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Transition of Care for the Young Adult with Cleft Palate: Stuck between Goodbye to the Pediatric Team and Hello to Adult-Centered Care

Linda Vallino
Craniofacial Outcomes Research Laboratory Nemours/A.I. duPont Hospital for Children

Brenda Louw
East Tennessee State University, louwb1@etsu.edu

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Brenda Louw, D. Phil.
East Tennessee State University
Linda D. Vallino, PhD
Craniofacial Outcomes Research Laboratory
Nemours/A.I. duPont Hospital for Children

Disclosures

- Both presenters gratefully acknowledge being invited and generously sponsored by the ACLAPA.

- Dr. Brenda Louw was a 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 employed full-time 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. David Zajac & Dennis Ruscello). She is employed full-time by Nemours/ A.I. DuPont Hospital for Children, Wilmington, DE.

Dr. Linda Vallino

Nemours/Alfred du Pont Hospital
Wilmington, Delaware

Dr. Brenda Louw

East Tennessee State University
Johnson City, Tennessee

Gamba

Hello

G'day

daru

gilee

Gudamulli

meng

Yaama

Yowallah

Wadamuli

ngapa

Weeimba

Niiyalang

nguruindhau

Yandanji

Ngara

Sew

Maiem

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.

Introduction

- Typically, team-provided services end abruptly at 18 years.
  - 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

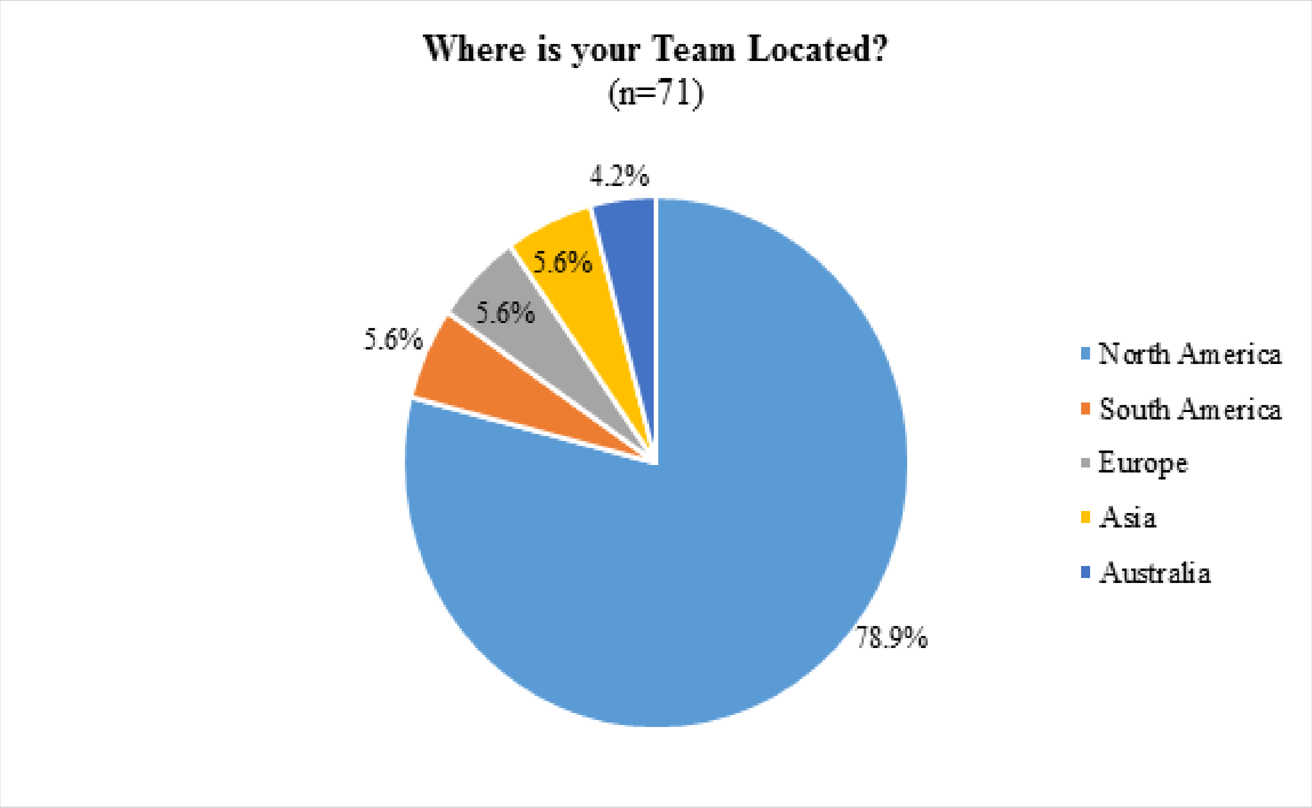
- Very limited research and information on the transition of care from pediatric interdisciplinary team to adult- and community-based services for individuals with CLP.

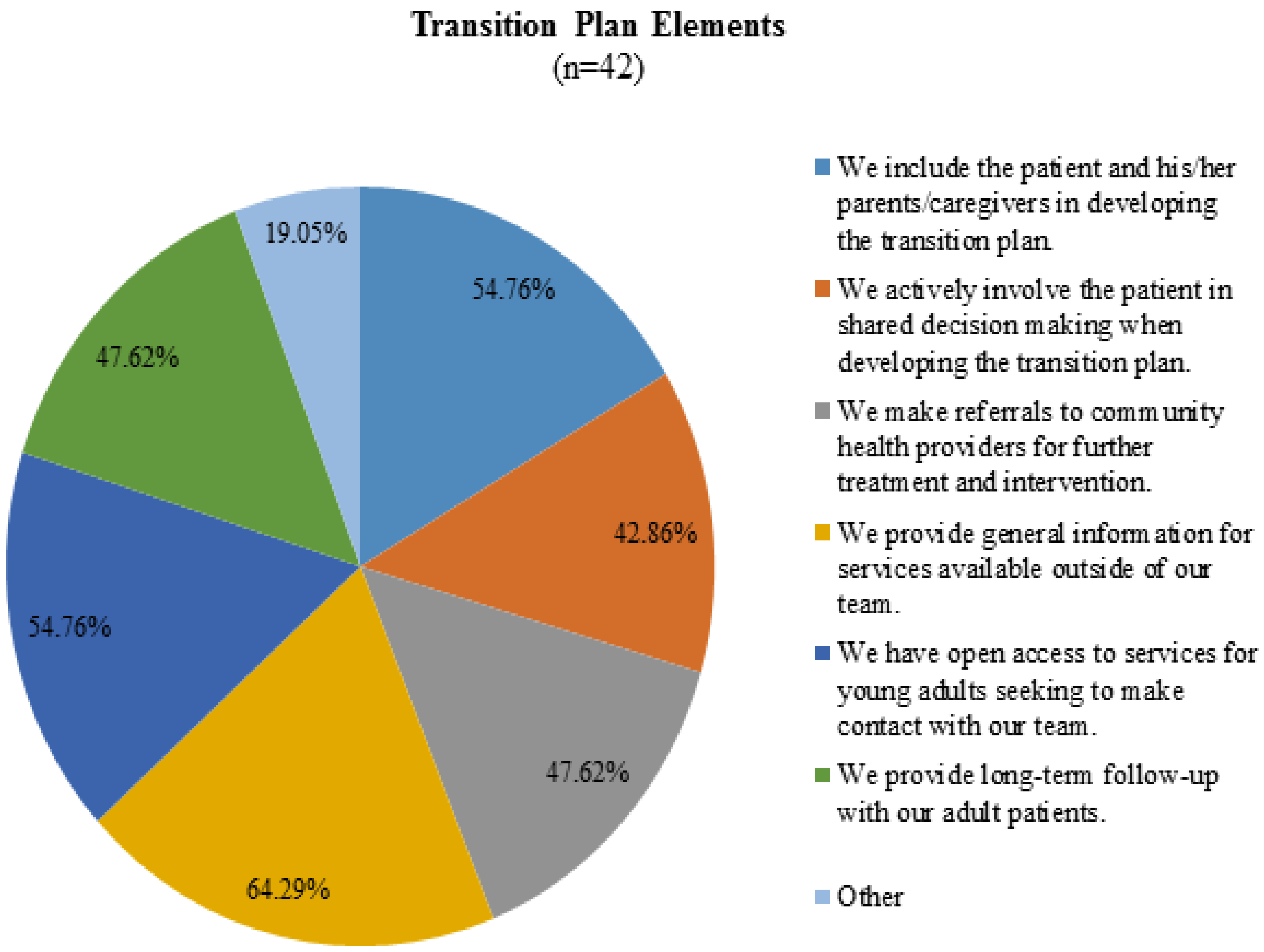
Transition of Care for Cleft Palate: A Survey of Teams

- 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





Note:

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

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.

WHO are we talking about?

Young Adults with CLP

Health Care Providers

Who are we talking about?

Their Parents

CLP Teams

The Young Adult is…

- Is leaving a pediatric-centered team to adult-centered care
- Experiencing a shift in responsibility from parent-run care to self-care and self payment
- Establishing communication with new provider in the community or adult-based team

Young adults with cleft palate….What do they say about leaving the team?

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).

What do parents say about leaving the team?

“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

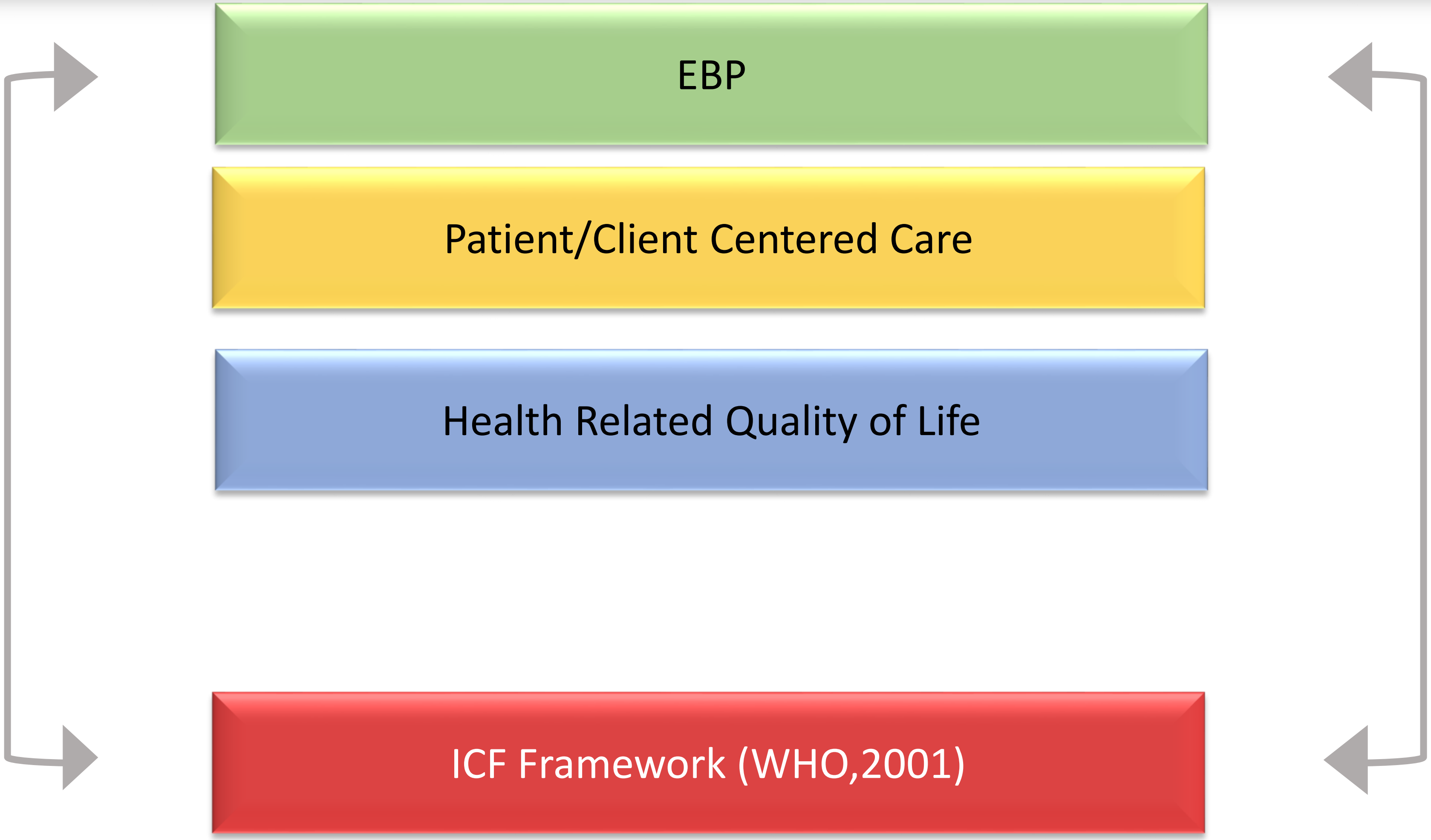
- New services in the existing team
- New team
- Community practitioners
- Independence

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.
- <u>*patient centered*</u>

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

Underlying theoretical constructs of the proposed Model of Transition of Care



EBP

Patient/Client Centered Care

Health Related Quality of Life

ICF Framework (WHO,2001)

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

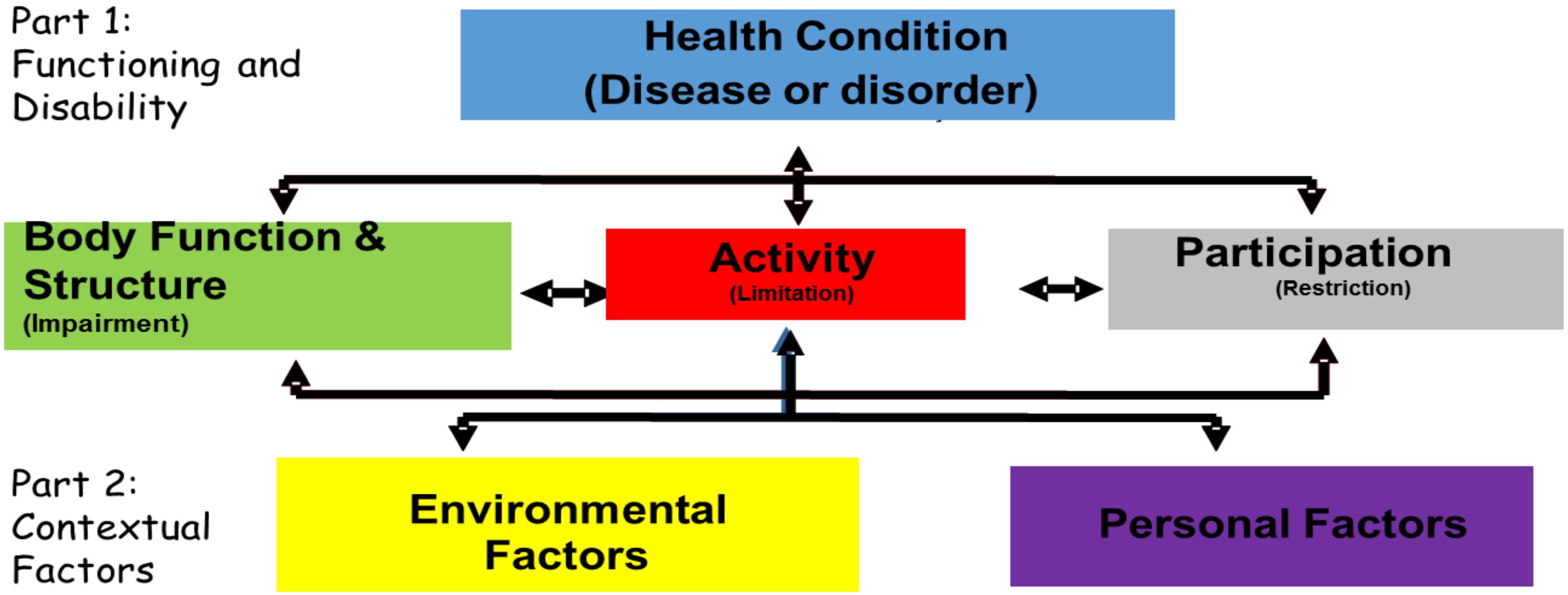
- Medical - Hierarchical
  - Care often dictated to person
  - Person's expertise in own condition seldom considered
- Medical diagnosis of problem is viewed ahead of cognitive or emotional
- Reduced interaction between diagnosis and patient's motivation to be treated

- 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 at the person's choices with respect to *QOL* and well-being

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)



Part 1:
Functioning and
Disability

Health Condition
(Disease or disorder)

Body Function & Structure
(Impairment)

Activity
(Limitation)

Participation
(Restriction)

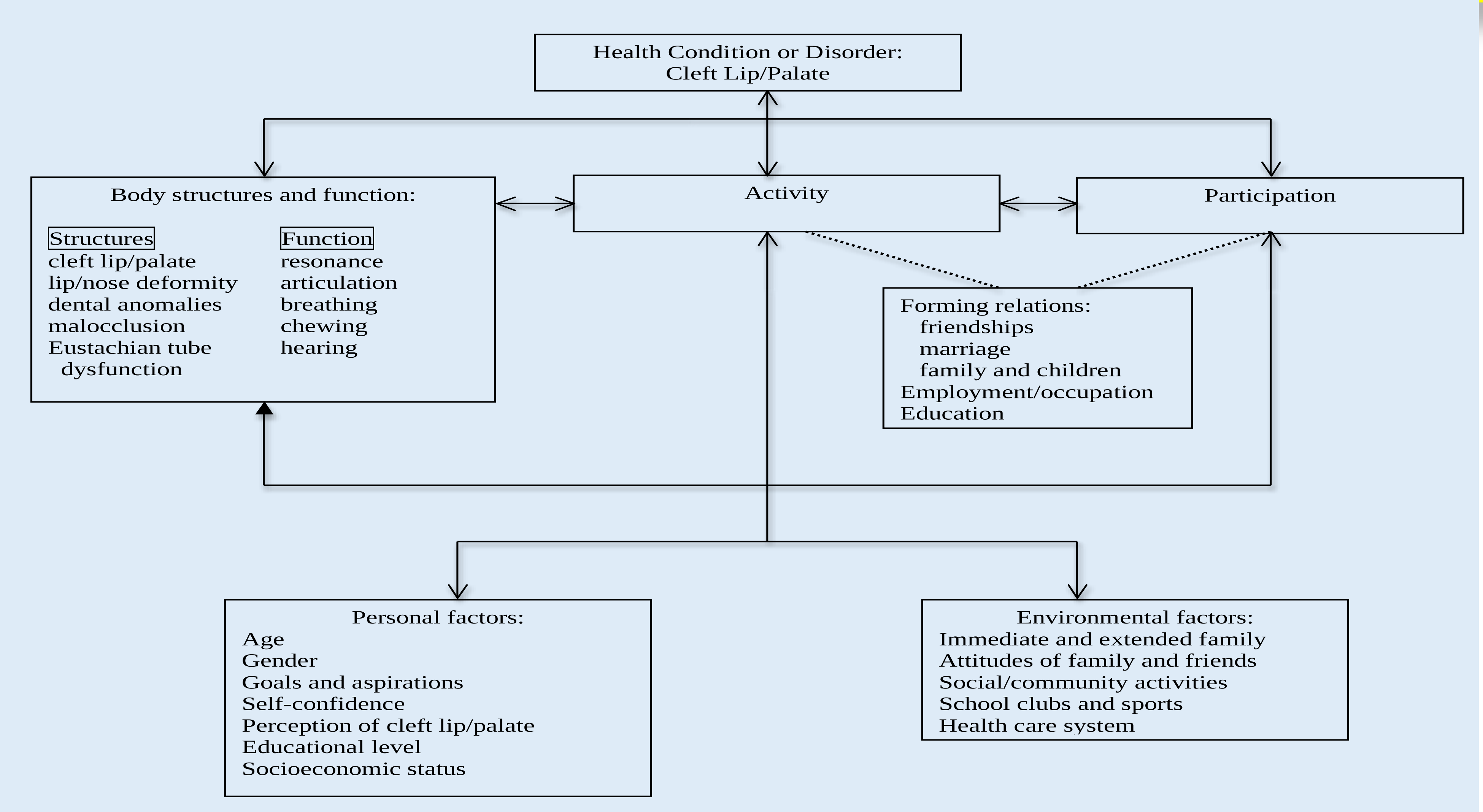
Part 2:
Contextual
Factors

Environmental Factors

Personal Factors

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

(Zajac and Vallino, 2017)



Health Condition or Disorder:
Cleft Lip/Palate

Body structures and function:

Structures	Function
cleft lip/palate	resonance
lip/nose deformity	articulation
dental anomalies	breathing
malocclusion	chewing
Eustachian tube dysfunction	hearing

Activity

Participation

Forming relations:
- friendships
- marriage
- family and children

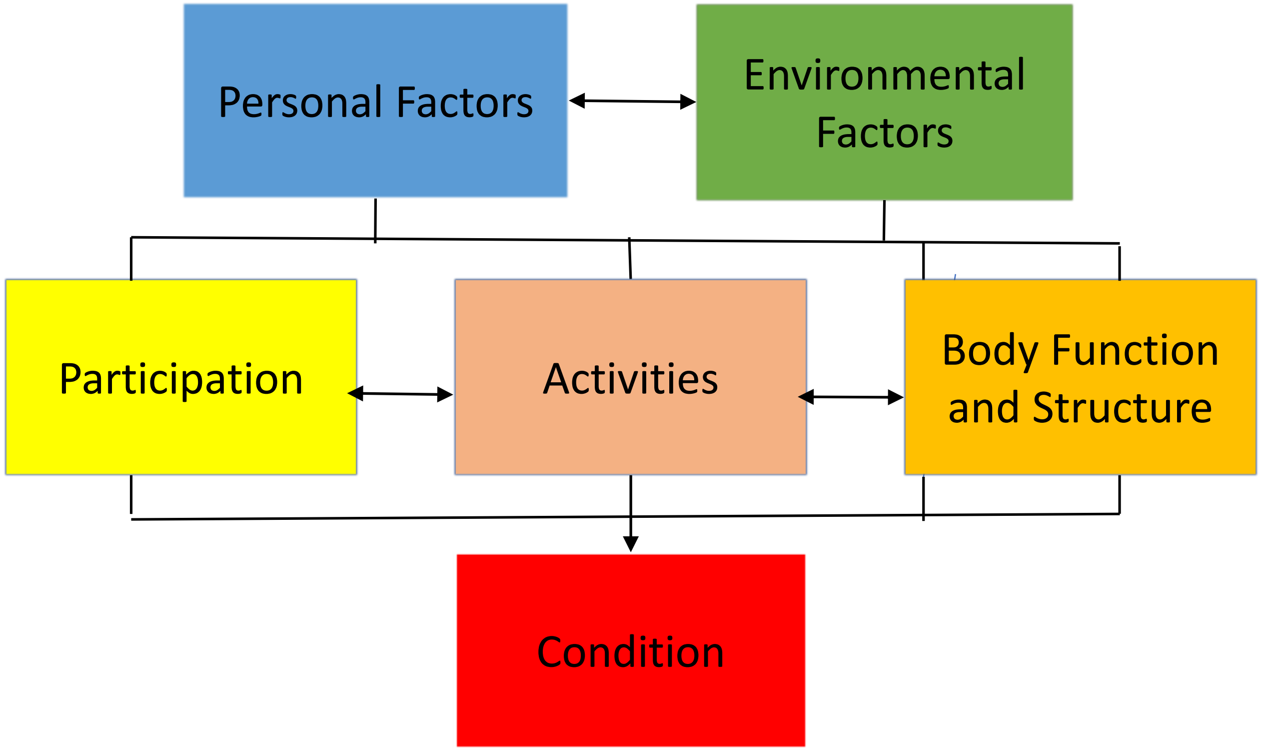
Employment/occupation
Education

Personal factors:
Age
Gender
Goals and aspirations
Self-confidence
Perception of cleft lip/palate
Educational level
Socioeconomic status

Environmental factors:
Immediate and extended family
Attitudes of family and friends
Social/community activities
School clubs and sports
Health care system

Person-Centered Approach to ICF

(Nguyen, 2015)



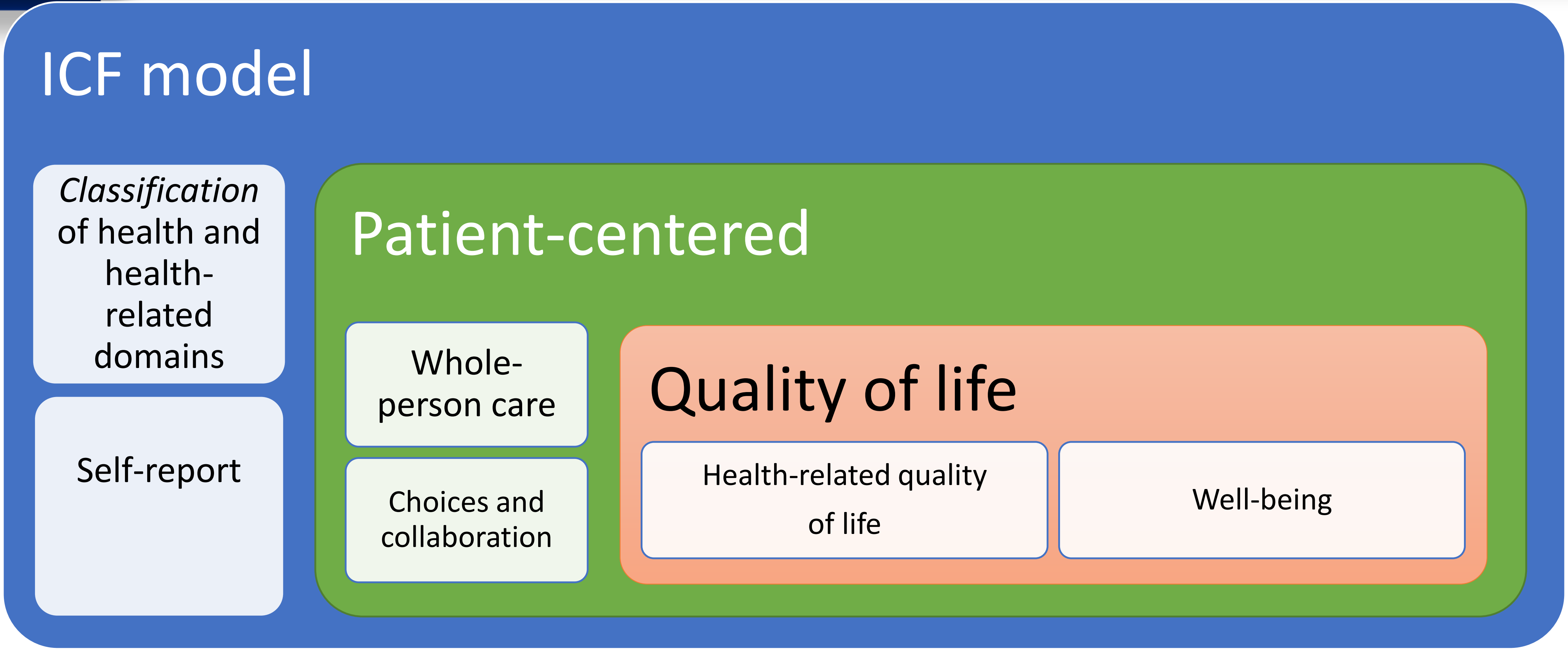
ICF and HRQOL

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)
- Health-related quality of life (focus on the impact of the condition or *health* status has on *quality of life*.
- Satisfaction with:
  - appearance (lip, nose, dentition)
  - speech
  - social functioning
- Stock et al., (2018) call for a conceptual shift in terms of appreciation of the wider context and broader experiences of individuals with congenital craniofacial anomalies(CFA’s).

Integrated Model of Care: Patient-Centered, ICF, and Quality of Life



ICF model

Classification of health and health-related domains

Self-report

Patient-centered

Whole-person care

Choices and collaboration

Quality of life

Health-related quality of life

Well-being

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 prescriptive 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

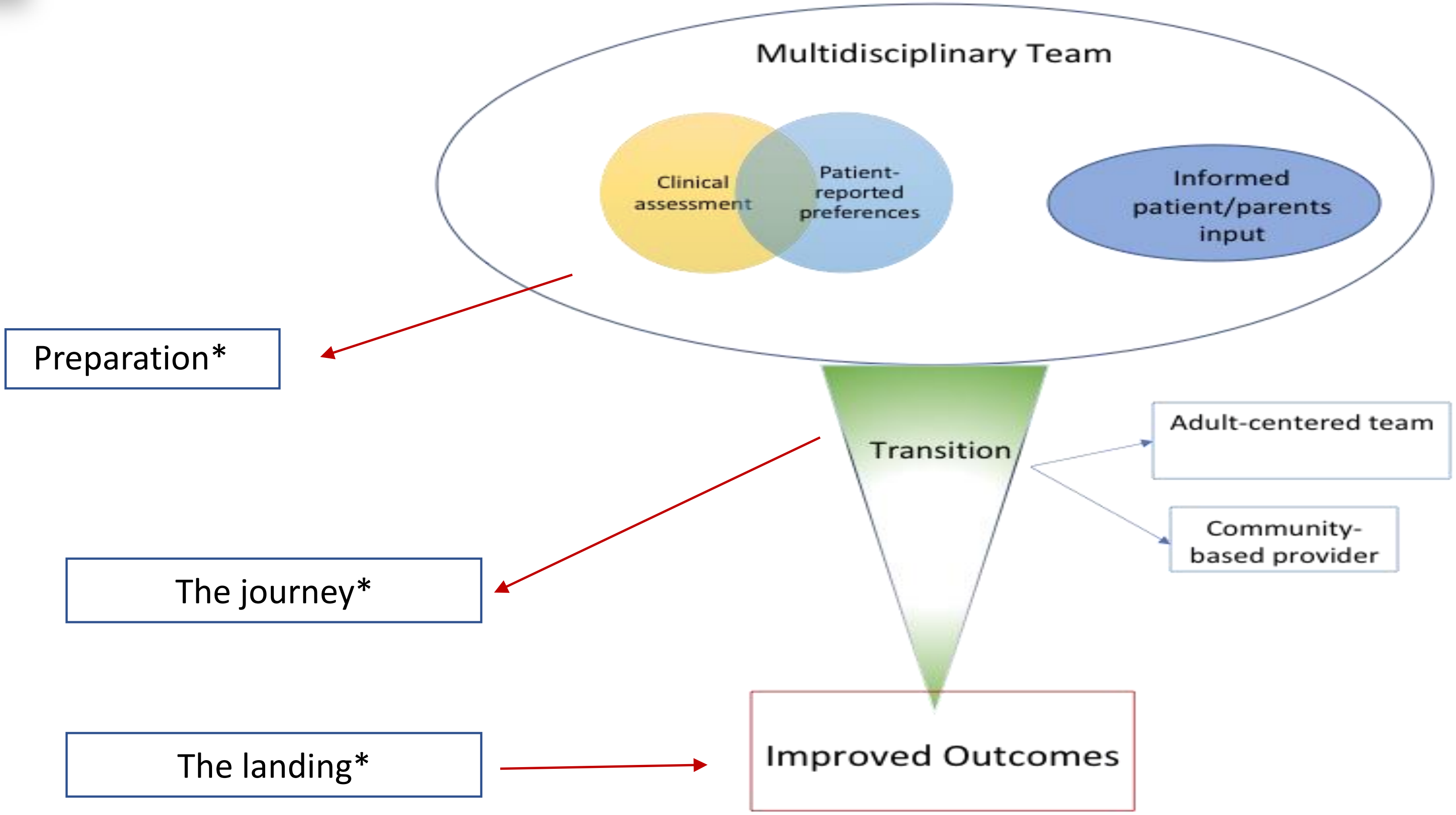
(Sydney Children's Hospital Network; Crowley et al., 2011)

- 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

Proposed Service Delivery Framework



Multidisciplinary Team

Clinical assessment

Patient-reported preferences

Informed patient/parents input

Preparation*

Transition

Adult-centered team

Community-based provider

The journey*

The landing*

Improved Outcomes

*Nguyen & Gorter, 2013

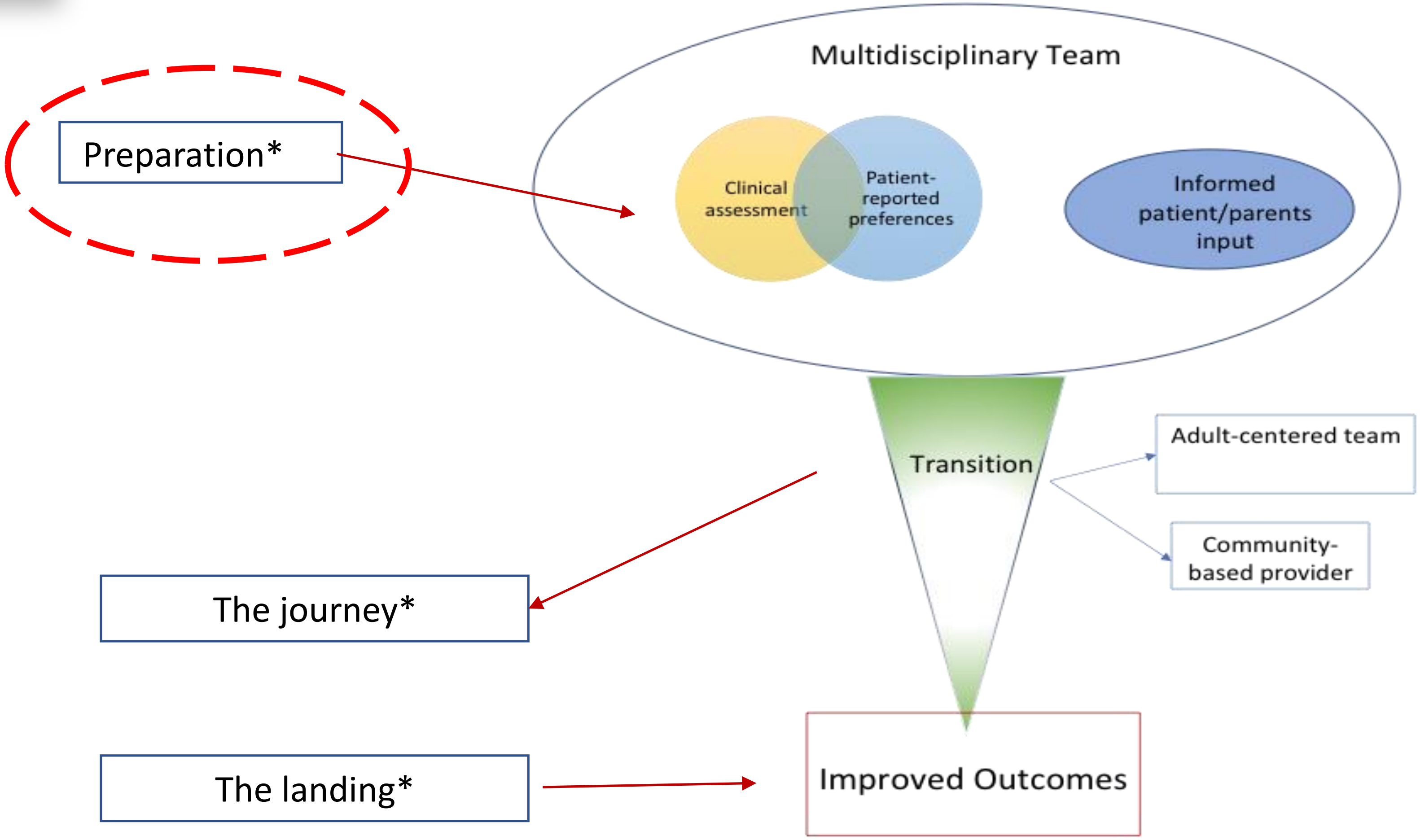
Preparation, The Journey, The Landing

(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 form 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)



Preparation*

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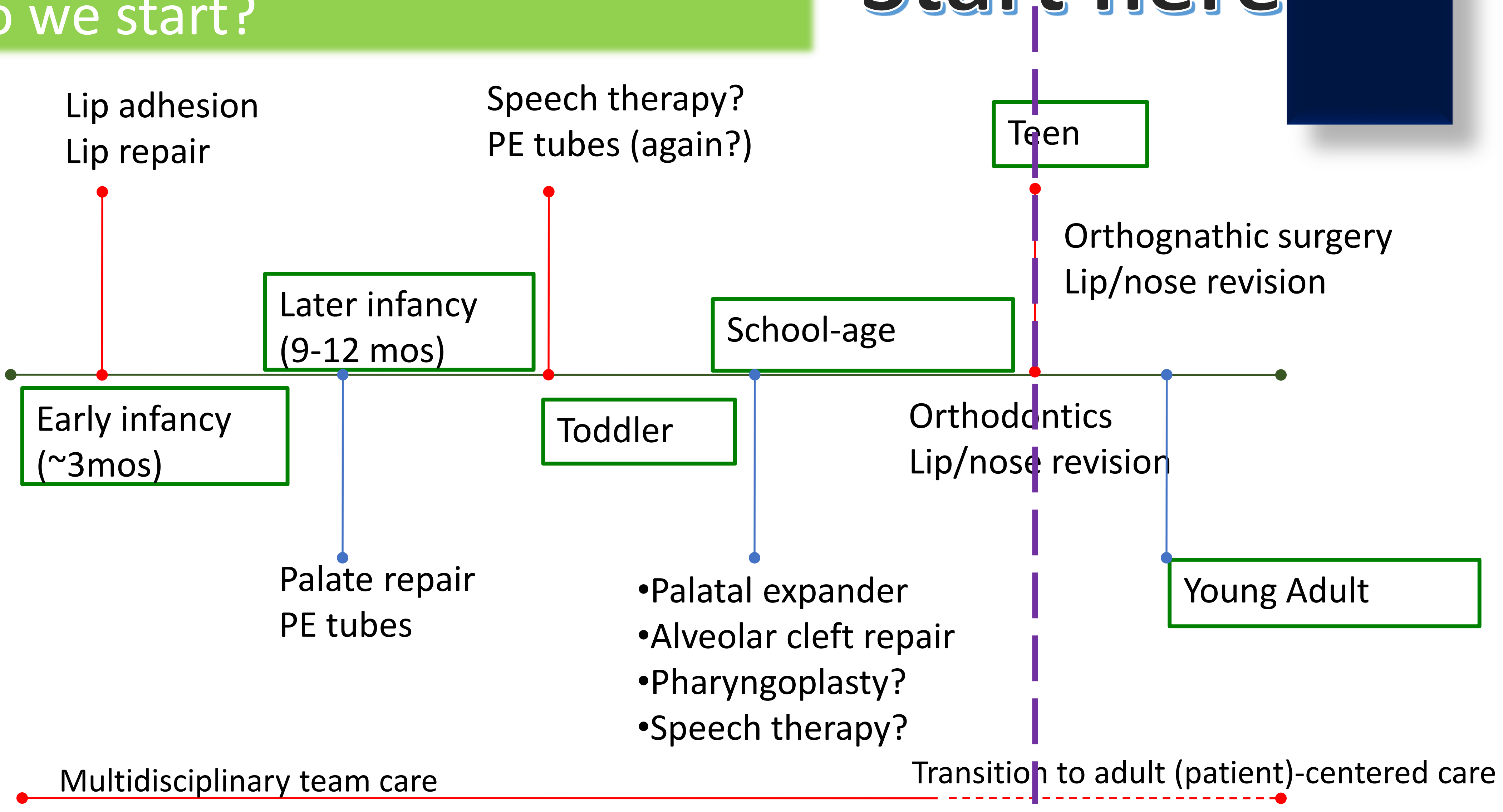
*Nguyen & Gorter, 2013

The preparation:
When do we start?

Start here



Early infancy (~3mos)

Lip adhesion
Lip repair

Later infancy (9-12 mos)

Palate repair
PE tubes

Toddler

Speech therapy?
PE tubes (again?)

School-age

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

Orthodontics
Lip/nose revision

Teen

Orthognathic surgery
Lip/nose revision

Young Adult

Multidisciplinary team care

Transition to adult (patient)-centered care

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

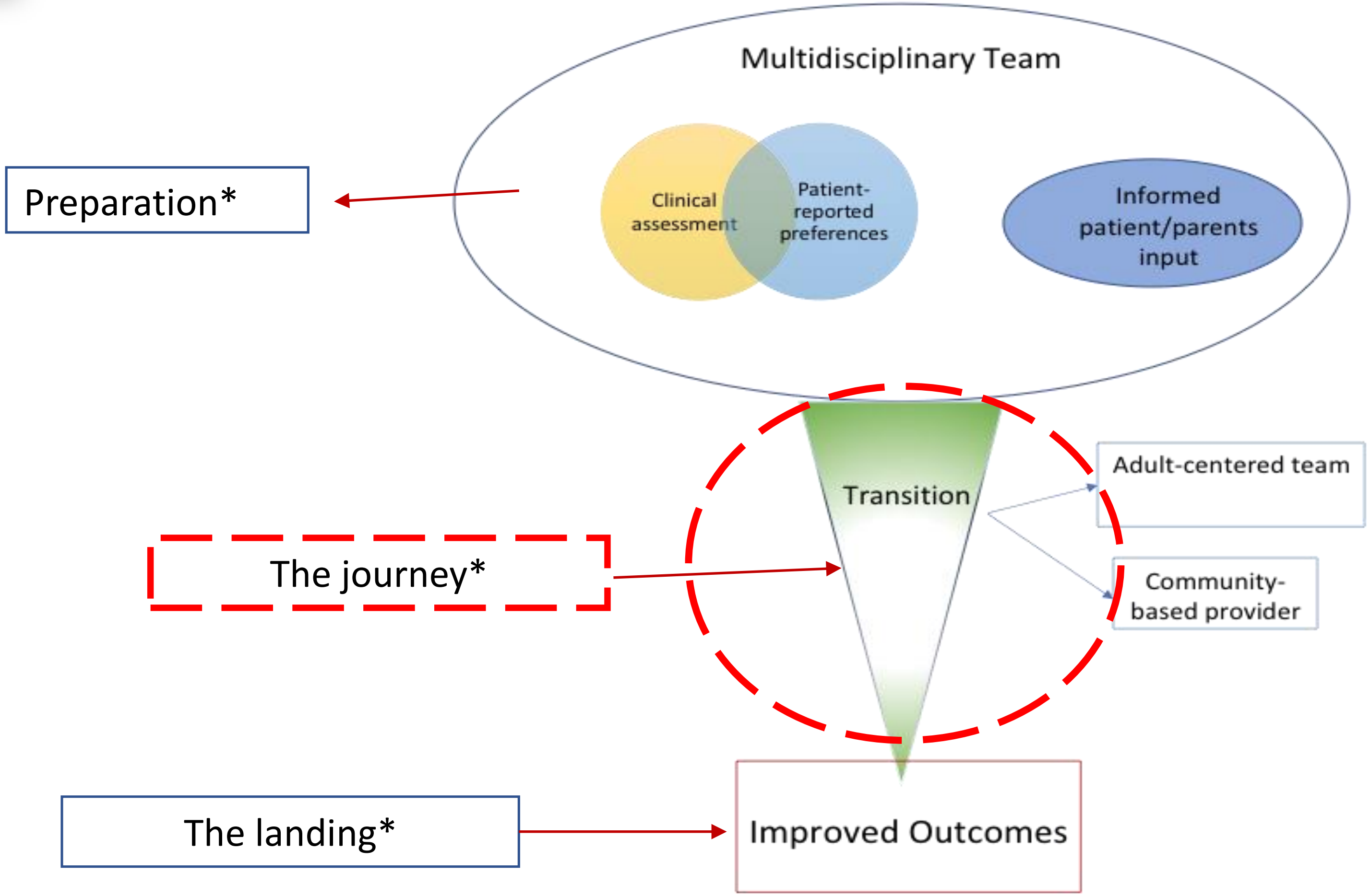
- Encourage patient to check in by him or herself
- Have the patient sit near the provider (not parent) and ask the patient the questions (problem, concerns) – look at the patient during questioning and answering
- If the patient does not know the answer – refer to parent
- Listen to the patient's needs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

Here’s what some team members are doing…*

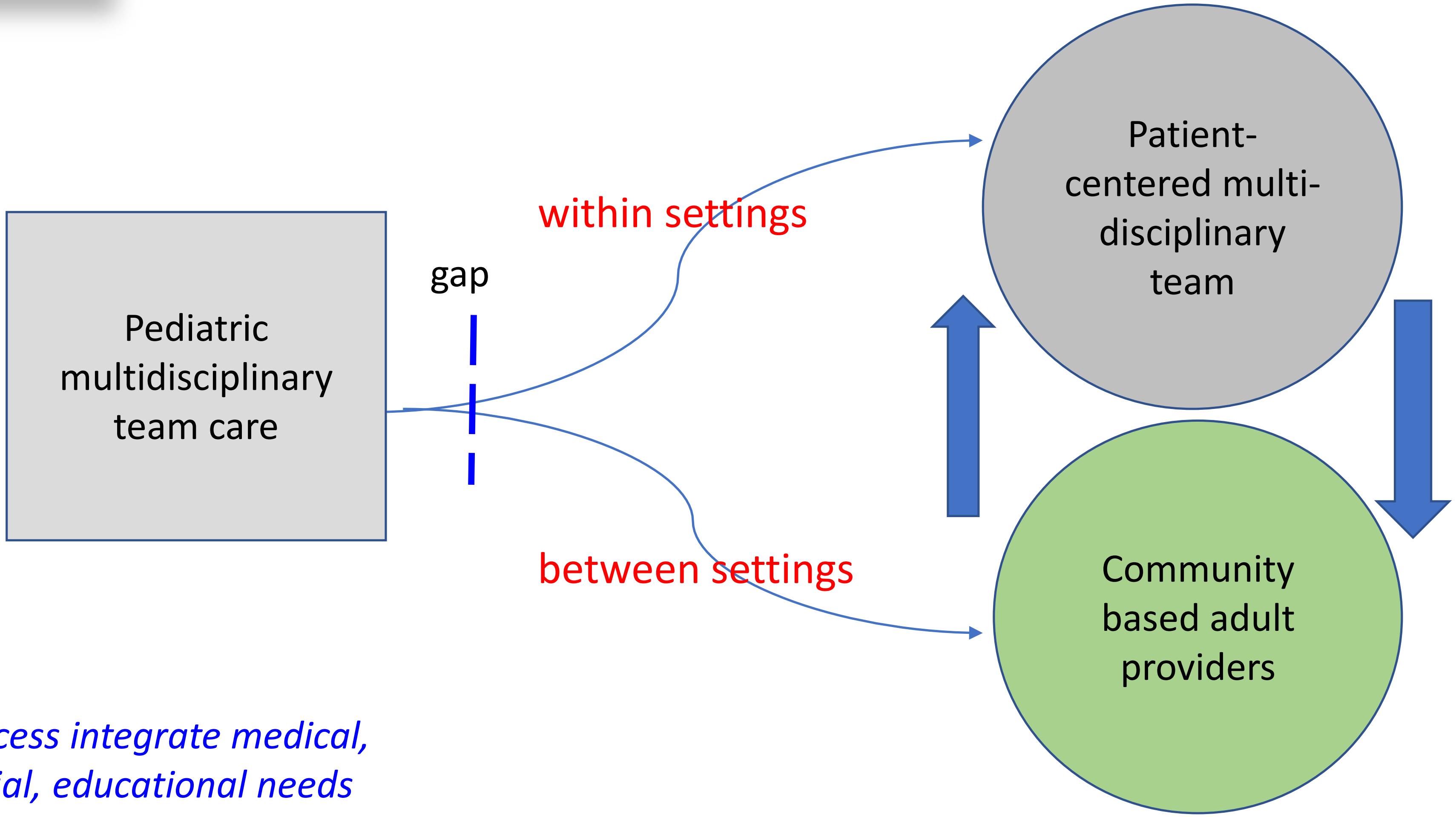
- Developed a quiz called “Test your Knowledge” regarding what the young adult knows about their providers their roles
- When coming to the team, ask the teens which providers they’d like to most see on that day and get them to explain why
- Developed a system to remain with the same provider
- Developed a template for letters about the young adult’s condition and care to share with outside team providers

From: 2018 ACPA audience participation

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.*



Pediatric multidisciplinary team care

gap

within settings

between settings

Patient-centered multi-disciplinary team

Community based adult providers

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")

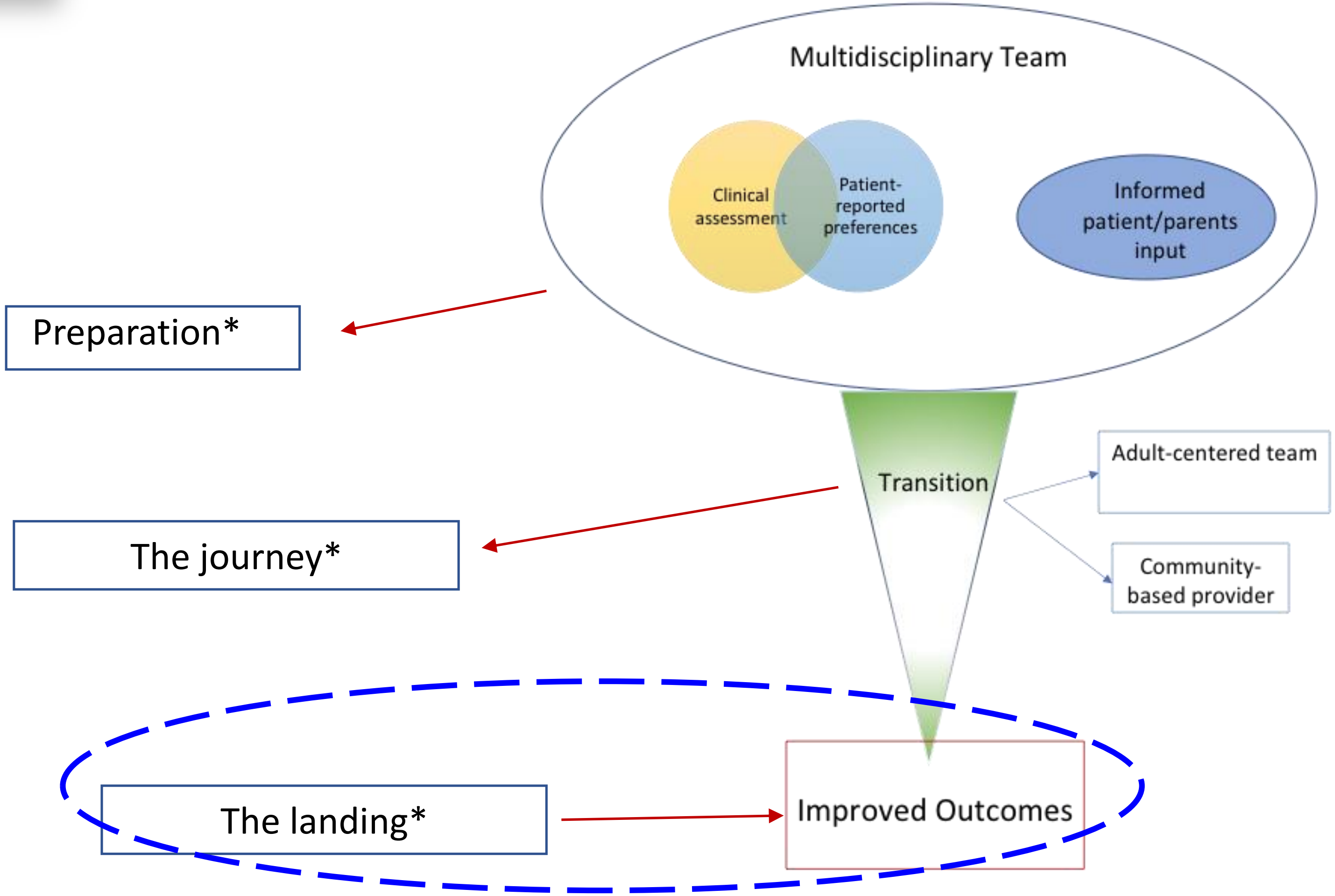
What would make for an successful transition?

(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)



Multidisciplinary Team

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The journey*

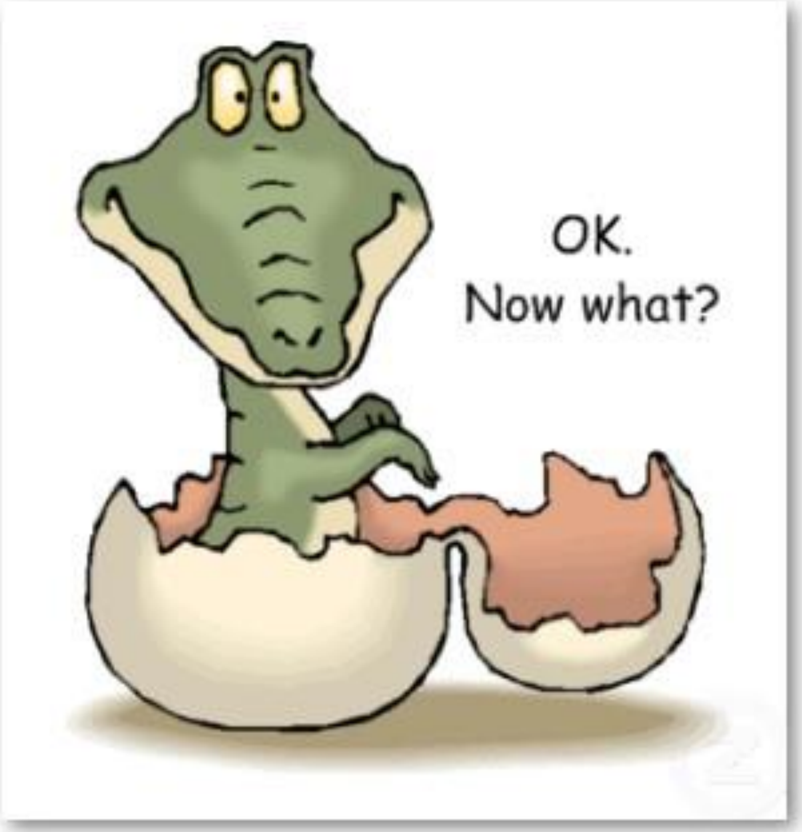
The landing*

Improved Outcomes

The Landing: Did they arrive?

- Difficult question to answer.

- Those who engage in transition of care programs should evaluate and share outcomes.



- Young adults are here and more will come throughout the years

- They’ve been neglected, pushed under the rug, and often thought of as invisible

- Need for change, new perspectives!


CHANGE
AHEAD

Questions & Discussion

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