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# Transition of Care for Young Adults with Cleft Lip and Palate: We've Got Some Growing Up to Do

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# Transition of Care for Young Adults with Cleft Lip and Palate: We've Got Some Growing Up to Do

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# Transition of Care for Young Adults with Cleft Lip and Palate: We've Got Some Growing Up to Do !

## ACPA 75<sup>th</sup> Annual Meeting

Pittsburg, PA

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# Disclosures

- Dr. Brenda Louw has no financial or non-financial disclosures; she is employed by East Tennessee State University, Johnson City, TN.
- Dr. Linda Vallino, co-author of *Evaluation and Management of Cleft Lip and Palate: A Developmental Approach* (with Dr. David Zajac) and *Cleft palate speech and resonance: An Audio and Video Resource* ( with Drs. Dennis Ruscello & David Zajac), is employed by Nemours/ A.I. DuPont Hospital for Children, Wilmington, DE. She has no non-financial disclosures.

# Learner Outcomes

- Participants will be able to:
  - Describe the characteristics and needs of young adults with CLP.
  - Discuss the model of transition of care for the young adult with CLP.
  - Extrapolate strategies that teams could use to improve the care of young adults with CLP.

# Good Morning Team!

- Disciplines represented by the audience
- Are you a CLP Team member?
- Does your team see young adults with CLP?
- Do you have an adult interdisciplinary team?
- Do you work in a freestanding hospital and...
- Do you have a transition plan for providers within your geographical region?

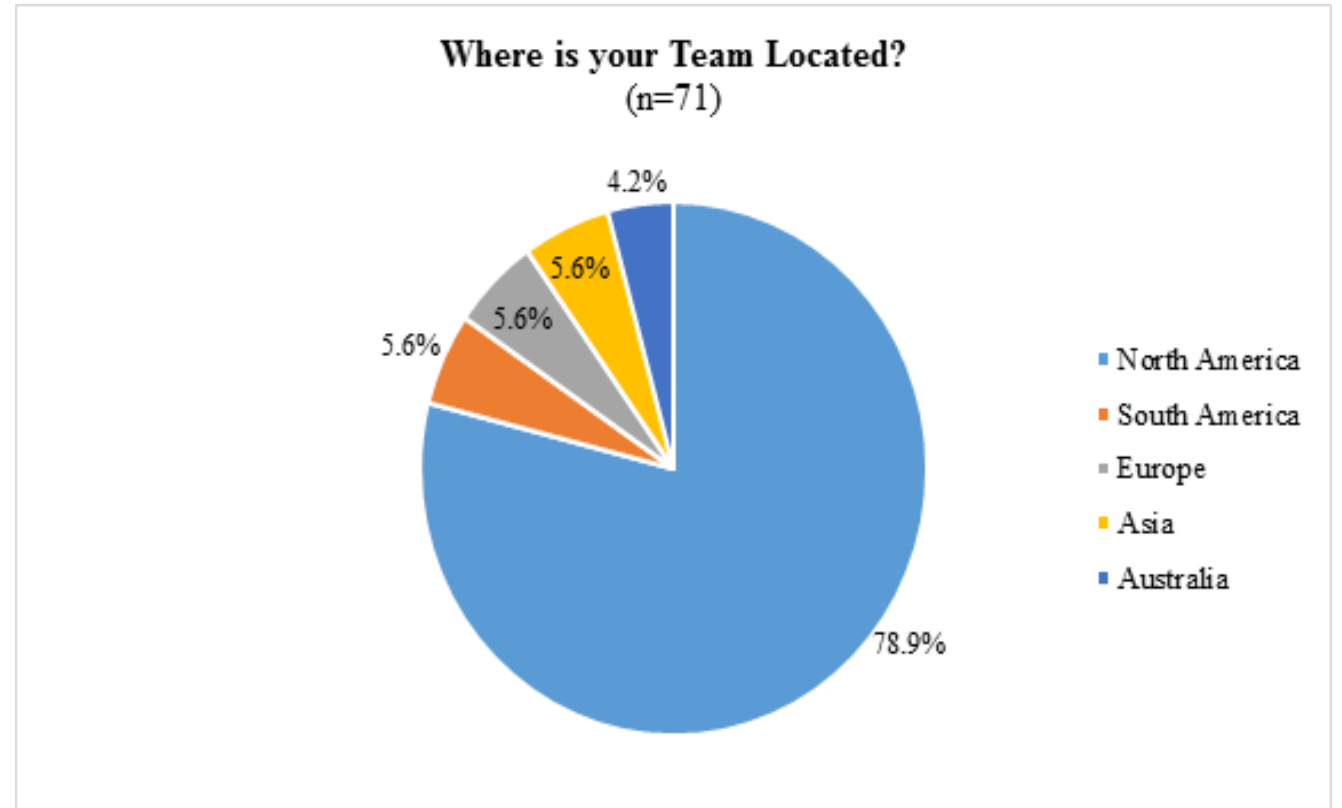


# Introduction

- Typically, team-provided services end abruptly at 18 years, and this is often the case in cleft palate.
  - Must depend upon community health care professionals for help with the transition from child-centered to adult-centered care.
- Transition of care from pediatric to adult-focused care for individuals with special health care needs – practiced among various disorders
- Very limited research and information on the transition of care from pediatric interdisciplinary team to adult- and community-based services for individuals with CLP.

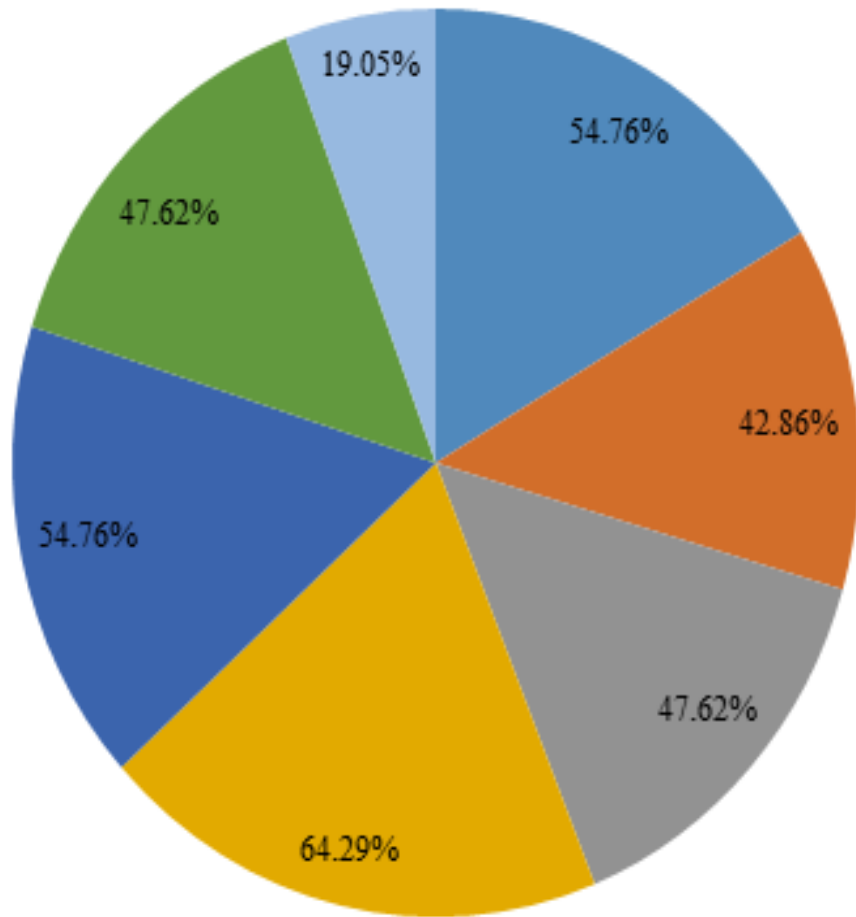
# Transition of Care for Cleft Palate: A Survey of Teams

- Surveyed 408 ACPA registered teams regarding Transition of Care (Bisceglia et al., 2017)
- 71 team coordinators from around the globe responded
- Low (18.4% ) response rate





## Transition Plan Elements (n=42)



- We include the patient and his/her parents/caregivers in developing the transition plan.
- We actively involve the patient in shared decision making when developing the transition plan.
- We make referrals to community health providers for further treatment and intervention.
- We provide general information for services available outside of our team.
- We have open access to services for young adults seeking to make contact with our team.
- We provide long-term follow-up with our adult patients.
- Other

### *Note:*

59% of the 71 respondents indicated that they had a Transition of Care Plan on their teams.

On transition...one person's story



# Purpose

## ➤ Purpose

- To propose an evidence-based conceptualized model for the transition of care for young adults with CLP within the ICF framework.

## ➤ Rationale

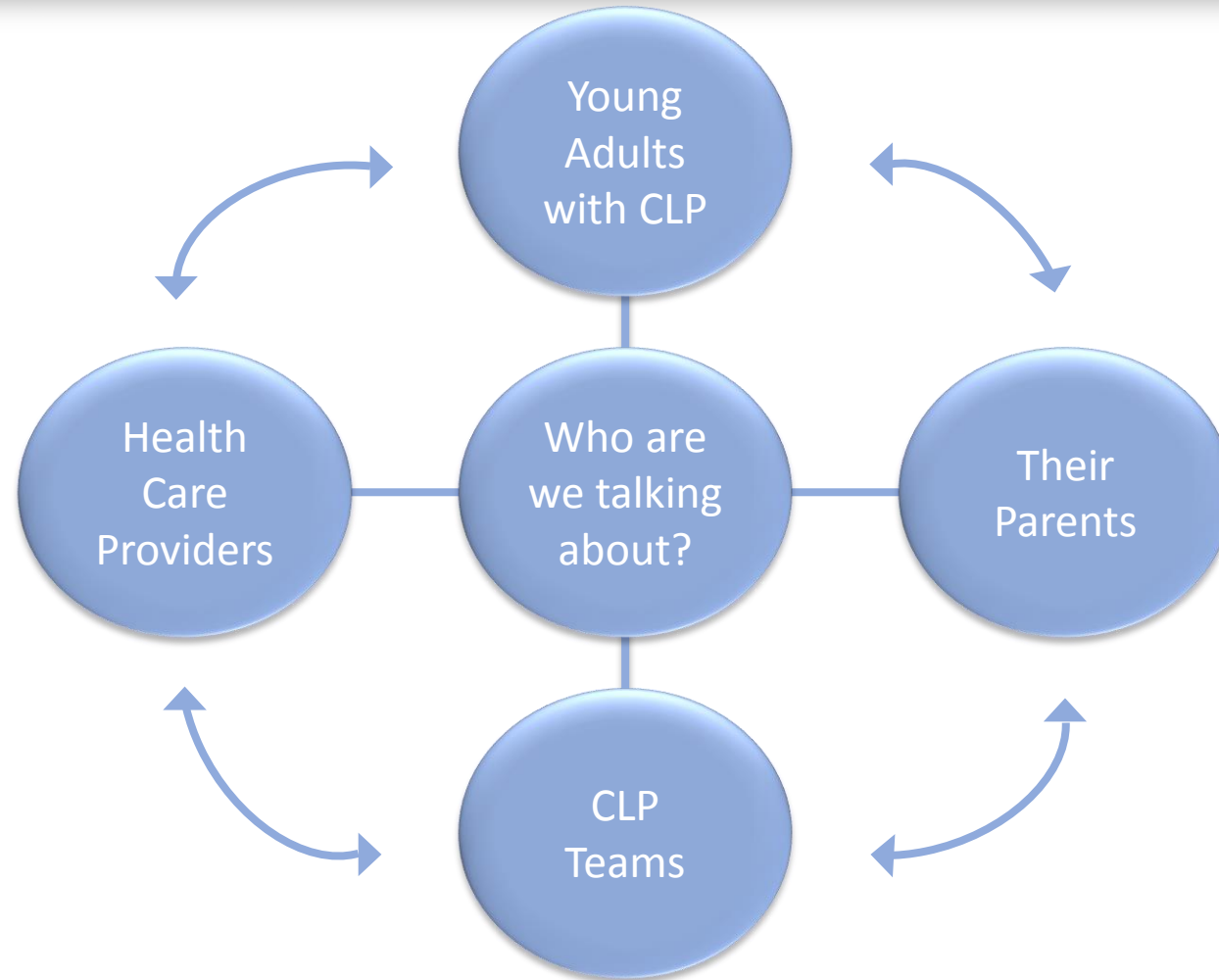
- The transition of care for young adults with CLP necessitates a change in perspective and embracing constructs such as person centered care and the ICF.

# Methods/Description

Using an evidence-based approach we will:

- Present an overview of the young adult with CLP and their multidisciplinary needs
- Describe an evidence-based service delivery model for the transition of care for the young adult with CLP that considers the components of the ICF model and concepts of QOL.
- Suggest strategies for teams to improve the care for young adults with CLP.

# WHO are we talking about?

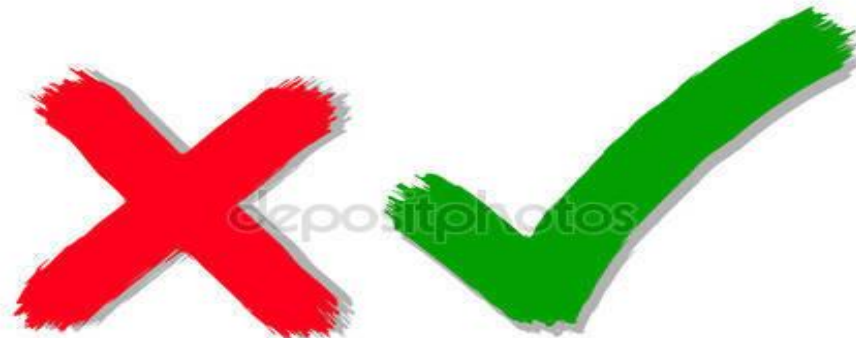


# WHO are we talking about ?

- Just “tall children” ?

OR

- *Millennials & iGeneration / Generation Z ?*
- *Young adults with CLP?*



# Millennials and iGeneration /Generation Z

- Millennials: born between 1980/82-2002/2004.
- iGeneration/ Generation Z: born between 1996-2012/14.
- Important to have an understanding of the established millennial and emerging iGeneration characteristics to provide services and to address transition of care.
- Environmental and cultural factors shape the characteristics of millennials and the iGeneration.

# Differences between children and adults with (CLP)

	Children	Adults
Physiologic changes	rapid	slows down
Transitions	rapid and frequent	often more gradual and less frequent
Environment and social network	changing	more stable
Care, decision making, goals	-parent driven -team driven	-adult driven -shared decision between adult and team or adult provider
Report of outcomes	clinician reported	adult reported
Paying for care	parent's insurance or assistance	self-payment or assistance



# What we know about the adult with CLP?

(Zajac and Vallino, 2017)

- Most are socially well-adjusted (some aren't).
- There are those who perceive CLP as affecting certain aspects of their lives (e.g., social attitudes, acceptance).
- Impact of CLP can be different based on age, gender, generation.
- Overall the **health related quality of life** is quite good for many young adults with CLP.

# But we also know that...

- Two different people each having a cleft can be affected differently – the impact of a cleft is different for each person.
- There are factors beyond the presence of a cleft that can influence how a person's life will be affected (Havstam & Lohmander, 2011).
- Indices often associated with (but not exclusively) satisfaction include social relationships, marriage and children, education, employment, economic comfort (Han et al., 2014), treatment outcome.
- All of these variables can influence a person's life – their *quality of life*.

# Young adults with cleft palate....Here's what they have to say?

Adults really are just now finding their voices and realizing that 18 was not the end...when complications arise you can find the right surgeon and speak well and with passion about the things you need help with.

I was literally kicked from the State system. I was in college and had just turned 18 and the dr. said "so what else do you want from me?"

To be honest there needs to be a specific group of surgeons solely based on helping adults with ongoing life issues related to their clefts. No more kid office visits. No more patching up an adult with what you would do to a child. That's the most frustrating!

# Parents of Young Adults with CLP

- Apprehensive about their child's transition to:
  - college, world of work, from child to adult services
- Face emotional challenges :
  - to develop a balance between protecting their child, offering support and facilitating their independence.
- Have concerns about stigmatization and attempt to help their child by ensuring that they take advantage of all clinical services have to offer (Nelson et al., 2012).

# Comments about transition

"It came so soon."

"It just stopped."

"I wasn't ready."

"I had been with this  
team for so long"

# Transition of Care

In some cases age 18 leads to “*Goodbye team*” !

However we need to reframe that to:

***HELLO*** to one or more of the following

- New services in the existing team
- New team
- Community practitioners
- Independence



# Transition of Care (TOC) is:

- a *process* of moving from pediatric to adult-centered care.
- *gradual* and *purposeful* not static event.
- *not* synonymous with transfer of care.
- *patient centered*

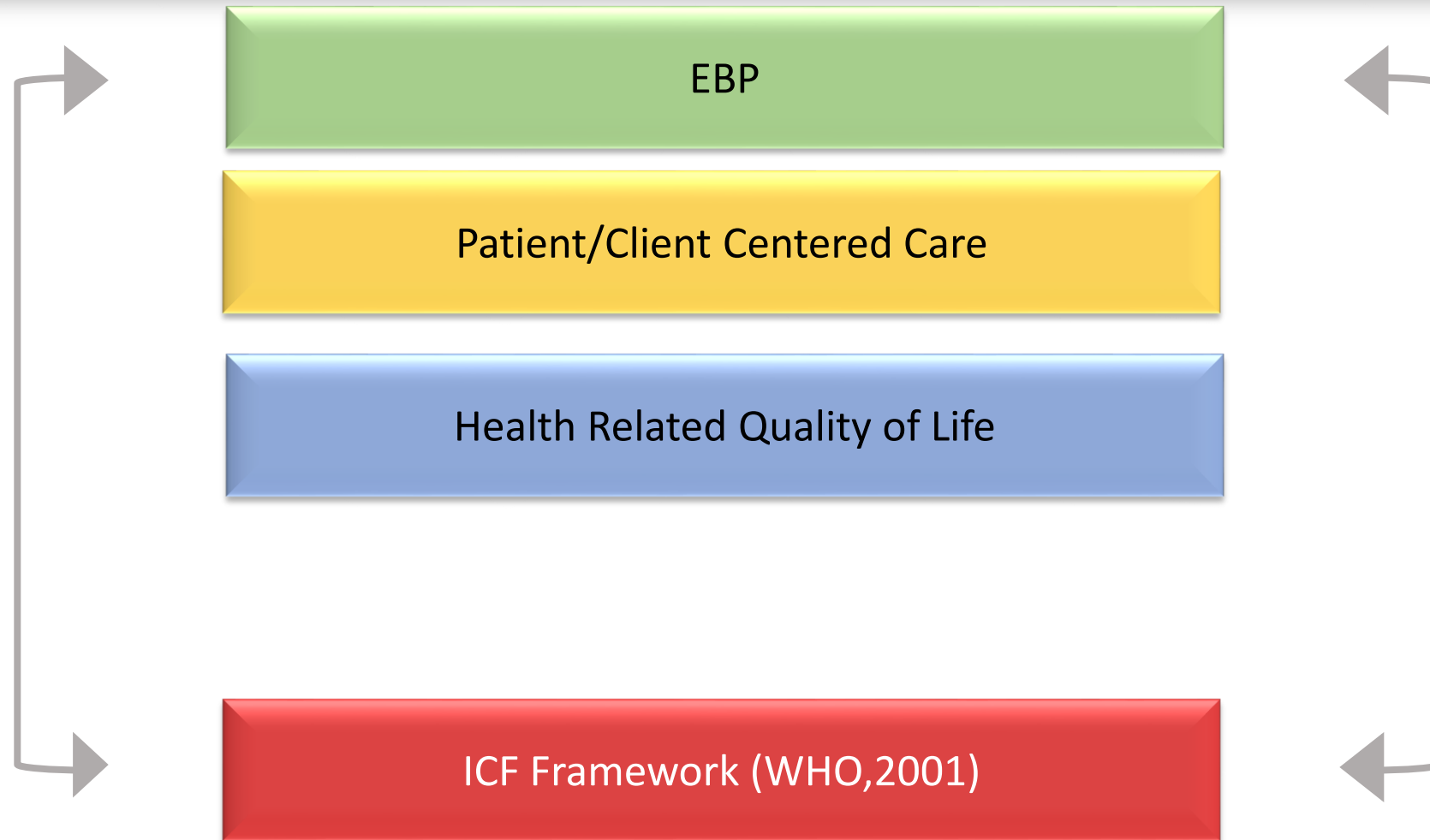
**The optimal goal of TOC** : uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive (Blum, 1993).

# Transition of Care

- **Cornerstones:**
  - flexibility, responsiveness, continuity, comprehensive ness and coordination (Nguyen et al.,2017)
- **The essence:**
  - team to move forward through assessment, planning, and the generation of interventions to optimize satisfaction (Blum, 1993; Sawyer, Blair & Bowes, 1997; McDonagh, 2003).



# Underlying theoretical constructs of the proposed Model of Transition of Care



# Patient/Client Centered Care

- Based on biopsychosocial model whereby  
the patient is viewed a whole person
- Defined as "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).
- "At its heart, PCC is an ethical encounter with the patient as a person" (Levesque, Hovey & Bedos, 2013).
- Leads to better patient satisfaction and better treatment outcomes( Stewart et al.,2014).

# Medical model vs Patient-Centered

- Medical - Hierarchical
  - Care often dictated to person
  - Person's expertise in own condition seldom considered
- Medical diagnosis of problem is viewed ahead of cognitive or emotional
- Reduced interaction between diagnosis and patient's motivation to be treated
- Patient-Centered
  - Care is *collaborative*
  - *Choice* is integral to determining care
- Treat *person as a whole being* not solely the disorder
  - Interaction of diagnosis of problem is important as well as the person's choices with respect to QOL and well-being

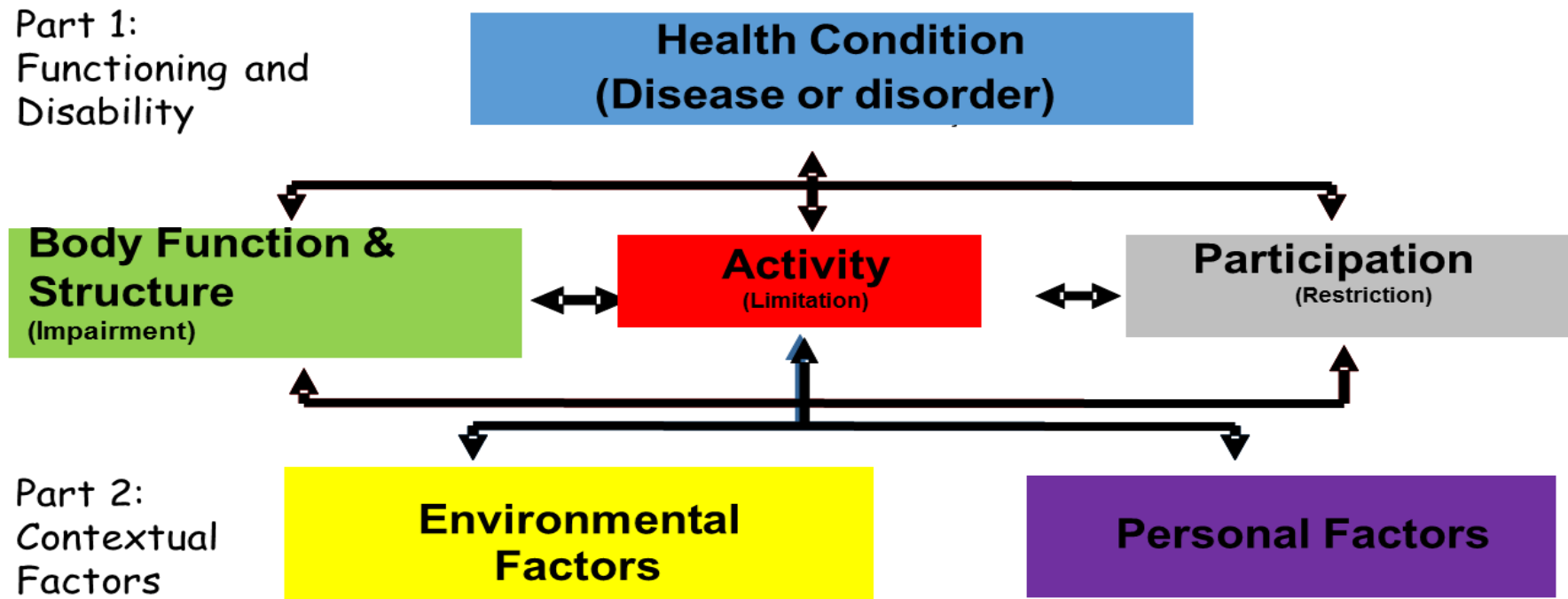
# Patient-Centered Care and Quality of Life

- *Quality of life (QOL)*: a broader concept which covers all aspects of life (that goes beyond health)
- *Health-related quality of life (HRQOL)*: a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning.
- *Well-being*: Global judgments of life satisfaction (happy, sad)
- *Patient-centered* care has been shown to improve outcomes and QOL
- Need to encourage providers to pay attention to QOL/HRQOL

# ICF (WHO,2001) Framework

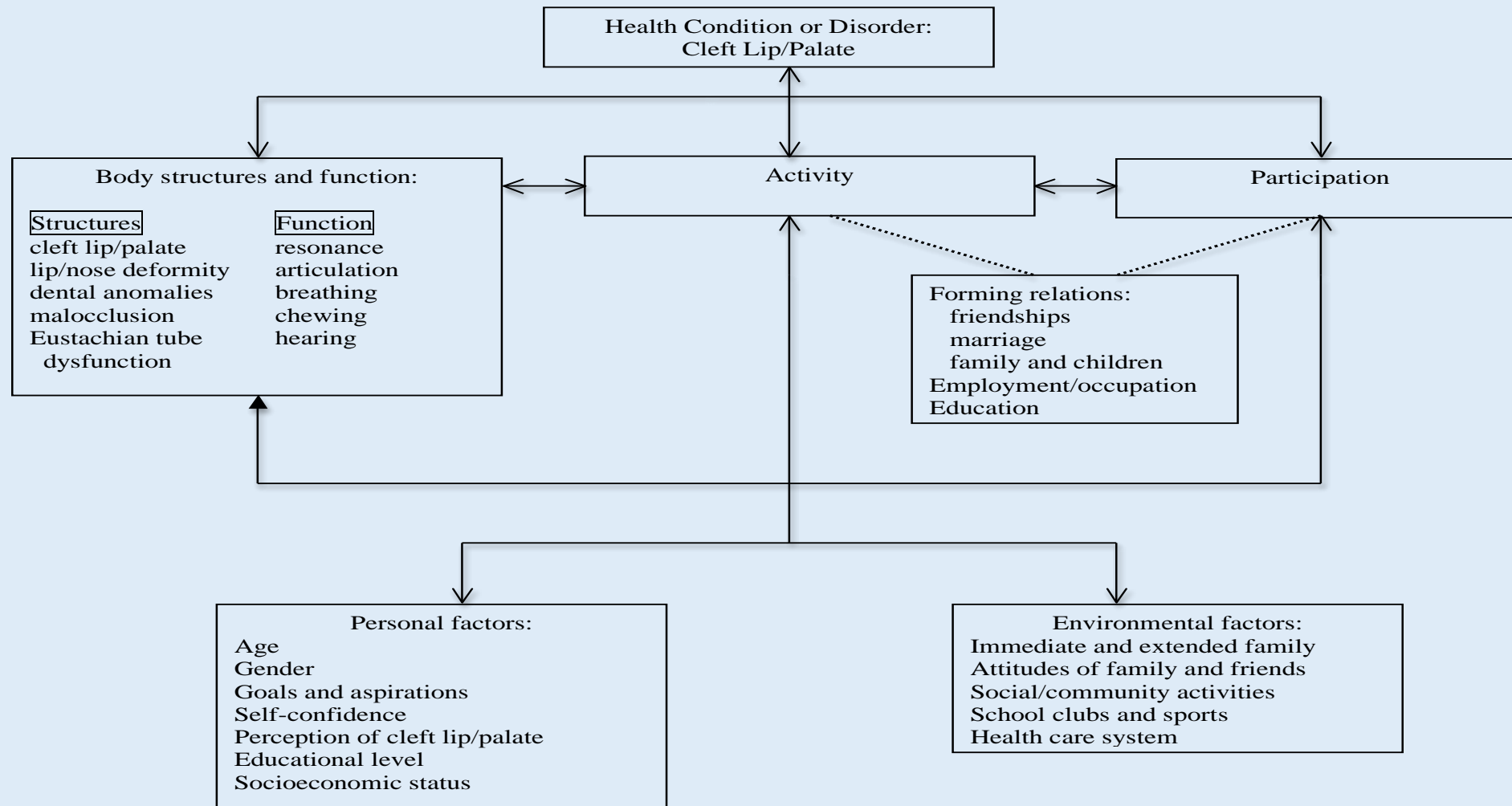
- International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) is the most widely recognized conceptual framework for describing the impact of a disorder.
  - Represents a shift from body impairment-centered descriptions of disability to a more comprehensive documentation that includes a wider range of functionality.
  - Emphasis on self-report rather than clinic report
  - Basis of patient-centered care

# ICF Framework (WHO, 2001)



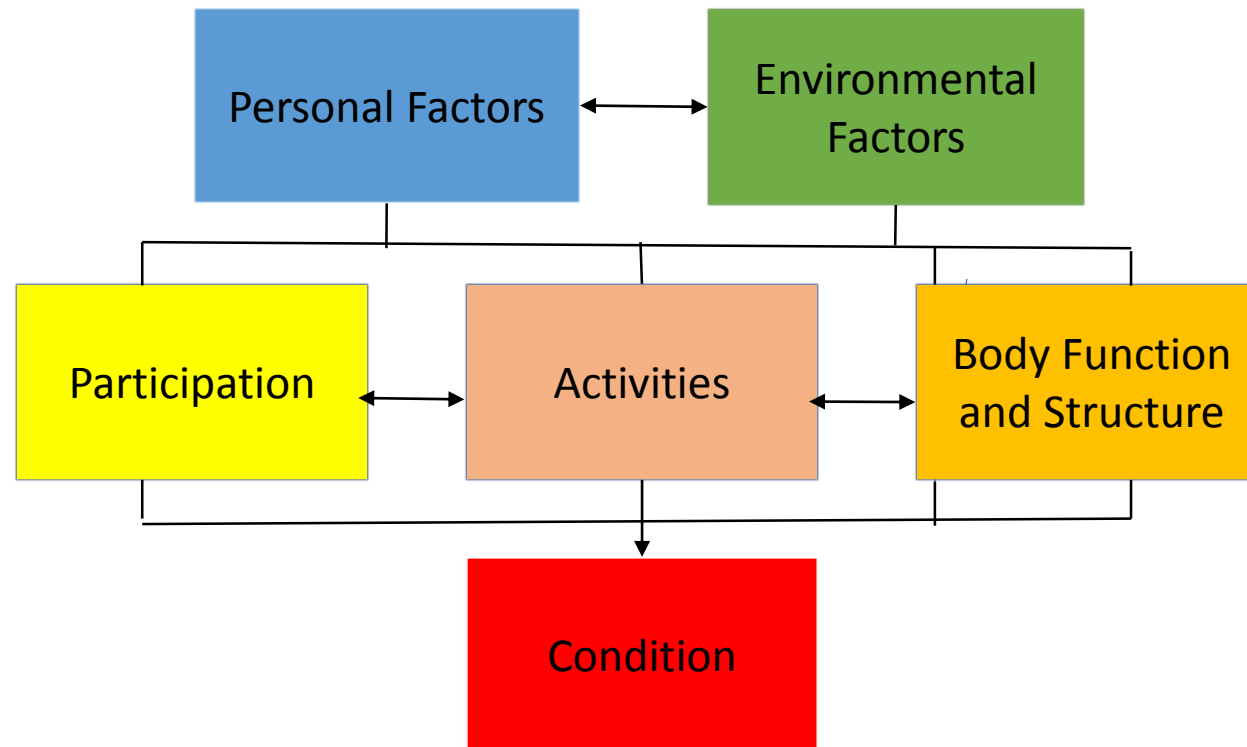
# Health-related quality of life of individuals with cleft lip and palate

(Zajac and Vallino, 2017)



# Person-Centered Approach to ICF

(Nguyen, 2015)





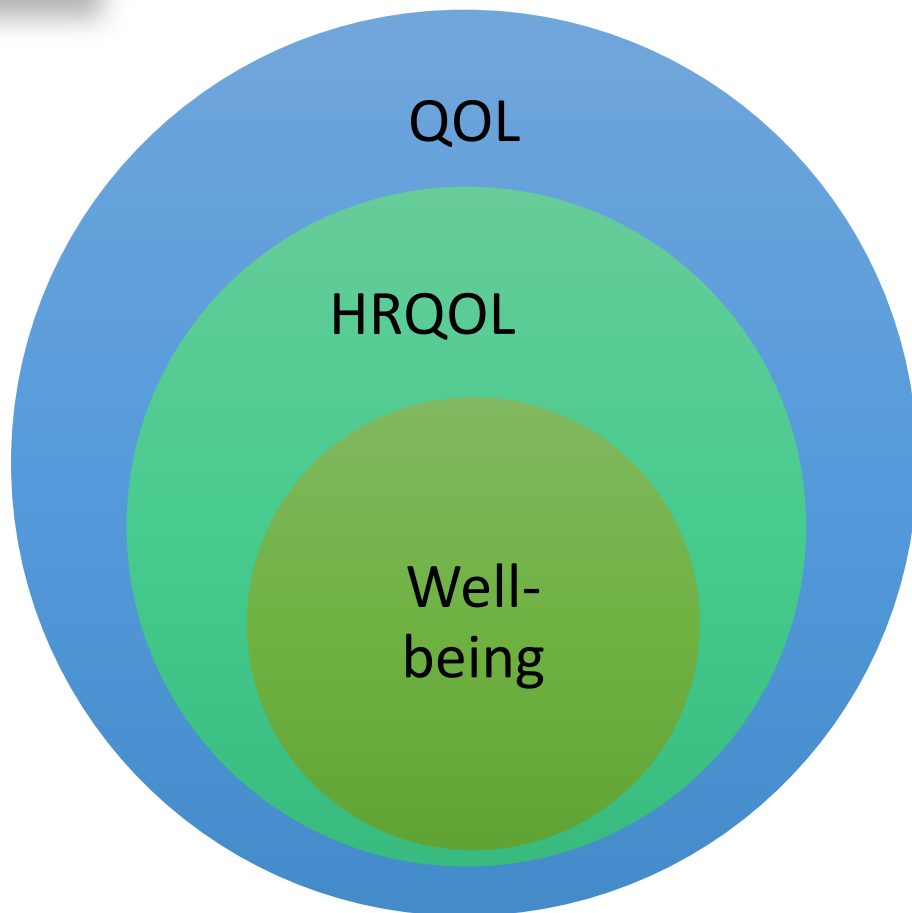
# Integration of ICF and HRQOL

Multidimensional perspective that encompasses the cleft condition with the person's psychological and social functioning.

Look at ratings of:

- Overall quality of life (e.g., attitude towards self, sociability, well-being, family life)
- Satisfaction with:
  - appearance (lip, nose, dentition)
  - speech
  - social functioning
- Stock et al., (2018) call for a conceptual shift to appreciation of the wider context and broader experiences of individuals with congenital craniofacial anomalies (CFA's).

This is important because:



1. **Emphasis:** the self-reported impact of the cleft **not** the cause.

2. Useful measures for tracking the impact of the cleft and effects of treatment... **based on the person's perspective.**

# Proposed service delivery model of care for the young adult with CLP: A framework



# Proposed Model

- The purpose of this proposed model is not to define a descriptive model, but to
  - provide a framework for the redesigning the way services are delivered to a young adult with cleft palate.
- Programs may vary, however, there are common underlying concepts to be considered when moving to a new model of care.

# Proposed Model

- The key to the success in preparing for the transition of care of the young adult with CLP is a change in perspective from the medical model to one of patient centeredness.
- Professionals also need to be ready for transition.
- It is not an either-or paradigm, but rather a unique blend of clinical findings and active participation of the young adult, an appropriate balance of parental and clinician input, and the services that can be provided within a given context.

# The model is a unique blend of:

- Active participation of the young adult (and when appropriate, input from the parents).
- Services provided (type of service, provider, mode of service delivery, tools used for care).
- Contexts (adult team, community-based).

# Principles to Transition

(Sydney Children's Hospital Network; Crowley et al., 2011)

- Systematic and formal transition process is required
- Early preparation. Education around empowerment and self-management
- Designate a transition coordinator/facilitator
- Good communication supporting patient-centered care (patient, family, other providers)
- Individual transition plan
- Empower, encourage, and enable young people to self-manage
- Follow-up

# Service Delivery Model: The Components

## Patient-centered

- Self-reported concerns and needs
- Person-centered functional goals

## Relevant disciplines

- Appropriate to specific phase of care
- Expertise/experience managing cleft

## Point person

- To channel communication between patient and interested parties in community

## Access to care

- Multidisciplinary team/community members
- Financial

## Outcomes measures

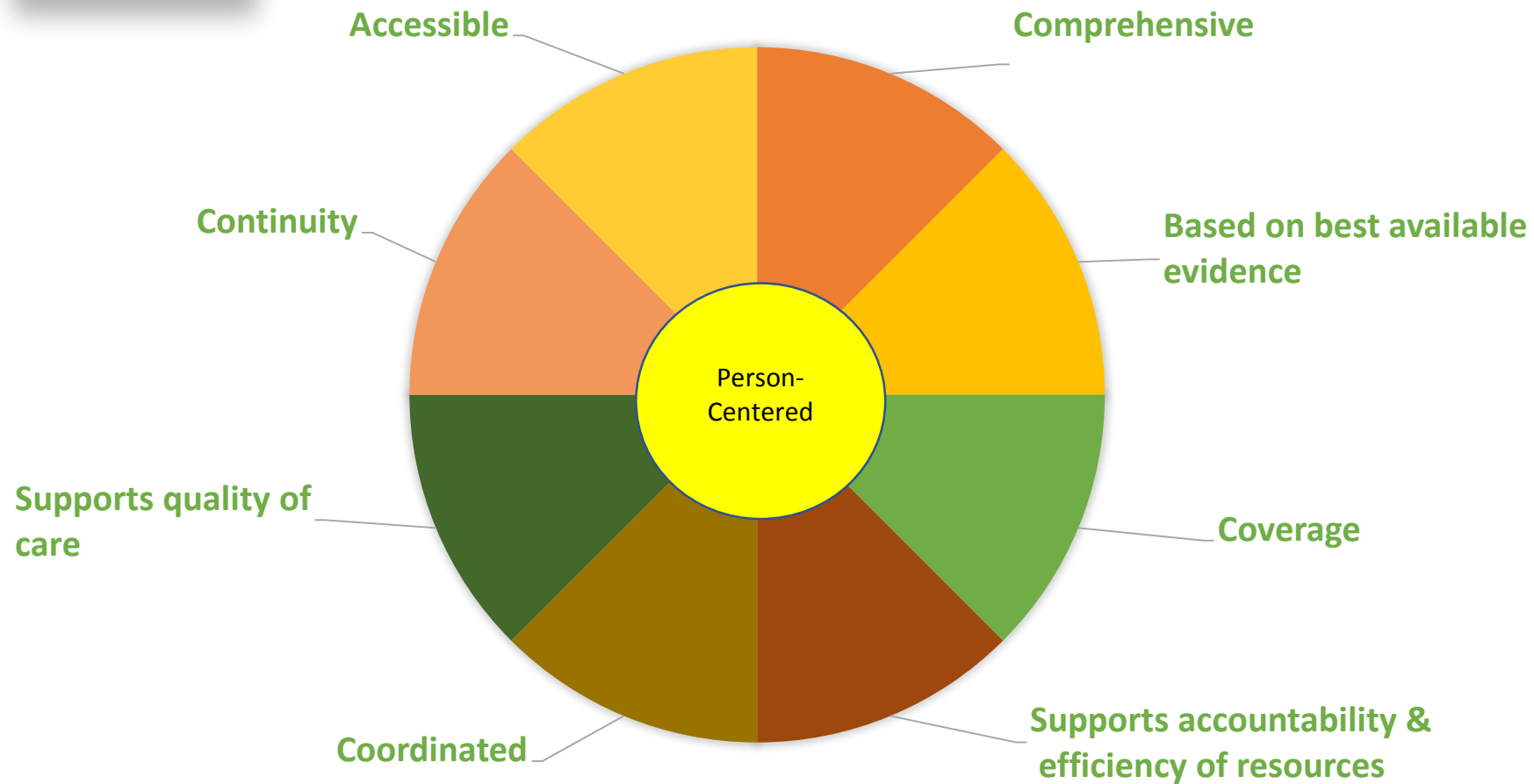
- SF 36, satisfaction surveys (speech/hearing, surgery, oral health, psychology)

## Culturally sensitive

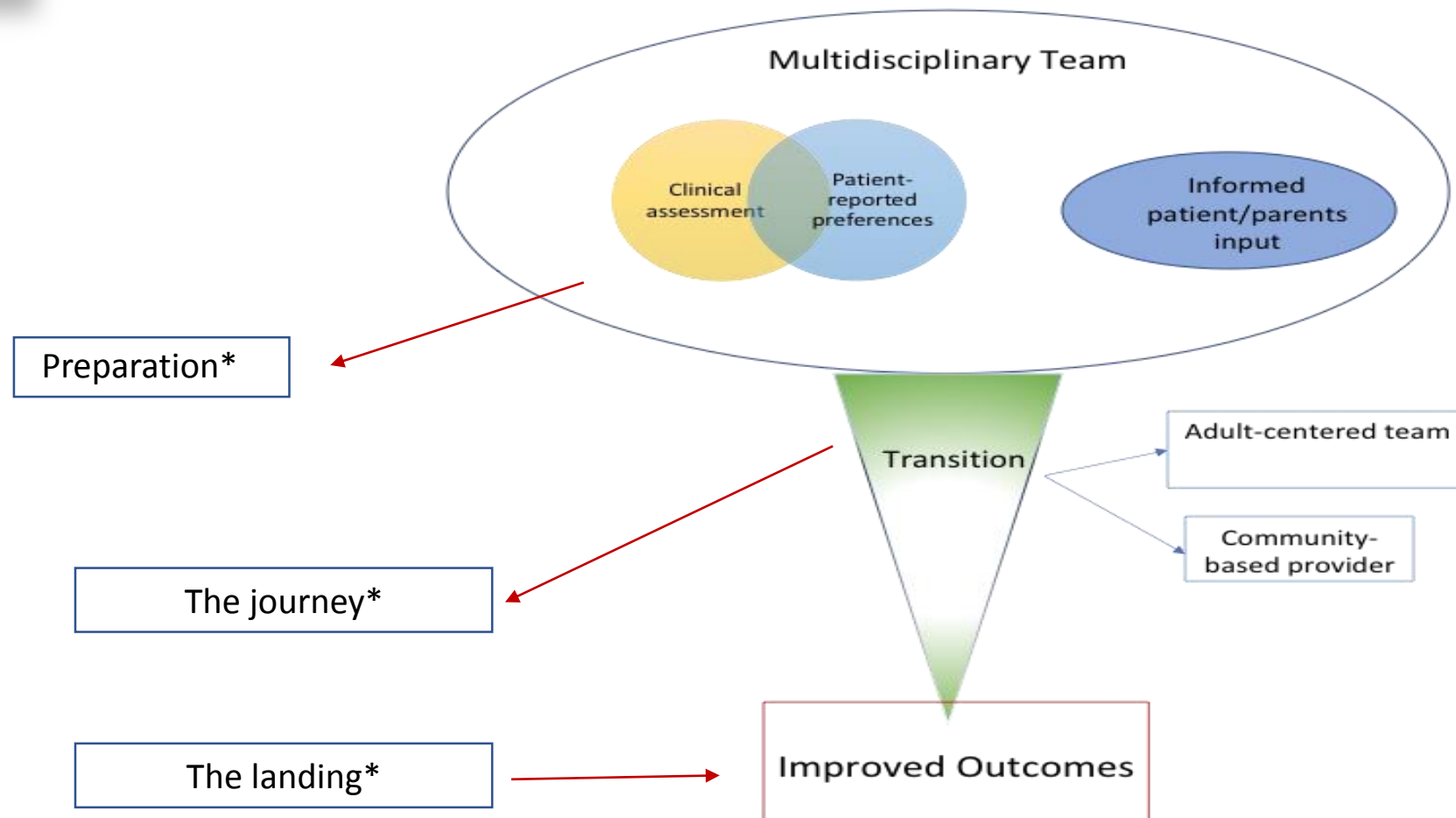
- Providing services with his/her own community



# Characteristics that define a service delivery model for young adults with CLP



# Proposed Service Delivery Framework



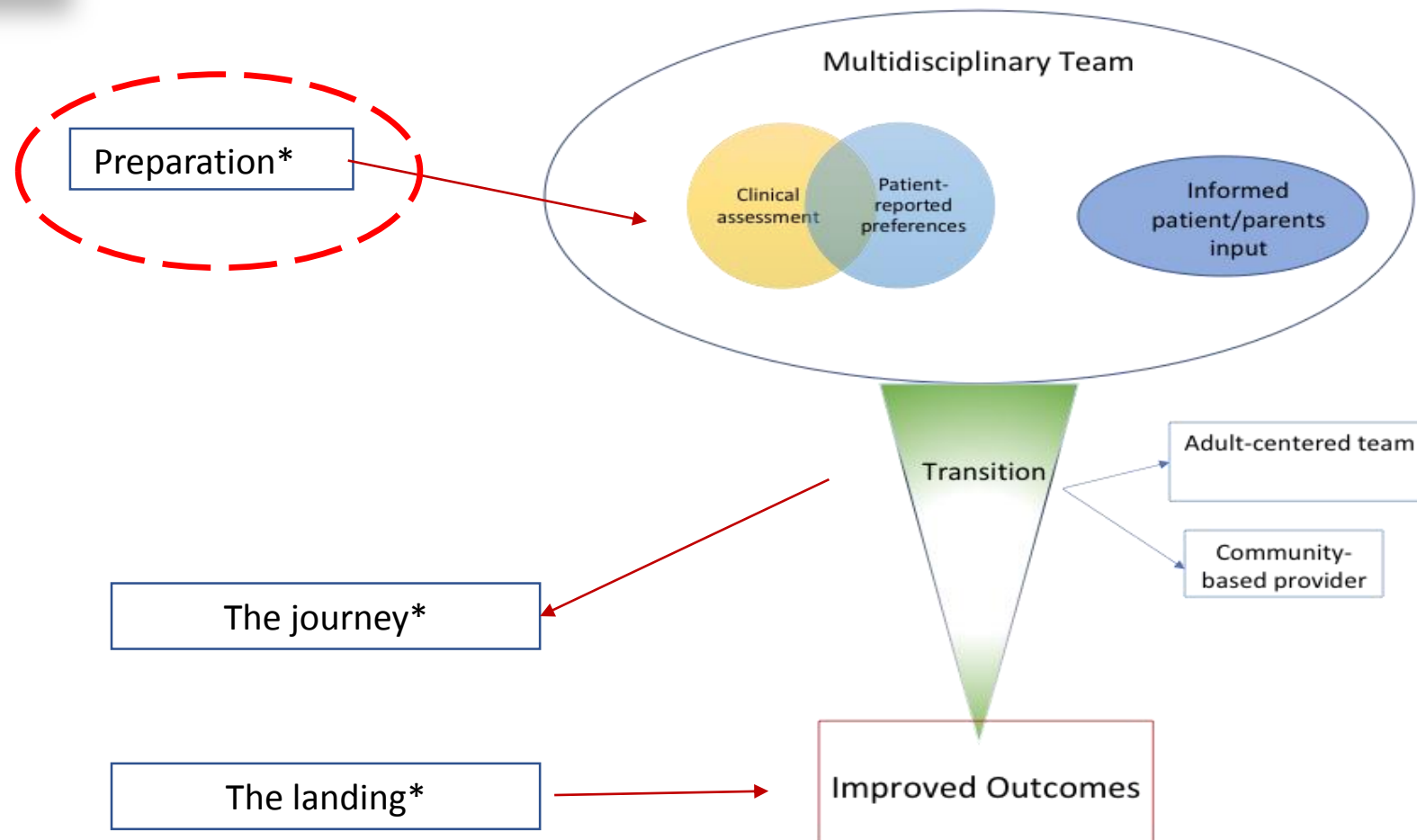
# Preparation, journey, landing

(adapted from (Nguyen and Gorter, 2013))

- **Preparation:** help clinicians, patient, and parents think about current and future functioning.
- **The Journey:** the transition itself, the time the adolescence is experiencing changes from one developmental stage, environmental or role to another (Stewart et al., 2009).
- **The Landing:** the point at which the goals and outcomes are met (Nguyen and Gorter, 2013).

# Proposed Service Delivery Framework

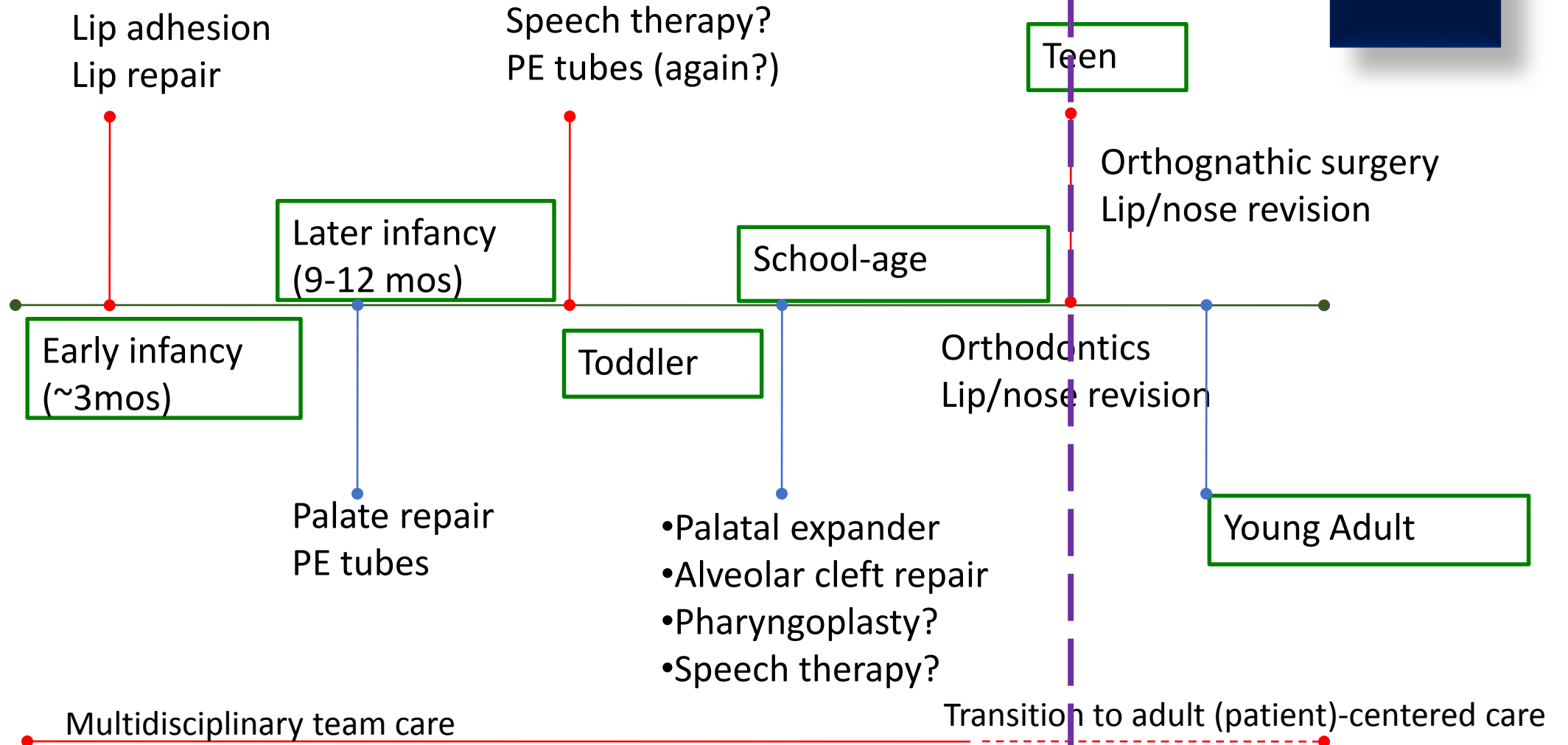
(Adapted from Nguyen and Gorter, 2013)



\*Nguyen & Gorter, 2013

# The preparation: When do we start?

## Start here



# Proposed service delivery model of care:

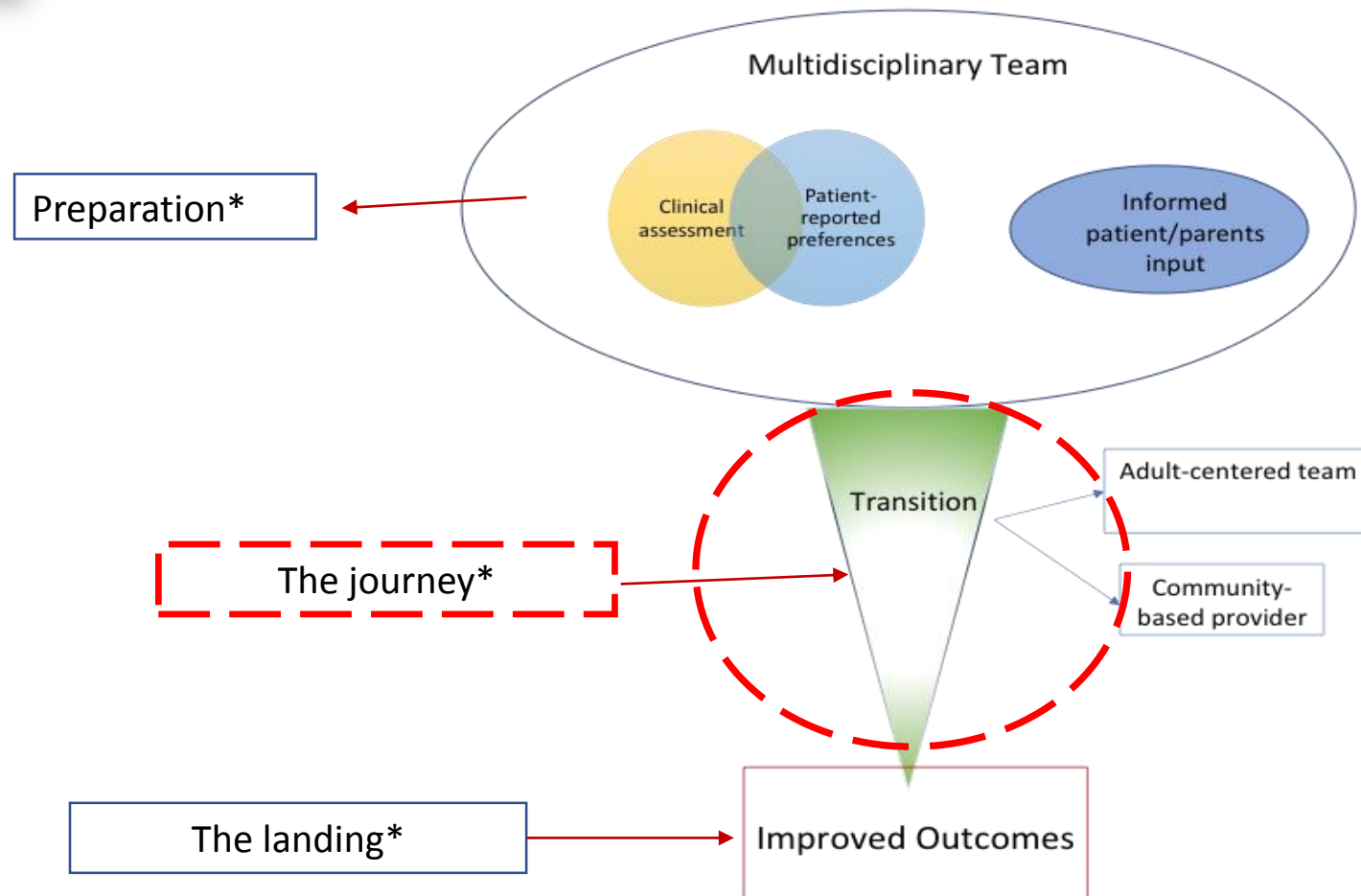
## Preparation

- When: within team during teen years.
- Identify a point person who will coordinate transition at your institution (e.g., member of transition team, coordinator) - involve them in team discussions.
- Involve both patient and family in discussion – find an acceptable balance between parent support and the young adult's autonomy.
- Team discussions should address the ICF model – perceptions (may need to develop tools for use).

# Preparation stage: Practical Points

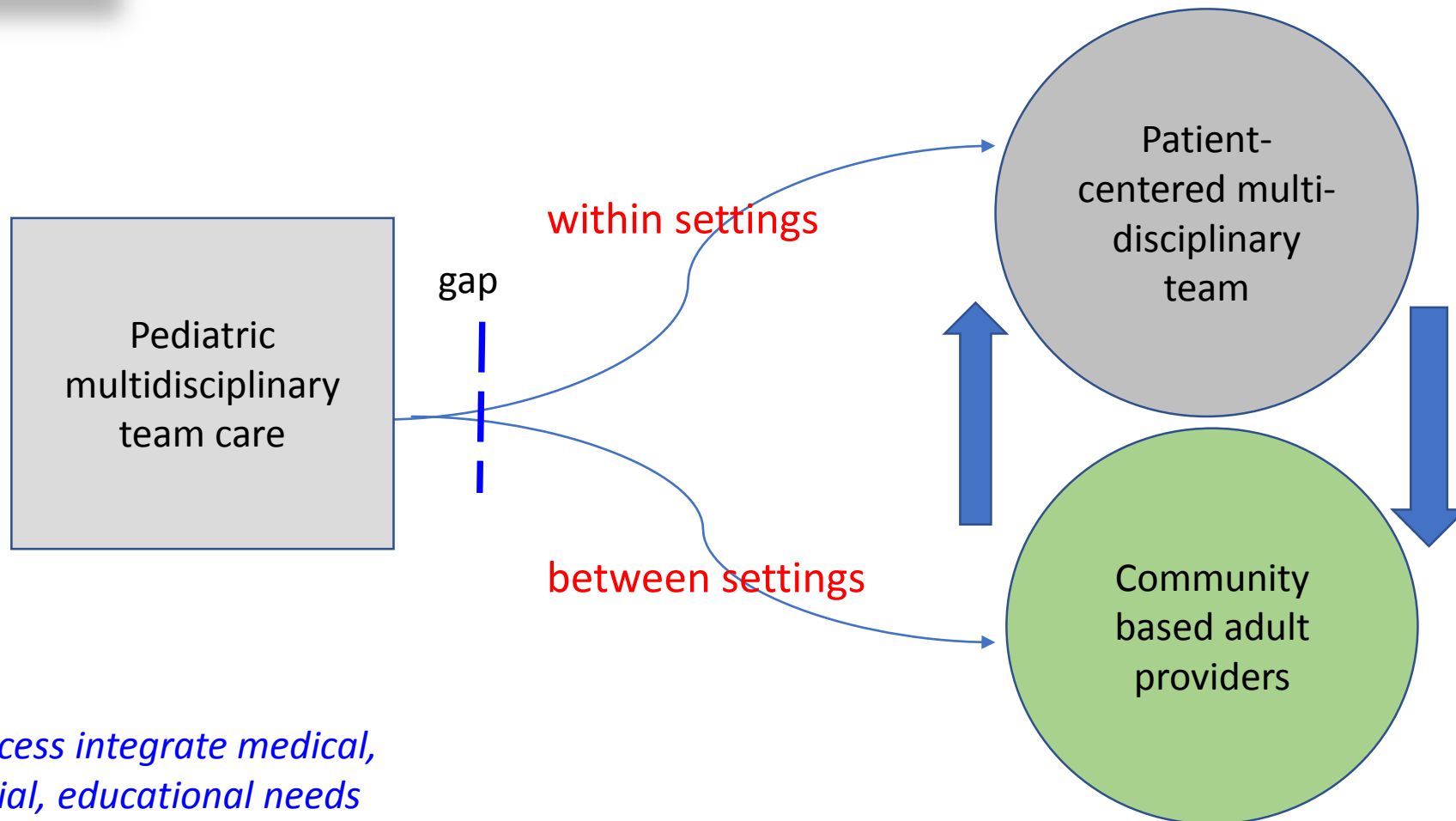
- Encourage patient to check in by him or herself
- Have the patient sit near the provider (not parent) and ask the patient the questions (problem, concerns) – look at the patient during questioning and answering
- If the patient does not know the answer – refer to parent
- Listen to the patient's needs and concern
- Listen to what he or she knows about the cleft condition

# The Journey: Transition (Nguyen and Gorter, 2013)





**The Journey:** the movement a person makes between health care practitioners and settings as their care needs change over time *active process integrate medical, psychosocial, educational needs.*



*Active process integrate medical, psychosocial, educational needs*

# The Journey:

## **Young adult**

The point in the transition process in which the young person is experiencing the changes and journeys from one developmental stage, environment or role to another (Nguyen, 2009).

## **Parents**

The point in the transition process in which parents also experience changes in their role as decision makers to providing support and a safety net.

# The Journey:

## **The Team Members**

The point in which the team is experiencing changes and moving from one role to another:

- From child-centered to adult centered care
- Stepping back and providing input (“letting go”)

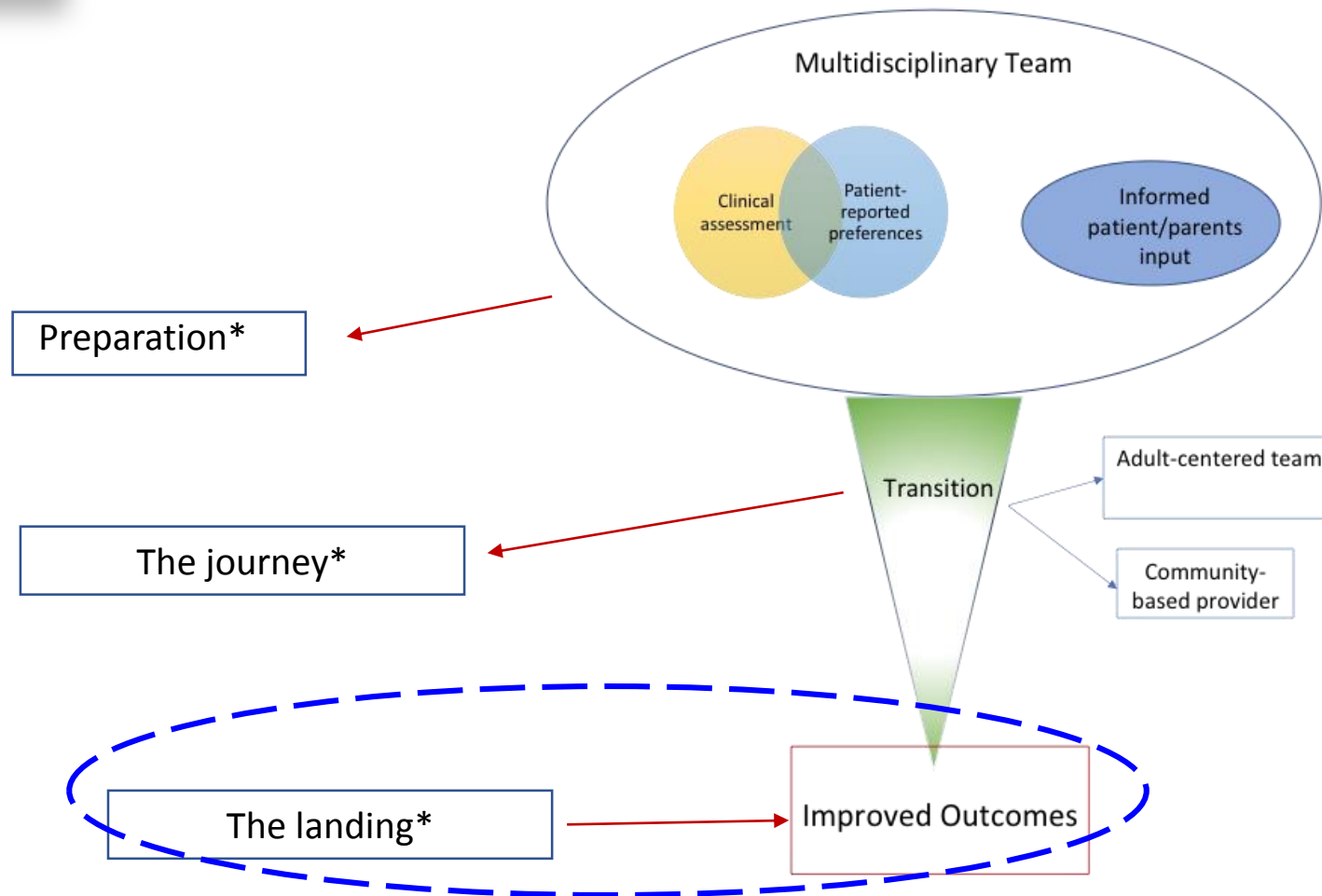
# What would make for an successful transition?

(Garvey et al., 2012)

- Adequate preparation for the transition
- Little to no gap between pediatric and adult care
- Patient satisfaction with the transition process

On the plus side: The ICF model can contribute to a more comprehensive, less fragmented and redundant services in the adult health care system.

# The Landing (Ngyuen & Gorter, 2013)



# The Landing: Did they arrive?

- Difficult question to answer.
- Those who engage in transition of care programs should evaluate and share outcomes.

## In Conclusion:

- Be open to new perspectives and follow a different approach to adults.
- Embrace constructs such as: person-centered care, ICF framework.
- Acquire new knowledge e.g. impact of CLP on adults.
- Read wider than the CLP literature.
- Ask new questions in a different manner.
- Listen to young adults' answers.



# Questions & Discussion





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