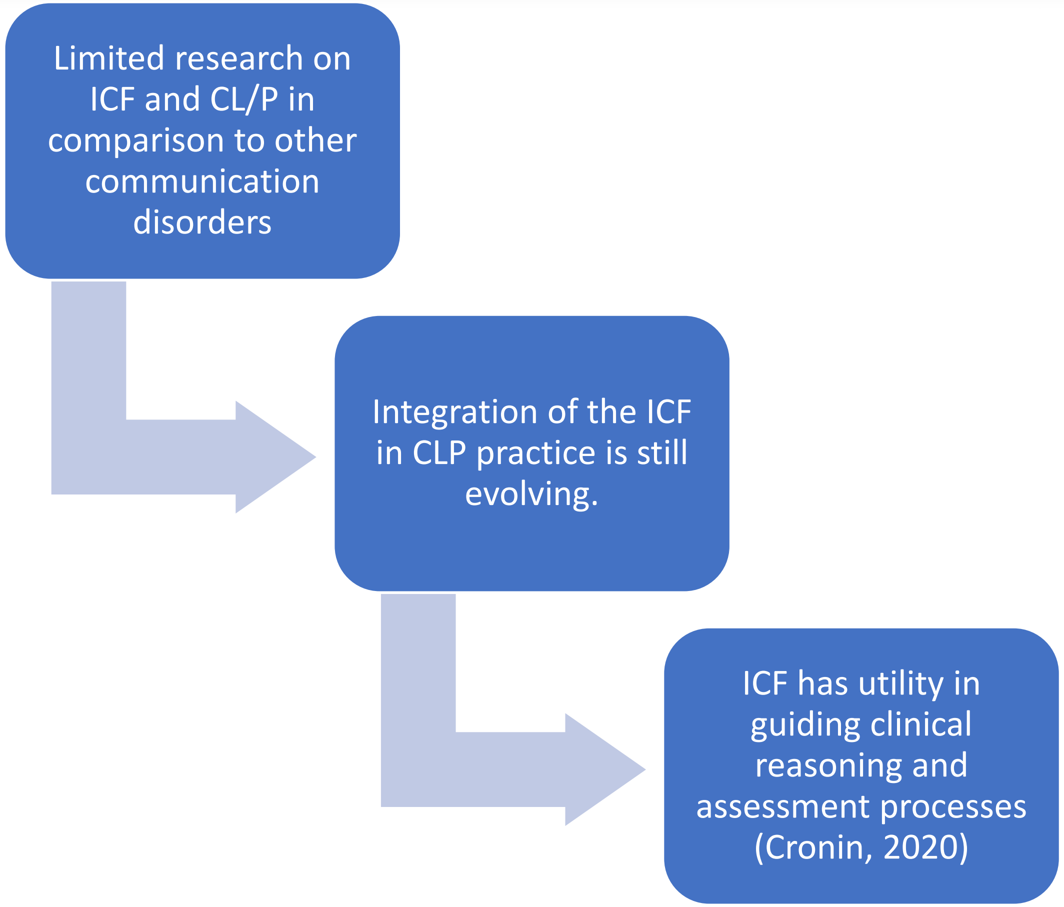
Participation

Activities

Body Function and Structure

Health Condition: Cleft Lip & Palate

ICF and Cleft Lip and Palate



Limited research on ICF and CL/P in comparison to other communication disorders

Integration of the ICF in CLP practice is still evolving.

ICF has utility in guiding clinical reasoning and assessment processes (Cronin, 2020)

Again…Case study : The brothers

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- *Mom comments: some providers connect better with the boys as " a whole person" than others ; recommend SLPs ask-tell me about your child NOT what is the problem*

Theoretical Underpinnings: Family-and-Child Centered Care (FCCC)

Terminology:

- Person, Patient, Client, Family, Family-and Child …….Centered Care
- Family-and- Child Centered Care (FCCC) preferred term

Description FCCC

- based on mutual respect and trust, sharing information, open communication and shared decision-making (An & Palisano, 2014)
- incorporates family beliefs, values, needs, preferences (An & Palisano, 2014)
- collaborate with families to help them decide what matters most!(CYDA, n.d.)

FCCC requires SLPs to

- consider strengths of the child and family
- privilege the voices of their parents, caregivers, family, educators
- collaborate with families for effective outcomes
- support families and children in medical and nonclinical settings(Cronin, 2020; Heidecker et al., 2009)

continued

The American Academy of Pediatrics (AAP)

- identified family-centered care principles to ensure that families are part of decision- making and that their concerns, preferences and needs are incorporated in treatment plans for their children.

Core elements of FCCC :

- respect for all team members (including families as team members); focus on family strengths and resources; cultural competence, balanced and trusting relationship between families and providers, active partnerships between families and team members, empowerment and individual goal-orientated and community focused services (Braun et al.,2017)

Currently FCCC high –priority focus area in health care and associated with increased family satisfaction, QoL, improved outcomes and family follow-up (Pfeifauf et al., 2020)

FCCC key to Culturally responsive care

Getting to know the family:

- Family structure
- Gender roles and family values
- Child rearing practices
- Access to health care
- Health beliefs and practices
- Causal attribution

Assessment

- Be aware of implicit bias in standardized SAE measures; own implicit bias
- Bi -and multilingualism considerations
- Dynamic assessment
- Ethnographic interviewing

Resources:

- Moore(2016);
- https://www.leadersproject.org/

Shared Decision Making :
Pinnacle of Person Centered Care (Barry et al., 2012)

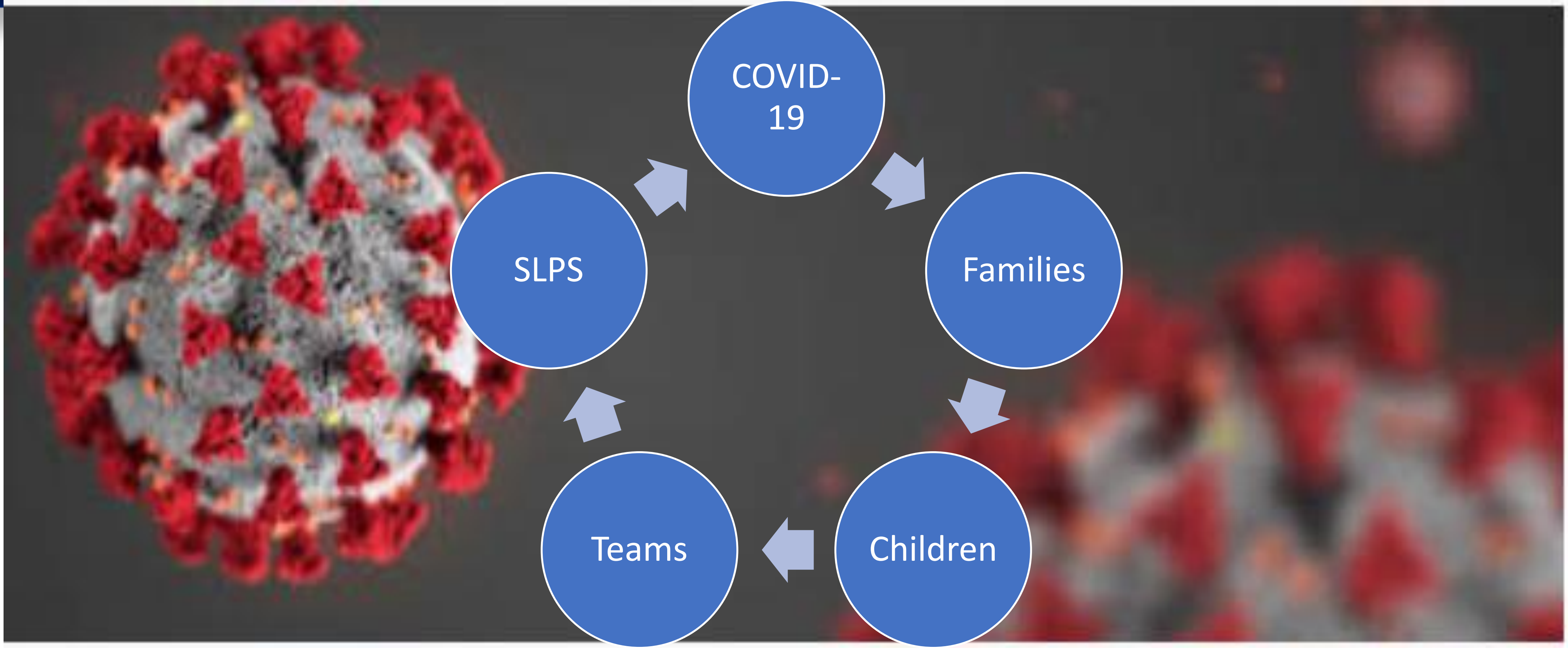
IOM: PCC is care that is respectful of and responsive to individual patient preferences, needs, values

Need to ask clients what the *outcome* is THEY want

Client rather than clinician centered

Need to co-create goals and focus on desired client and family outcomes

COVID-19 underscores importance of FCCC



COVID-19

Families

Children

Teams

SLPS

Don’t forget siblings’ voices!

(Stock et al., 2016)

Sibling bond

Sibling rivalry

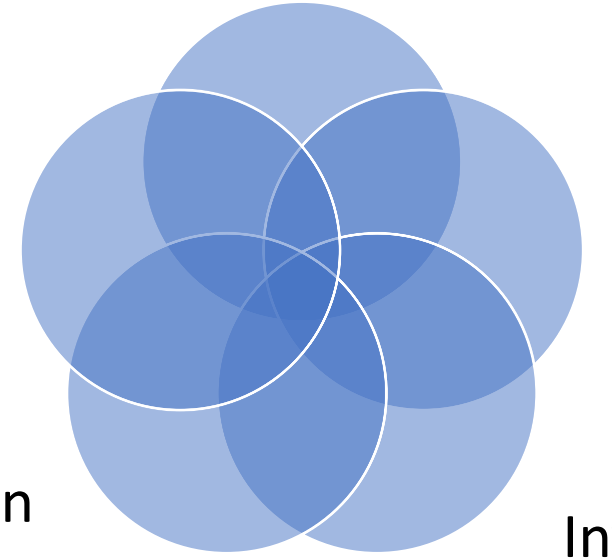
Sibling anxiety

Positive impact

Sibling and parental support needs

Mode of support

And.. Don't forget the grandparents who often play a key role ! (Guest et al.,2019)



Emotional impact

Social experiences

Involvement

Information needs

Support needs

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Implications of the ICF and FCCC for SLPs

View clients with CL/P holistically

- go beyond body structure and function to gain deeper understanding
- reframe and expand assessment areas and tools
- identify areas of a child’s life impacted by a CL/P (Cronin,2020)
- understand that although significant ,medical and therapy issues are only part of their story-home, school is where the rest of their life- story takes place
- develop respectful relationships with children to hear their voices !

Elicit and listen to families’ and children/adolescents’ voices

- shared decision-making
- knowledge of their world allows for changing/altering barriers in their environment
- Treat family how THEY want to be treated(Harley,2021)
- Treatment choices ,EBP and goal setting

Listening to families' and clients' voices

- Letting families and clients speak embraces core principles of FCCC
- Working with families important during the entire process of medical treatment, assessment , intervention
- Families are experts on their children and integral part of clinical decision making

Cleft Palate Teams and FCCC

Team Approach too CL/P and Craniofacial Disorders

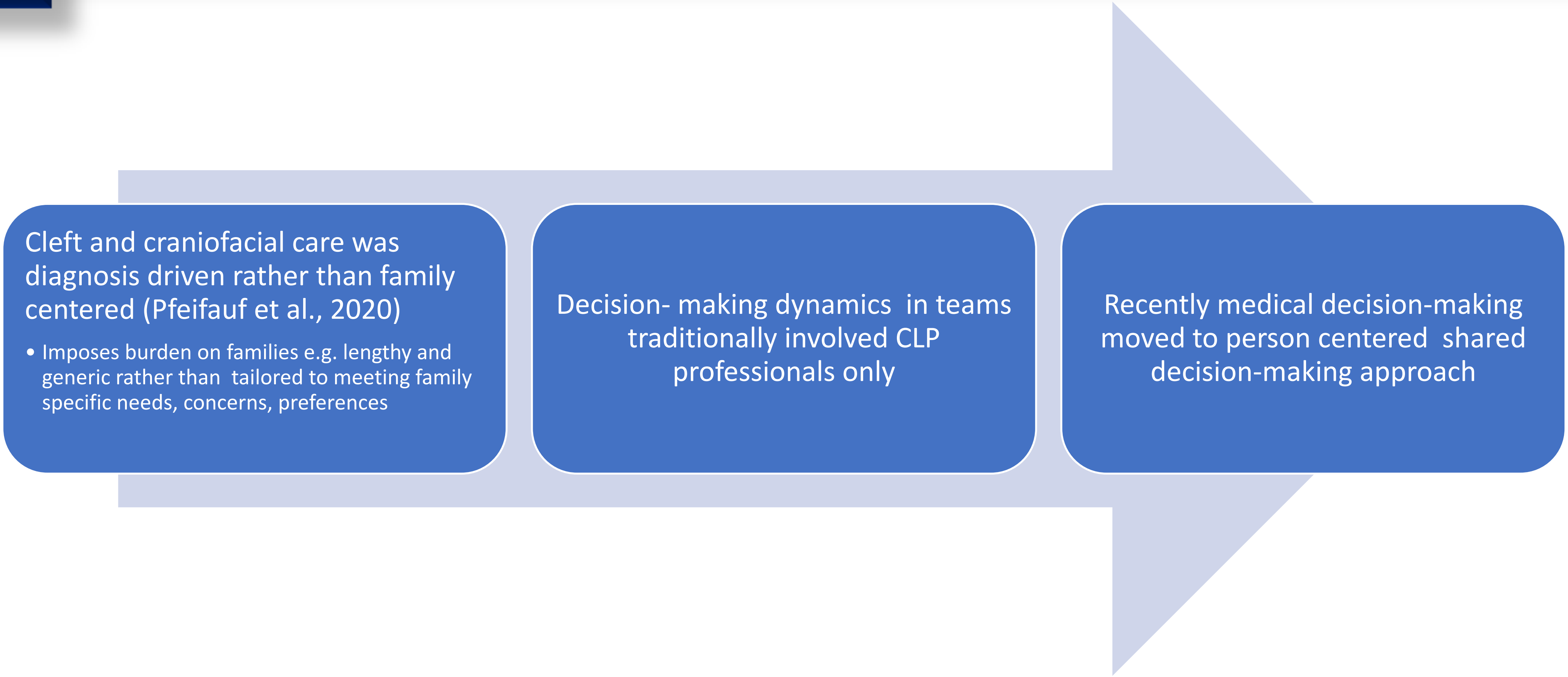
Different types of teams e.g.

- Cleft Lip and Palate
- Craniofacial Disorders
- Disorder specific e.g. 22q11.2 Deletion Syndrome
- Etc.

Team Collaboration with Community SLPs e.g.

- Referrals
- Consultations
- Exchange of reports, information
- Guidance re intervention
- Co-provision of care
- Etc.

Traditionally in teams



Cleft and craniofacial care was diagnosis driven rather than family centered (Pfeifauf et al., 2020)

- Imposes burden on families e.g. lengthy and generic rather than tailored to meeting family specific needs, concerns, preferences

Decision- making dynamics in teams traditionally involved CLP professionals only

Recently medical decision-making moved to person centered shared decision-making approach

Recent trends in Teams: Shared-Decision making

Shared decision-making with children and adolescents complex:

- concerns re their ability to fully understand implications of treatment decisions
- their position in the 3-way relationship between parents and professionals
- protective attitude of parents and professionals
- cognitive maturation during adolescence

Adolescents want to *"have a voice"* during decision-making

Speech and appearance concerns can impact QoL and crucial for children and adolescents to be able to:

- voice their concerns; have sense of control over treatment, receive support
- provide less intimidating environment than current team meetings to express their views

(Wogden et al.,2020)

Recent trends in teams: FCCC

Shared decision-making

- Shared decision-making with adults critical element of preference-sensitive health-care decisions
- Dearth of literature regarding shared-decision making by children with CL/P re revision-related surgeries

Cleft-related revision surgeries occur at age where children can participate meaningfully in such decisions

- Choice to pursue revision surgeries preference-sensitive given aim is to improve aesthetics and function that impact QoL and child assent is required

Caregivers important stakeholders but documented disagreement of opinions between children and caregivers re appearance related complaints and procedures

continued

Surgeons need to facilitate increased participation in treatment decisions

- Promotes FCCC
- Improves outcomes
- Increases health care efficiency

Child assent should be incorporated into treatment decisions to show respect for dignity and ever- increasing levels of autonomy

- Requires education and age appropriate language for child to understand their condition, recommended treatment, risks, benefits and alternatives
- Challenging but important as long-term repercussions when opinions are not considered

Teams need to start educating children with CL/P early to empower them to contribute meaningfully to surgical decisions (Bennet et al., 2020)

continued

Pfeifauf et al.(2020): developed model and process to reorganize their CL/P team to family-centered e.g.

- Partner with families early, frequently(family specific needs, preferences, shared decision making)
- Family Advisory Council
- Patient reported Outcomes measurement(PROMIS)

Recent trends in Teams: Transition of Care (ToC):

- Many young adults need to leave security of pediatric multidisciplinary team at age 18 as not all teams provide adult services
- Young adults must obtain services in the community independent of their team and find resources to carry the cost
- ToC growing trend in teams nationwide
- Preparation needs to start in teen years and has to be *person-centered*
- Involve both *patient and family* in discussion
  - find an acceptable balance between parent support and the young adult's autonomy.
  - active participation of the young adult (and when appropriate, input from the parents).
- SLP needs to educate, support , use person-reported outcomes(i.e. person's thoughts re impact of speech on functioning such as oral presentations in class)

(Vallino & Louw,2017)

What does ToC mean for the young adult with CLP?

(Louw& Vallino, 2021)

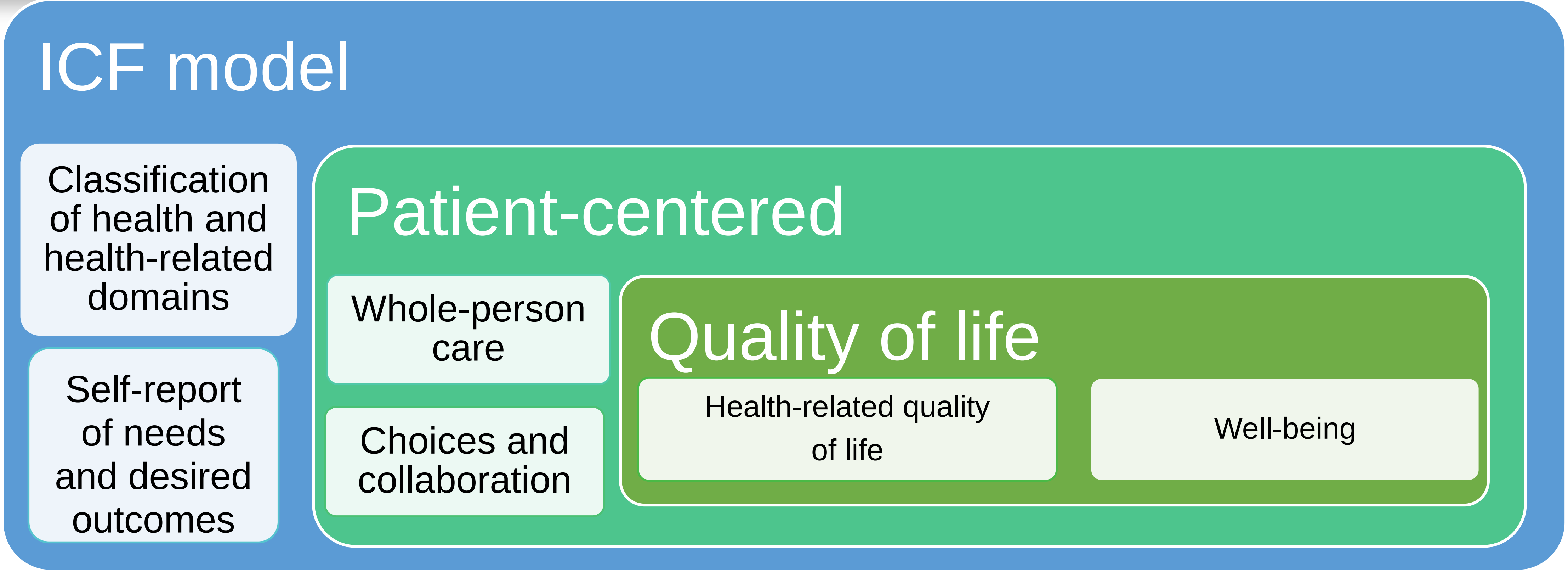
Building knowledge and skills to understand and independently manage their healthcare needs

Building skills to advocate for themselves and their healthcare needs

Finding new doctors and providers who can treat them as adults and finding ways to pay for it

Preparing them to manage their care independently

Essential to successful transition is: *Integrated Model of Care* (Louw& Vallino, 2021)



ICF model

Classification of health and health-related domains

Self-report of needs and desired outcomes

Patient-centered

Whole-person care

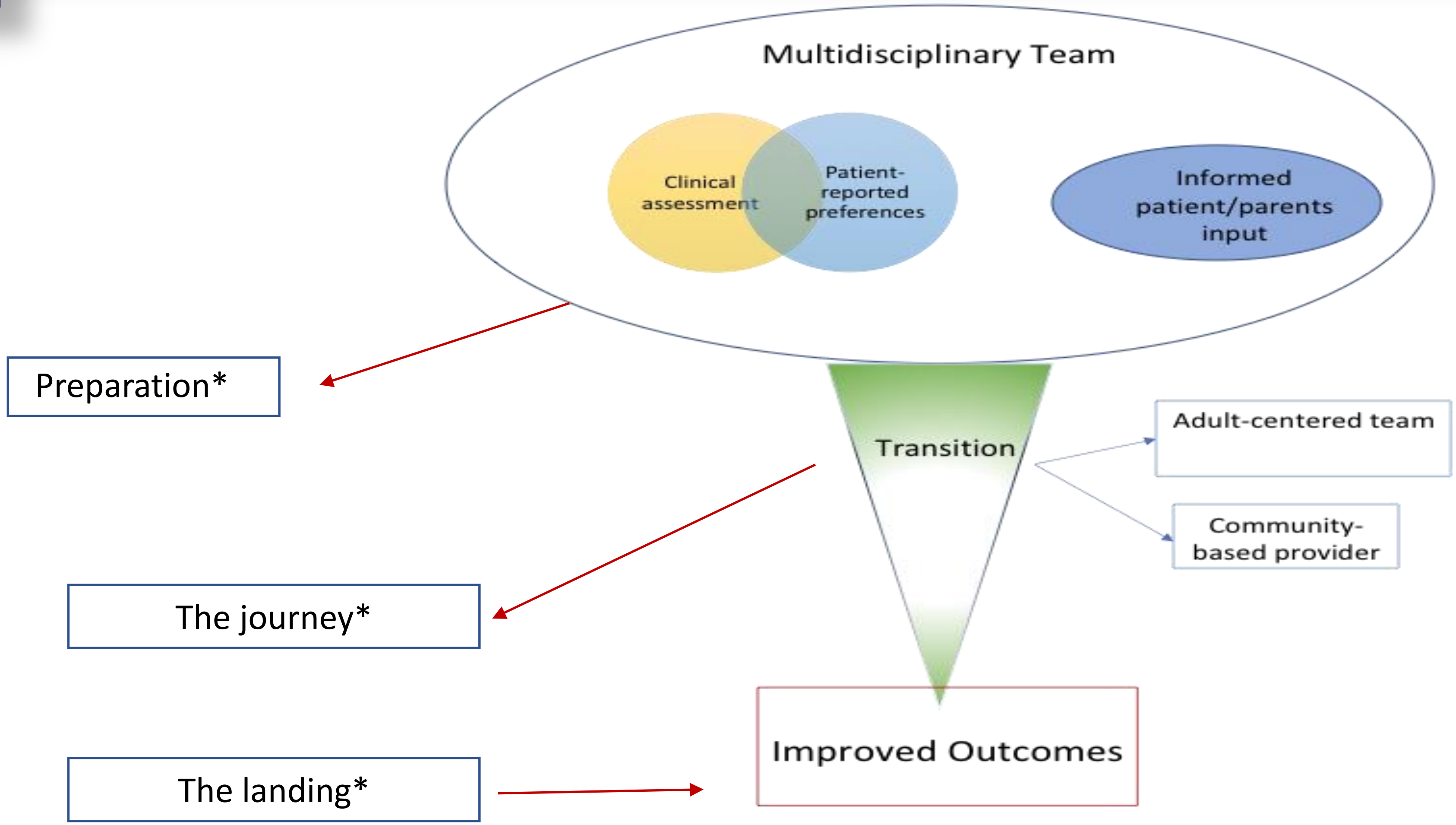
Choices and collaboration

Quality of life

Health-related quality of life

Well-being

Proposed Service Delivery Framework for Transition of Care (Vallino& Louw,2017)



*Nguyen & Gorter, 2013

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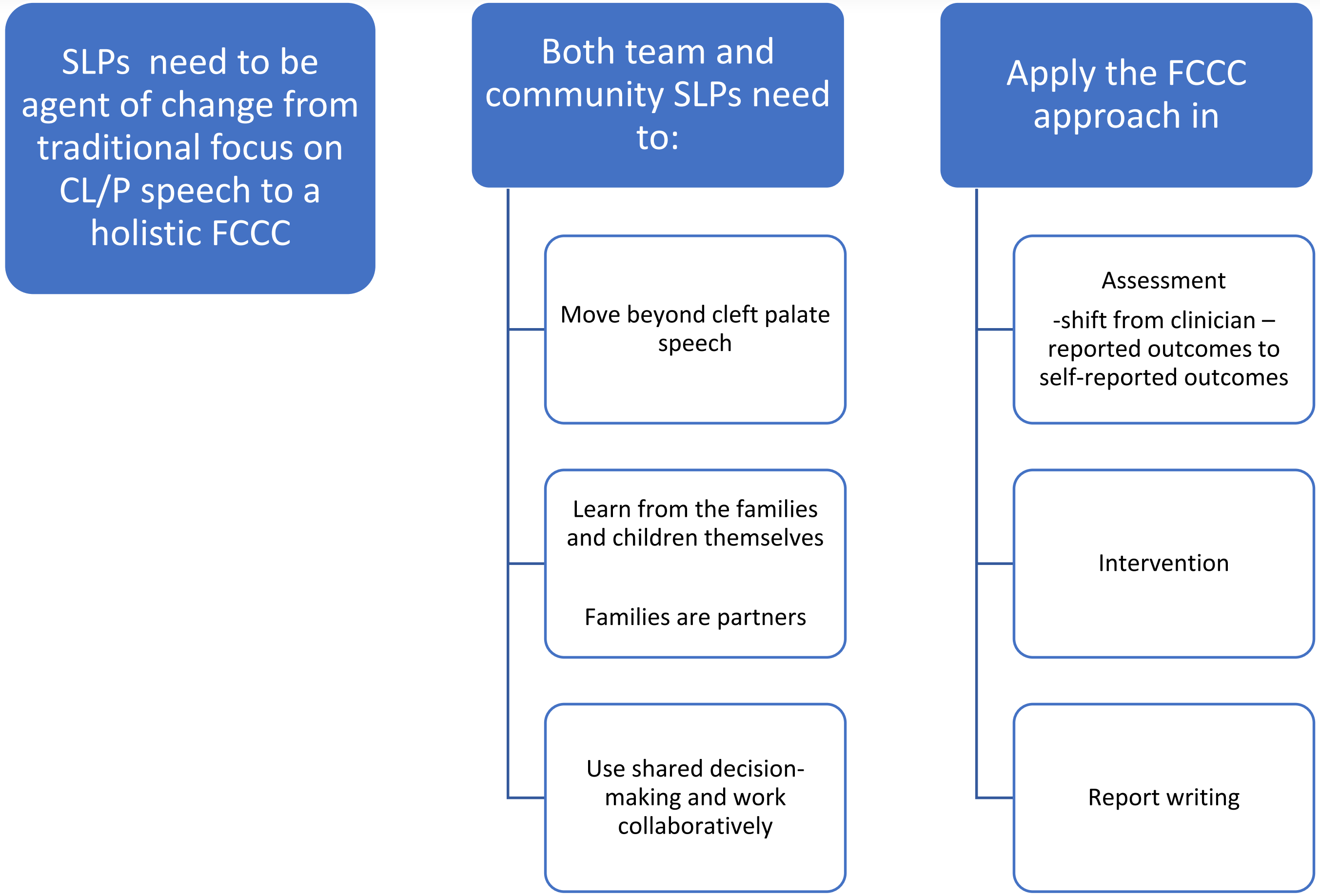
Changes in teams: Implications for SLPs



SLPs need to be agent of change from traditional focus on CL/P speech to a holistic FCCC

Both team and community SLPs need to:

- Move beyond cleft palate speech
- Learn from the families and children themselves

  Families are partners
- Use shared decision-making and work collaboratively

Apply the FCCC approach in

- Assessment

  -shift from clinician – reported outcomes to self-reported outcomes
- Intervention
- Report writing

Assessment within the ICF framework and FCCC approach

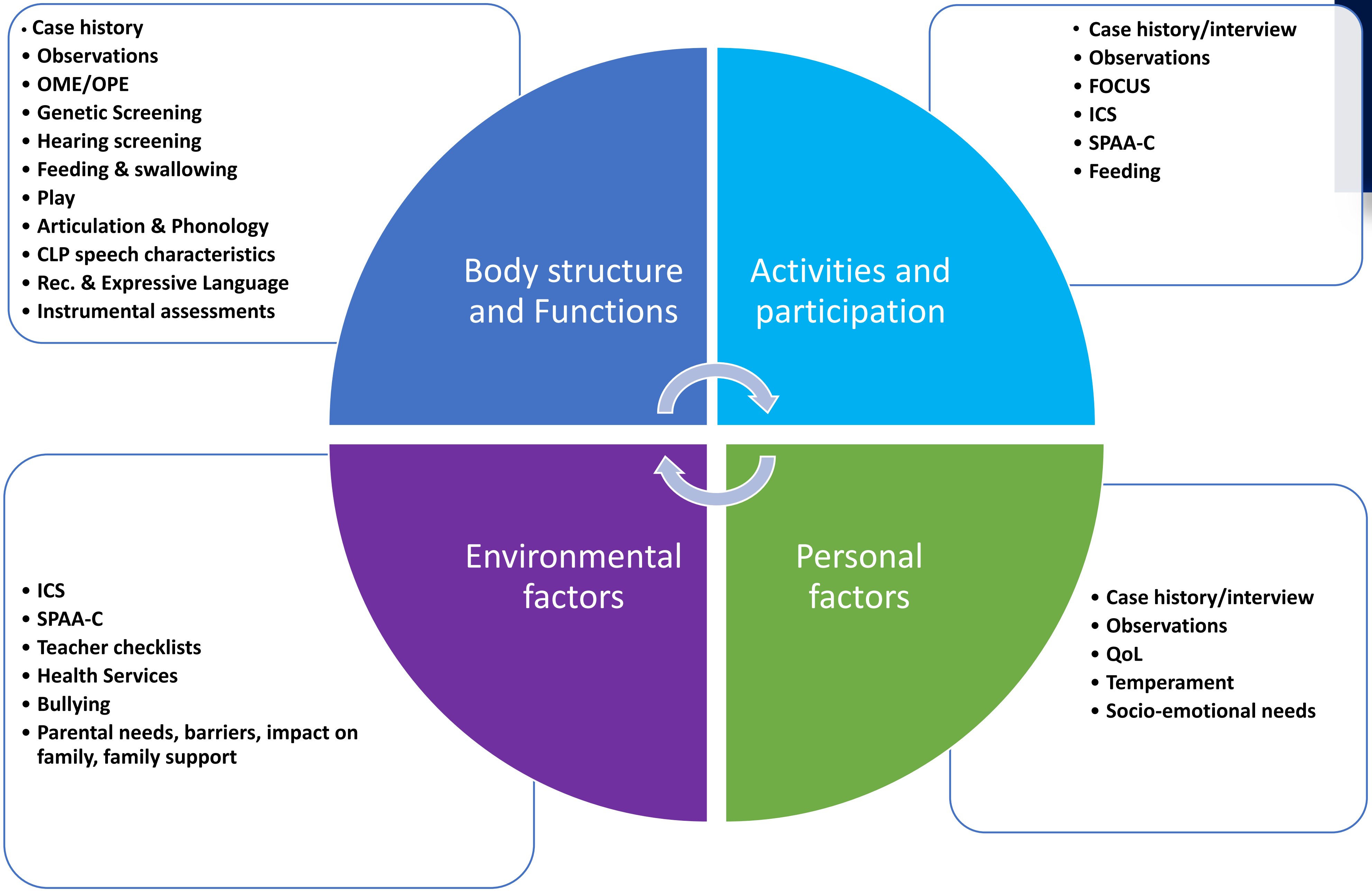
To hear Family and Child Voices, SLPs need to:

Collaborate and engage with families and children we need assessment tools that allow their *voices to be heard*

Expand our assessment battery to look beyond the therapy room and the CL/P and view clients and families holistically

Use the ICF framework to guide assessment and clinical reasoning

Consider the suggested assessment protocol (Louw, 2018; Cronin et al, 2020)



Body structure and Functions

- Case history
- Observations
- OME/OPE
- Genetic Screening
- Hearing screening
- Feeding & swallowing
- Play
- Articulation & Phonology
- CLP speech characteristics
- Rec. & Expressive Language
- Instrumental assessments

Activities and participation

- Case history/interview
- Observations
- FOCUS
- ICS
- SPAA-C
- Feeding

Environmental factors

- ICS
- SPAA-C
- Teacher checklists
- Health Services
- Bullying
- Parental needs, barriers, impact on family, family support

Personal factors

- Case history/interview
- Observations
- QoL
- Temperament
- Socio-emotional needs

Examples of ICF-CY and QoL Resources to use with Children with CLP

Clinical Tool	Author	Weblink / Reference
Intelligibility in Context Scale (ICS)	McLeod, Harrison, & McCormack, 2012	http://www.csu.edu.au/__data/assets/pdf_file/0010/399970/ICS-English.pdf http://www.csu.edu.au/research/multilingual-speech/ics
Focus on the Outcomes of Communication under Six (FOCUS-34)	Thomas-Stonell, N., Oddson,B., Robertson, B.& Rosenbaum, P.L.(2010)	https://www.canchild.ca/en/resources/304-focus
Speech Participation and Activity in Children (SPAA-C)	McLeod, S.(2003)	http://www.csu.edu.au/research/multilingual-speech/spaa-c
VPI effects on Life Outcome (VELO)	Skirko,J.R., Weaver,E.M. ,Kinter, S. & Sie, K.C. (2012) Kinter, S. et al(2018)	*Arch Otolaryngol Head Neck Surg,* 2012,138(10:929-935.); Perspectives of the ASHA Special Interest Groups, 3(5), 64-77. doi: 10.1044/persp3.sig5.64
Parental Appraisal of Cleft Questionnaire (PACQ)	Shuttlewood,E.,Dalton,L. & Cooper,M(2014)	Cleft Palate Cranio-Facial Journal, 2014,51(2): 207-221

The Focus on the Outcomes of Children Under Six ©(FOCUS-34) (Thomas-Stonell in Washington et al.,2015)

The FOCUS-34 © :

- Is an outcome measure for preschool children (1.5 – 6 yrs.) attending speech-language therapy.
- Can be used with children who have a variety of communication disorders.
- Is primarily a parent measure as it measures children's use of communication at home and in the community.
- A Clinician Form is available if the parents cannot complete the FOCUS.
- Clinicians need to consult with the primary caregiver or ECE teacher in order to complete

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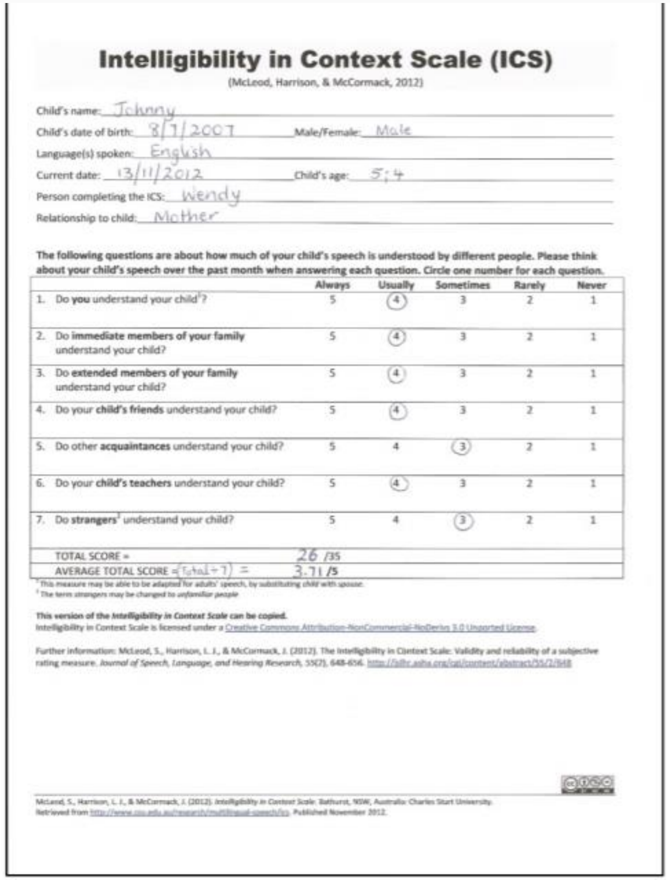
Measure	Description
Purpose	Criterion-referenced measure of ‘real world’ outcomes of communication interventions
Population	Preschool children (<6years)
Description of domains	50 items (statements) in two parts: Part I: respondents describe how well items describe the child Part II: respondents identify the amount of cueing required by the child to complete items
Administration and test format	2 versions with identical items Items are rated at the start and completion of intervention Time to complete: 10 minutes Testing format: parent/clinician responds to written statements Scoring: 7-item Likert scale ranging from “not at all like my child” to “exactly like my child” Training: No training required
Psychometric properties	No available scale development sample due to nature of the measure Testing of the measure occurred with 165 families of children (mean age 3.8 years) 72% male 13% with specific medical diagnoses High Reliability: Cronbach’s alpha 0.97 at start of therapy and 0.94 upon completion High construct validity The FOCUS is currently undergoing research to establish its responsiveness to change
How to order	The user version is available from https://www.canchild.ca/en/shop/30-focus-34

The Intelligibility in Context Scale (ICS)

- McLeod, Harrison & McCormack,2013
- Freely available: https://www.csu.edu.au/research/multilingual-speech/ics

The Intelligibility in Context Scale (ICS)

- Measure of functional intelligibility:
  - measures intelligibility with a variety of listeners in various environments
  - is holistic, ICF-CY assessment approach for intelligibility
- 7-item, parent-report measure of children's speech intelligibility with a range of communicative partners
- High internal: Reliability, Sensitivity, Construct validity
- Criterion validity established through significant correlation between the ICS and the PPC.



Intelligibility in Context Scale (ICS)

(McLeod, Harrison, & McCormack, 2012)

Child's name: Johnny
Child's date of birth: 8/7/2007 Male/Female: Male
Language(s) spoken: English
Current date: 13/11/2012 Child's age: 5;4
Person completing the ICS: Wendy
Relationship to child: Mother

The following questions are about how much of your child's speech is understood by different people. Please think about your child's speech over the past month when answering each question. Circle one number for each question.

	Always	Usually	Sometimes	Rarely	Never
1. Do **you** understand your child[1]?	5	[✓ 4]	3	2	1
2. Do **immediate members of your family** understand your child?	5	[✓ 4]	3	2	1
3. Do **extended members of your family** understand your child?	5	[✓ 4]	3	2	1
4. Do your **child's friends** understand your child?	5	[✓ 4]	3	2	1
5. Do other **acquaintances** understand your child?	5	4	[✓ 3]	2	1
6. Do your **child's teachers** understand your child?	5	[✓ 4]	3	2	1
7. Do **strangers**[2] understand your child?	5	4	[✓ 3]	2	1
TOTAL SCORE =	26 /35				
AVERAGE TOTAL SCORE = (Total ÷ 7) =	3.71 /5				

[1] This measure may be able to be adapted for adults' speech, by substituting *child* with *spouse*.
[2] The term *strangers* may be changed to *unfamiliar people*

This version of the *Intelligibility in Context Scale* can be copied.

Further information: McLeod, S., Harrison, L. J., & McCormack, J. (2012). The Intelligibility in Context Scale: Validity and reliability of a subjective rating measure. *Journal of Speech, Language, and Hearing Research, 55*(2), 648-656. http://jslhr.asha.org/cgi/content/abstract/55/2/648

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Figure 1. Example of how to complete the ICS

	Always	Usually	Sometimes	Rarely	Never
1. Do **you** understand your child[1]?	5	4	3	2	1
2. Do **immediate members of your family** understand your child?	5	4	3	2	1
3. Do **extended members of your family** understand your child?	5	4	3	2	1
4. Do your **child's friends** understand your child?	5	4	3	2	1
5. Do other **acquaintances** understand your child?	5	4	3	2	1
6. Do your **child's teachers** understand your child?	5	4	3	2	1
7. Do **strangers**[2] understand your child?	5	4	3	2	1

TOTAL SCORE = /35

AVERAGE TOTAL SCORE = /5

McLeod, S., Harrison, L. J., & McCormack, J. (2012). The Intelligibility in Context Scale: Validity and reliability of a subjective rating measure. *Journal of Speech, Language, and Hearing Research, 55*(2), 648-656. doi: 10.1044/1092-4388(2011/10-0130)

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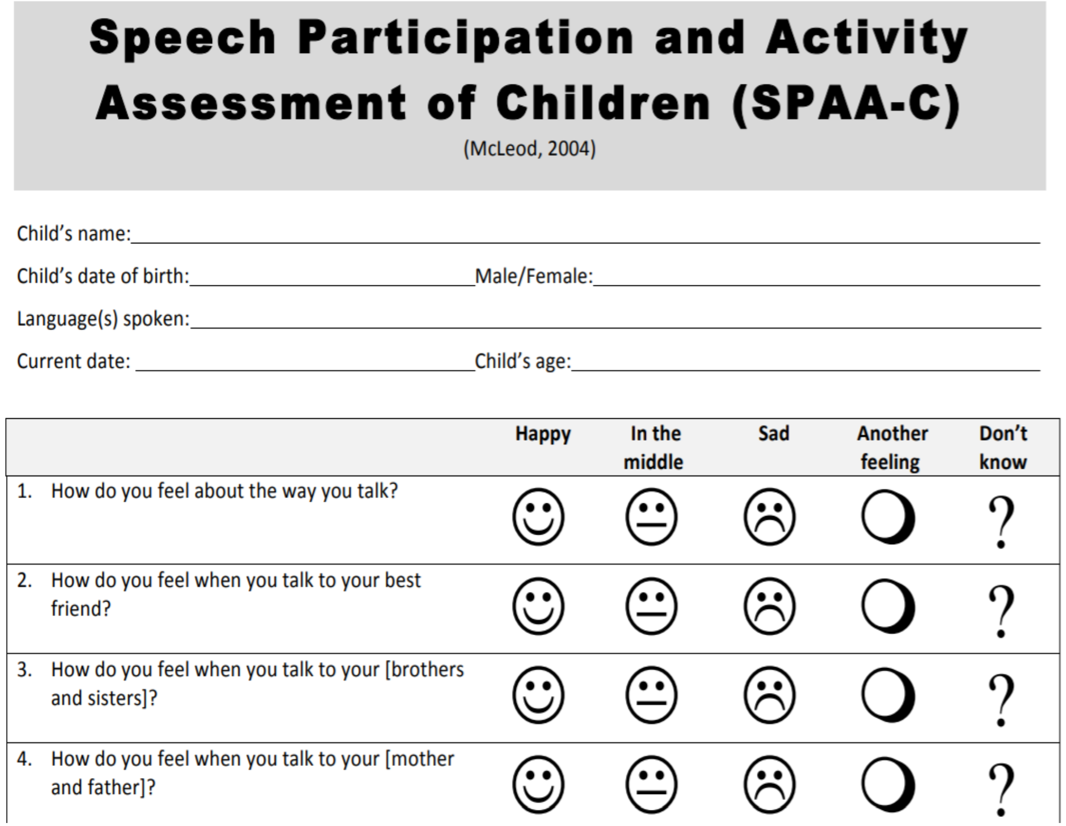
The Speech Participation and Activity Assessment of Children

- The SPAA-C evaluates activity and participation of children with speech impairments, by collecting information on the impact of the speech impairment on the child’s life from various parties (i.e. parents, teachers, child, friends, siblings) (McLeod,2012)
- It is intended to
  - Increase understanding of individual children and the context they live in
  - Act as a guide in planning intervention to help impact the child’s life as a whole (ICF-CY framework).
- Available free in different languages at :

http://www.csu.edu.au/data/assets/pdf_file/0005/227660/SPAAC2.pdf



Speech Participation and Activity Assessment of Children (SPAA-C)

(McLeod, 2004)

Child’s name:____

Child’s date of birth:____________________ Male/Female:____________________

Language(s) spoken:____

Current date: ____________________ Child’s age:____________________

	Happy	In the middle	Sad	Another feeling	Don’t know
1. How do you feel about the way you talk?	☺	😐	☹	◑	?
2. How do you feel when you talk to your best friend?	☺	😐	☹	◑	?
3. How do you feel when you talk to your [brothers and sisters]?	☺	😐	☹	◑	?
4. How do you feel when you talk to your [mother and father]?	☺	😐	☹	◑	?

SPAA-C Description

The SPAA-C includes questionnaires for:
  - The Child (27 questions)
  - Friends (6 questions)
  - Parents (20 questions)
  - Siblings (5 questions)
  - Teachers (19 questions)
- Administration and scoring:
  - Semi-structure interview schedules
  - Not scored-designed to elicit qualitative information
  - Used in research and identified major themes relevant to children's experiences (McCormack et al., 2010; Barr, McLeod & Daniel, 2008)
- Child, parent, and teacher sections have more questions and questions with greater depth.
  - Questionnaires take approximately 10 minutes to complete
- Questions for children and siblings do not directly refer to the child's speech abilities.

Audience	Examples of Questions
Friends	What do you like about your friend? Is there anything your friend has trouble with? What do you do when you don’t understand your friend?
Siblings	Tell me about your brother/sister? What do you like about your brother/sister? Is there anything your brother/sister has trouble with?
Child	What are your favorite things to do? Who do you like to talk to? When do you like to talk to people? Do you think your talking is different from other children’s?
Parent	Who does your child speak with in a normal week? Tell me about your child. Is there anything that makes your child particularly unhappy? What do you notice about your child’s speech compared to other children?
Teachers	How does this child get his/her message across? Is s/he teased at school? Does this child have a preferred modality for learning? Does his/her speech limit his/her involvement in school?
Others	How does this child interact with you and others? How well does this child get his/her message across

VPI Effects on Life Outcomes(VELO)

- VPI functional status measure 26 item parent report (VELO-P) and 23 item youth report (VELO-Y)
  - 6 domains: speech limitations, swallowing problems, situational difficulty, emotional impact, perception by others and caregiver impact
  - VELO-Y the same domains minus caregiver impact
  - Age 7 years and older
- Rated

  Rated on 5 point Likert scale

- Electronic version for tablet use
- Incorporate into standard assessment battery
- Valuable clinical tool -provides important information for decision making re VPI management
  - Educating/counseling family and client
  - Validating their perspective
  - Platform for dialogue between family, child, surgeon, SLP
  - Facilitates partnership to enhance informed clinical decisions

(Kinter, 2018)

Health related Quality of Life Assessment tools e.g.

- PEDSQL 4.0
    - http://www.pedsql.org/about_pedsql.html
- Child Perceptions Questionnaire for children aged 6 to 7 years old = CPQ_{6-7}
- Child Perceptions Questionnaire for children aged 8 to 10 years old = CPQ_{8-10}
- Child Perceptions Questionnaire for children aged 11 to 14 years old = CPQ_{11-14}
- Family Impact Scale questionnaire (FIS-SF)(Agnew et al.,2020).

Implications for SLPs

Follow holistic approach to assessment of children with CLP:

- to gain deeper, broader understanding of participation and communication skills of children with CL/P
- identify strengths and barriers to enable full participation in every day life

Use measures developed within ICF framework

- use results to justify and formulate person-centered goals (ASHA)

Intervention within the ICF framework and FCCC approach

Intervention key points

EBP [3]

Collaboration

Shared Decision-making

Functional goal setting

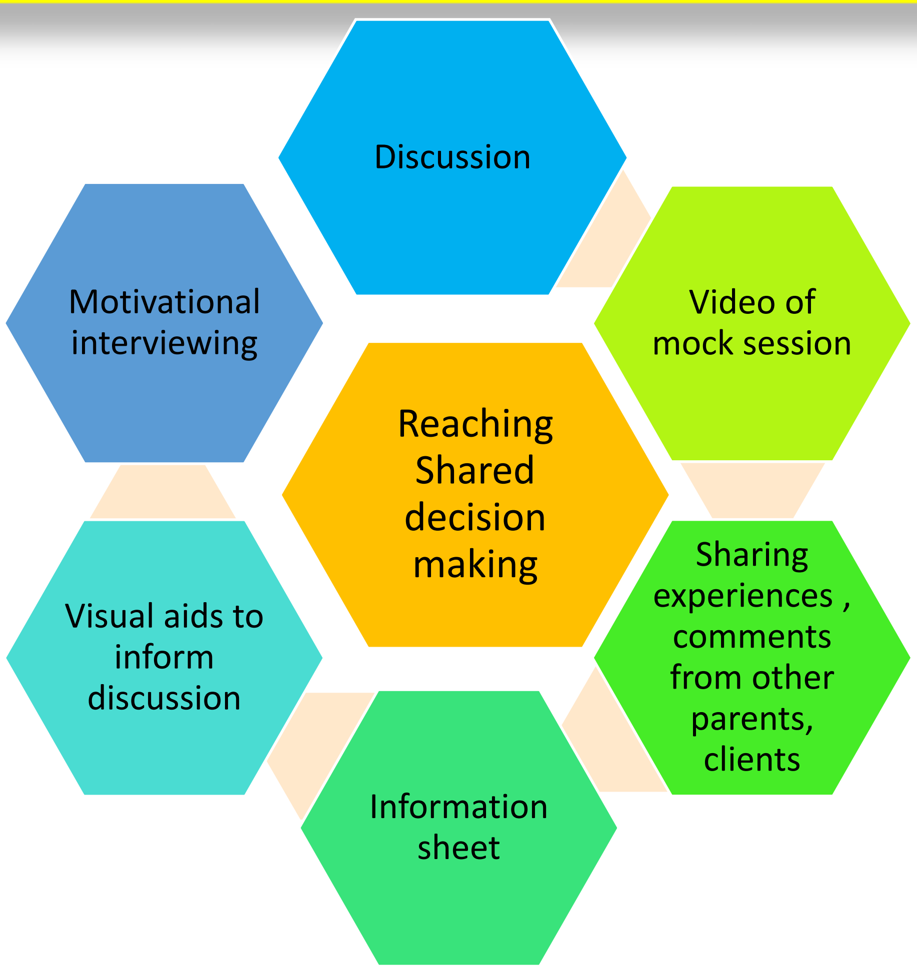
ICF and IDEA

Report writing

Evidence Based Practice ^{3} with a Family Voice (Heidecker et al.,2009,p213)

Traditional EBP ^{3}	**Family-Centered EBP ^{3}**
1. Choose question for a client specific decision	1. Choose questions important to the family-decision making
2. Search for research evidence related to question	2. Find relevant research evidence related to question
3. Evaluate research evidence for validity, relevance, and clinical applicability	3. Evaluate research evidence for its validity, family relevance, and family/ clinical applicability
4. Integrate evidence with clinical experience and client preferences	4. Integrate client and family values with evidence and clinical experience
5. Assess performance of steps to improve future decisions	5. Evaluate the family-professional collaborative process and family-relevant outcomes
(Heidecker et al., 2009, p213)	

How do you inform the family and client of evidence? (Baker,2012)



Discussion

Video of mock session

Sharing experiences , comments from other parents, clients

Information sheet

Visual aids to inform discussion

Motivational interviewing

Reaching Shared decision making

Collaborating with families to hear their voices (Klatte et al,2020)

Relational practice:

- Mutual understanding
- Relationship between family and SLP
- Parental/family empowerment

Participatory practice:

- Mutually agreed upon goals
- Shared planning
- Shared implementation
- Shared evaluation

Functional Goal setting

- Shared goal setting leads to relevant outcomes for the child
- ASHA Person Centered Focus on Function https://www.asha.org/siteassets/uploadedfiles/icf-cleft-palate.pdf

PERSON-CENTERED FOCUS ON FUNCTION:

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

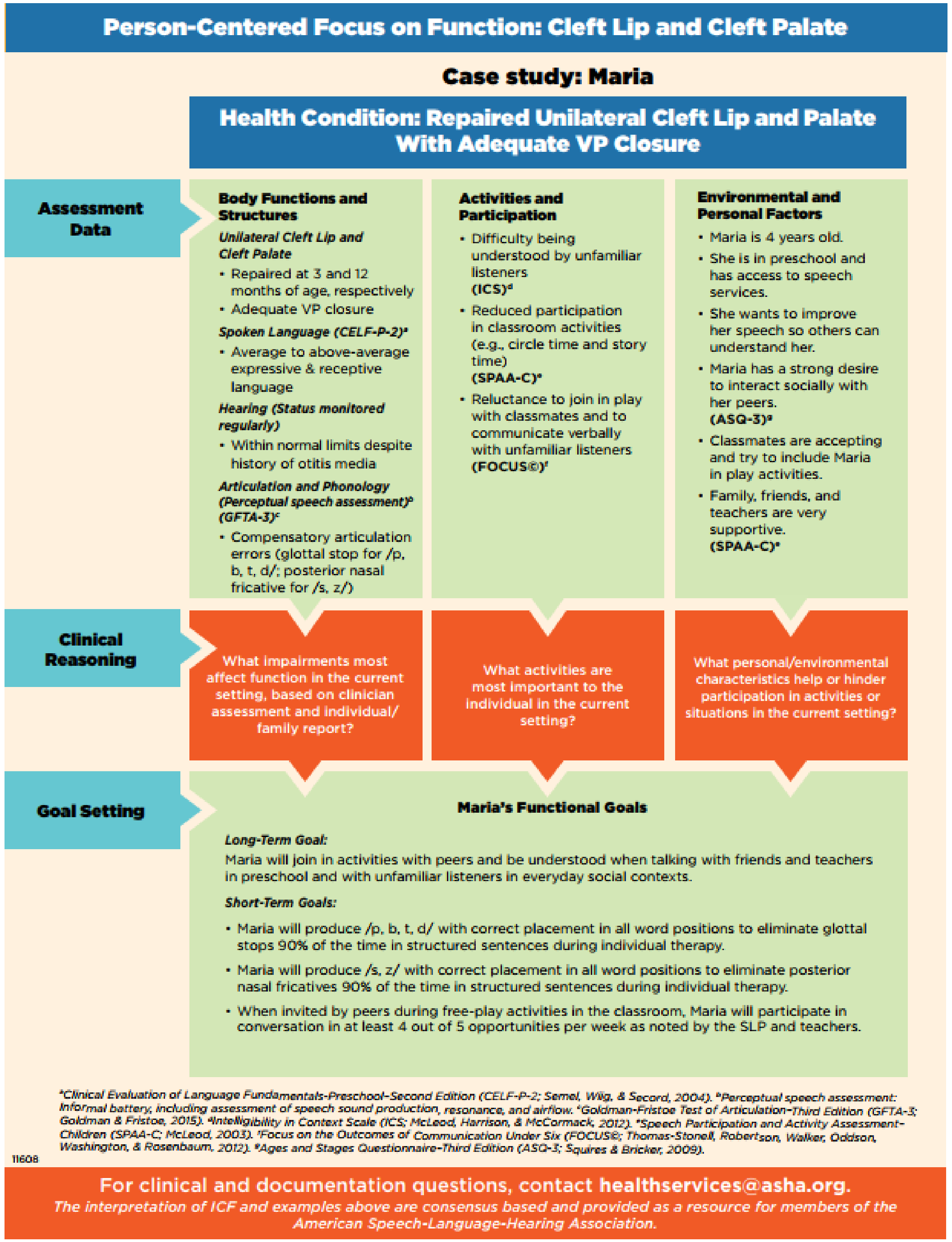
Health Condition
disorder or disease that informs predicted comorbidities and prognosis

Body Functions and Structures
anatomical parts and their physiological functions

Activities and Participation
execution of tasks or involvement in life situations

Environmental and Personal Factors
physical, social, attitudinal, and environmental factors and factors within the individual's life

ADDITIONAL RESOURCES: asha.org/slp/icf/ • who.int/classifications/icf/en/



Person-Centered Focus on Function: Cleft Lip and Cleft Palate

Case study: Maria

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

Assessment Data

Body Functions and Structures

Unilateral Cleft Lip and Cleft Palate
- Repaired at 3 and 12 months of age, respectively
- Adequate VP closure

Spoken Language (CELF-P-2)[a]
- Average to above-average expressive & receptive language

Hearing (Status monitored regularly)
- Within normal limits despite history of otitis media

Articulation and Phonology (Perceptual speech assessment)[b] (GFTA-3)[c]
- Compensatory articulation errors (glottal stop for /p, b, t, d/; posterior nasal fricative for /s, z/)

Activities and Participation
- Difficulty being understood by unfamiliar listeners **(ICS)[d]**
- Reduced participation in classroom activities (e.g., circle time and story time) **(SPAA-C)[e]**
- Reluctance to join in play with classmates and to communicate verbally with unfamiliar listeners **(FOCUS©)[f]**

Environmental and Personal Factors
- Maria is 4 years old.
- She is in preschool and has access to speech services.
- She wants to improve her speech so others can understand her.
- Maria has a strong desire to interact socially with her peers. **(ASQ-3)[g]**
- Classmates are accepting and try to include Maria in play activities.
- Family, friends, and teachers are very supportive. **(SPAA-C)[e]**

Clinical Reasoning

What impairments most affect function in the current setting, based on clinician assessment and individual/family report?

What activities are most important to the individual in the current setting?

What personal/environmental characteristics help or hinder participation in activities or situations in the current setting?

Goal Setting

Maria's Functional Goals

Long-Term Goal:
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.

Short-Term Goals:
- 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.
- 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.
- 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.

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

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For clinical and documentation questions, contact **healthservices@asha.org.**

The interpretation of ICF and examples above are consensus based and provided as a resource for members of the American Speech-Language-Hearing Association.

The ICF-CY and IDEA (Westby, & Washington,2017).

IEP Component	IDEA IEP Requirements	Integrating the ICF with IDEA
Current skill levels	A statement of the child's present levels of **academic achievement** and **functional performance** **(IDEA does not define functional)** Must ensure that children with disabilities can participate in **extracurricular** activities and other **nonacademic** activities.	The ICF defines current levels at both **capacity (skill)** level and **participation (performance)** level. ICF considers **personal** and **environmental** factors that serve as facilitators or barriers to current levels.

Report writing (Braun et al.,2017)

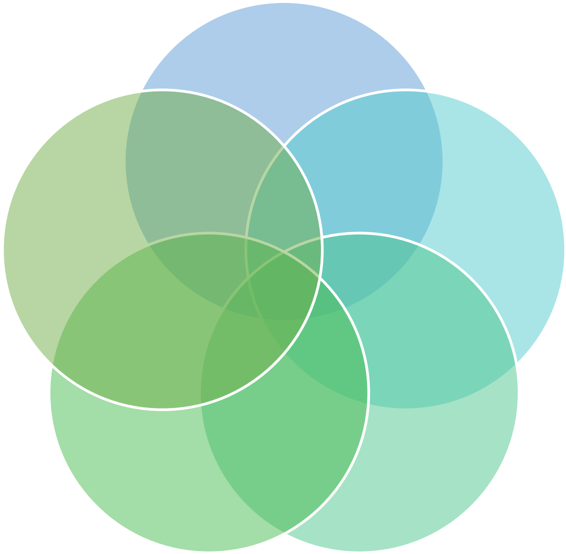
- Reports tend to be written from a deficit perspective because of diagnostic criteria
- Can write from strength based perspective and still document behaviors necessary for a diagnosis
  - Preserves dignity and maintains respect for child and family
- Assessment and progress reports need to reflect integration of the ICF framework and FCCC to demonstrate the biopsychosocial, strength-based 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.

The boys

continued

Take Home points



View families and clients with CLP holistically

Provide opportunities for families' and clients' voices to be heard

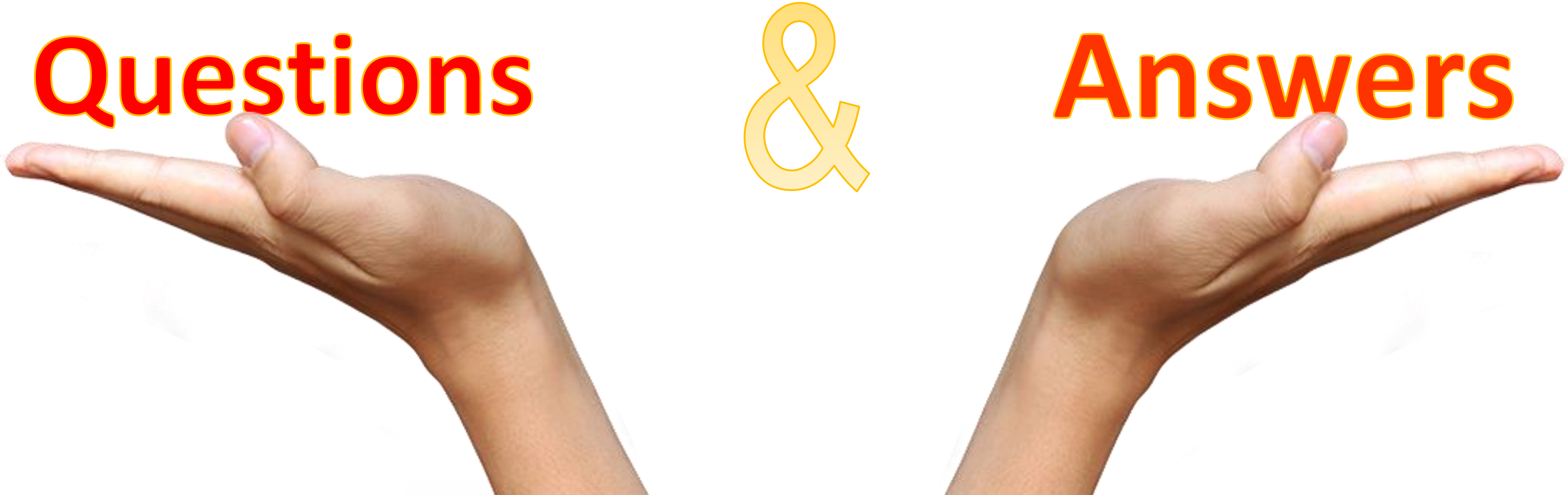
Respect families' capacity

Address critical needs of families

Provide wrap-around care for the whole family

Thank you !

Discussion



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