

Pediatric Rehabilitation Services: Expanding Horizons

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Objectives

Participants will:

- ❑ Reflect on current practices
- ❑ Challenge boundaries
- ❑ Re-think old assumptions
- ❑ Imagine new possibilities



Desired Outcomes of Pediatric Rehabilitation

- ❑ Meaningful participation at home, school, and community
- ❑ Self-determination and self-efficacy
- ❑ Wellness (physical, mental, emotional)
- ❑ Empowering families as decision makers and advocates
- ❑ Enabling inclusive communities
- ❑ Preparation for desired roles as adults

What is the Issue?



Transformative Services Paradigm Shift

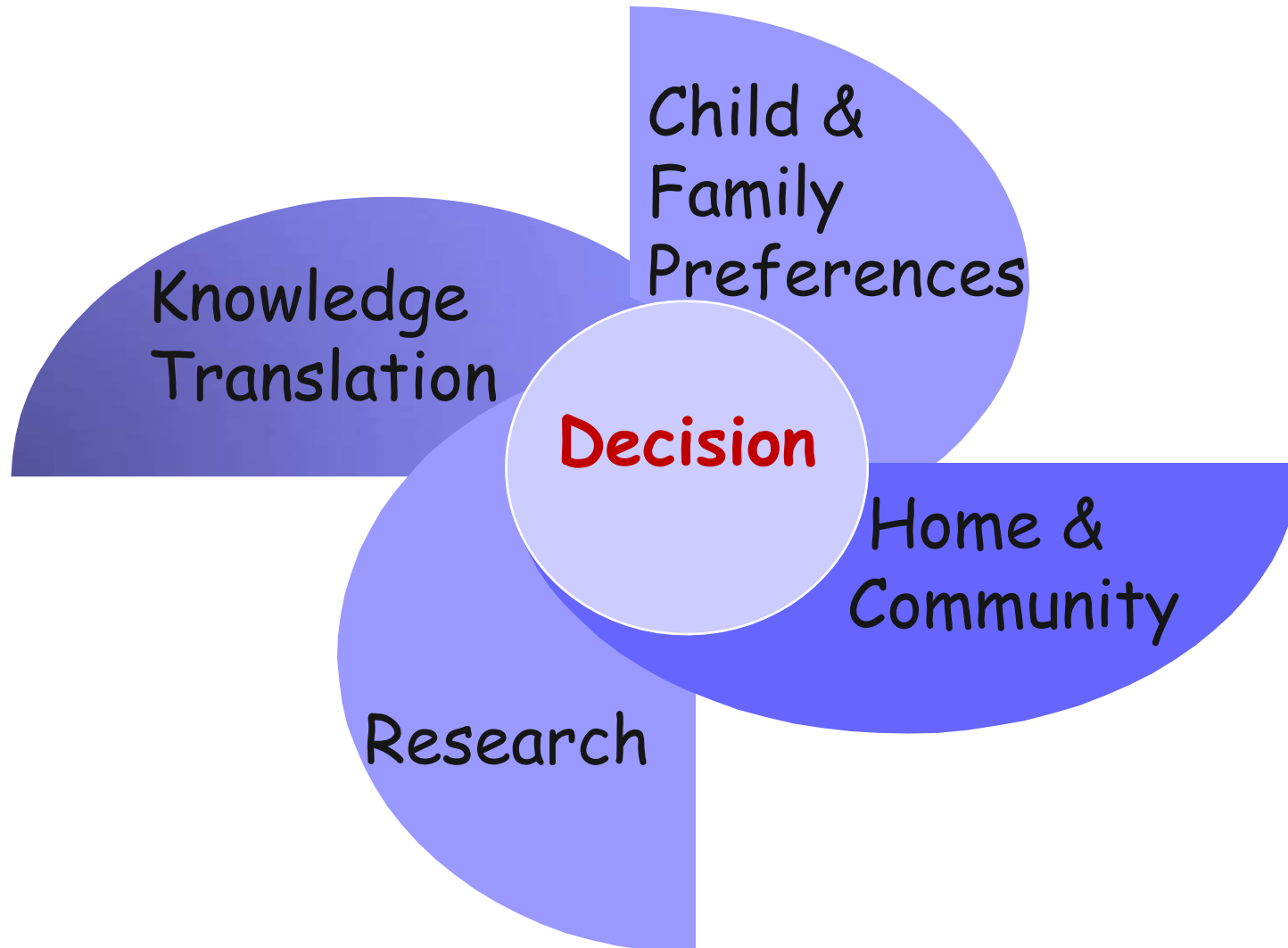
(Doing things in new ways)

What is the motivation:

- ❑ Research evidence?
- ❑ New perspectives?
- ❑ Family advocacy?
- ❑ Public policy?
- ❑ Costs / resources?



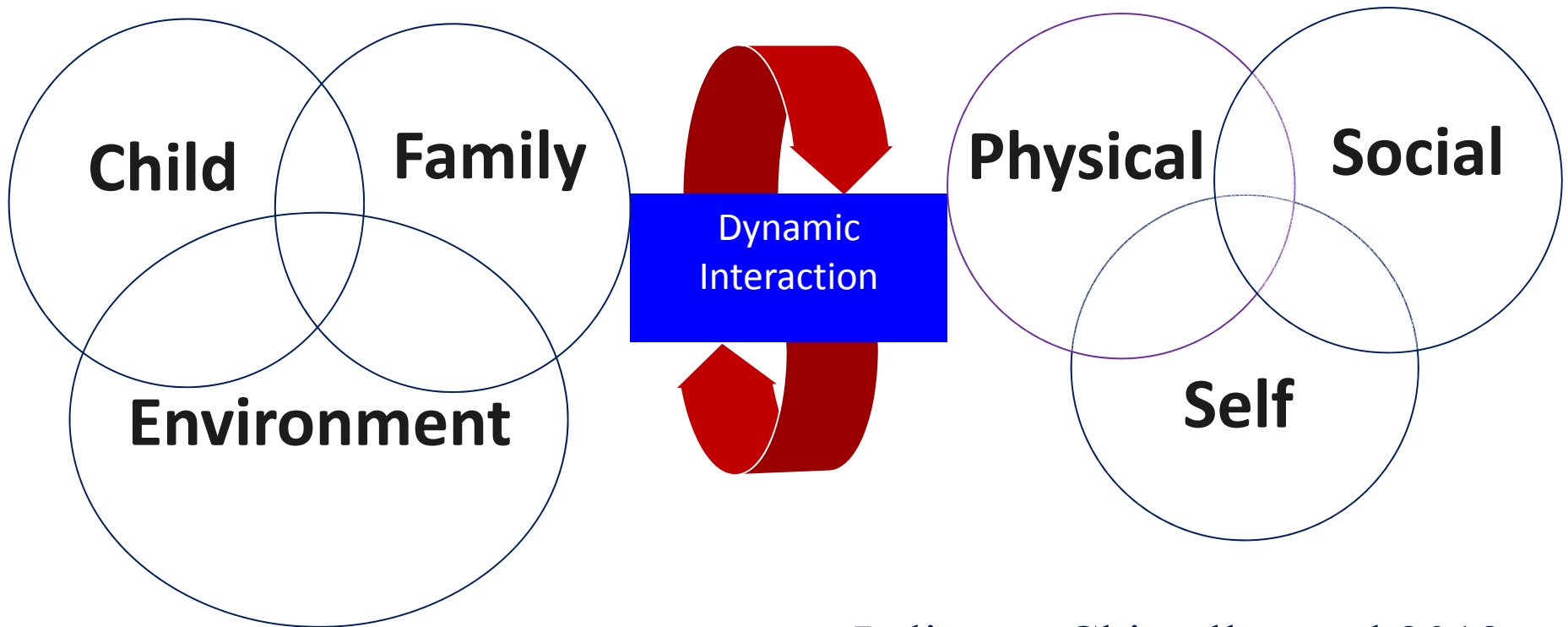
Evidence Informed Decision Making



Model of Meaningful Participation

Determinants

Dimensions



Palisano, Chiarello, et al 2012

Participation-based Therapy

Family/professional / community partnerships that focus on children's activity and participation in daily life

Collaborative

Goal oriented

Strengths
based



Solution
focused

Ecological

Palisano, Chiarello et al, 2012

Expanding Horizons

- ❑ Family-professional partnership
- ❑ Goals & outcomes meaningful to children and families
- ❑ Services that build child, family and community capacity
- ❑ Strengths based and solution focused interventions
- ❑ Task-oriented practice in meaningful contexts
- ❑ Real world life experiences
- ❑ Future planning & anticipatory guidance
- ❑ Reflective practitioners

Family – Professional Partnership

Needs to Guide ALL Aspects of
Service Delivery

Develops
Over Time

Partnership: “a shared responsibility for a common goal”

“Parents and other family members working together with professionals in pursuit of a common goal where the relationship between the family and the professional is based on shared decision-making and responsibility and mutual trust and respect”

(Dunst, Trivette, & Synder, 2000, p. 32).

Do we have a
common goal?

What needs to be considered
to develop a common goal?

What Goals are Meaningful to Children and Families?



Families are unique

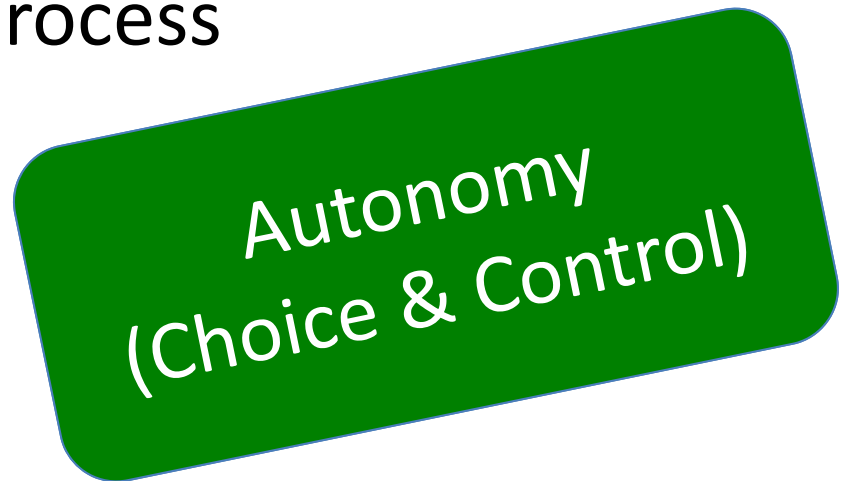
Do We Differentiate and Consider Goals and Outcomes?

- Goals: What the child and family wants to accomplish and learn
- Anticipated Outcomes: Significant and essential learning that will occur from this service provision
 - Connected to the goal
 - Can have more than one outcome related to a goal
 - Drive activities and intervention strategies

Services start
with the goal!

Whose Goal?

- Child and Family
- Not Provider
- Ownership is central to engagement and participation in the process



Credit is given to Kim Ward, PT, DPT, MPH, PhD Student Drexel University for her collaborative contributions

How Are Goals & Outcomes Identified?

- Collaborative process

Relatedness
(Connected & Supported)

- Involvement of child, family, and other members of the team

- Various inputs and perspectives
- Fosters engagement of families in therapy and positive outcomes

- Supportive conversations & discussions

- Art of goal setting

Listen to the
Family's Story

Competence
(Confidence & Efficacious)

How Many Goals & Outcomes?

- Prioritization
 - Focus
 - Concerted effort
 - Time for actions and practice

Less May be Better

What Might the Focus of Goals Be?

- Family priorities
 - Happy & fulfilling lives, self-determination, accepted by others
 - Individualized, unique, within context of their family life
 - For their children: self-care, mobility, sitting/standing, communication, play, socialization, recreation/sports, school work, household management, preparing for transitions, health (nutrition, fitness, safety, energy conservation), body functions & structures (balance, coordination, strength)
 - For themselves: information on services & community activities, planning for the future, personal time

What we have learned may be constrained by the lens of our research and families' experiences with services.

- Youth priorities: self-sufficiency (mobility, self-care, care management), physical activities (sports, fitness, recreation), socialization, education, household management, employment, transportation



Paralympic.org

Children's Health

- Influence of health related issues, such as seizures, nutrition, pain, sleep, and illnesses, on daily life may be an outcome to monitor to support children's wellness to pursue their goals

Monitor Children's Health

Children's Self-Determination

- Adaptive Behavior
 - Self-awareness
 - Goal setting and decision making
 - Responding to environmental demands
 - Communication and advocacy
 - Flexibility, persistence, and problem-solving
 - Interactions with others in a variety of situations

Adaptive behavior associated with gross motor function, self-care, playfulness, & participation

Shape Goals to Support Adaptive Behaviors & Playfulness



Children's Playfulness

- Initiate a play activity of their choice
- Participate in turn taking, share with others
- Use toy in unconventional manner
- Modify and expand an activity
- Take challenges and persists with an activity
- Enter into play activity with peers
- Support play of others
- Ask for needed assistance to play a game



*Engagement in Play
Approach to an Activity*

Children's Participation in Daily Life

- Family Routines
- School Routines
- Recreation and Leisure Routines
- Spiritual Routines
- Civic Routines
- Employment Routines

**Posture, Mobility, Manual Abilities, Self-Care,
Communication in Context of Meaningful Routines**



Past, Present, & Future

- Charlotte will balance on one foot with her hands on her hips for 10 seconds.
- Charlotte will balance on one foot with her hands on her hips for 10 seconds so she can participate in a dance class.
- Charlotte will participate in a 3 minute dance routine during her dance class without falling.

Integrated Team Goals

- Group of connected activities within a meaningful context
 - Team can support and focus on child's primary goal
 - PT can especially support mobility and balance
 - OT can especially support dressing and manual ability
 - Speech & language pathologist can especially support communication with teacher and peers
 - Child is motivated to learn and has fun!

Context is Important

Family Ease of Caregiving and Self-Efficacy

- Ease of Caregiving: parent perception of the level of physical difficulty experienced while helping a child to perform daily activities
 - Reflects ability of caregiver to safely and confidently provide physical assistance for a child to fulfill activities of daily living in a reasonable amount of time
- Self-efficacy: confidence and competence to nurture and care for their children

Identify Family Goals for
Themselves as Parents

How Should Goals and Outcomes Be Measured?

- Collaboratively
- In context
- Personalized
 - Be innovative: photos, video clips, journals
- Individualized goal attainment
- Selective standardized outcome assessments connected to the goal of interest



Personalizedmall.com

How Should Goals Guide Service Delivery?

- Service delivery approach
- Setting
- Activities
- People involved
- Intervention strategies
- Progress monitoring



Let the Child Be Our Guide

Service delivery

How can we expand the horizons of our services?



Service delivery

- ❑ Goal driven
 - Focused
- ❑ Collaborative
 - With children, parents and other health professionals
- ❑ Services that build child, family and community capacity
- ❑ **“Charlotte will participate in a 3 minute dance routine during her dance class without falling.”**

Services start with a
meaningful goal!

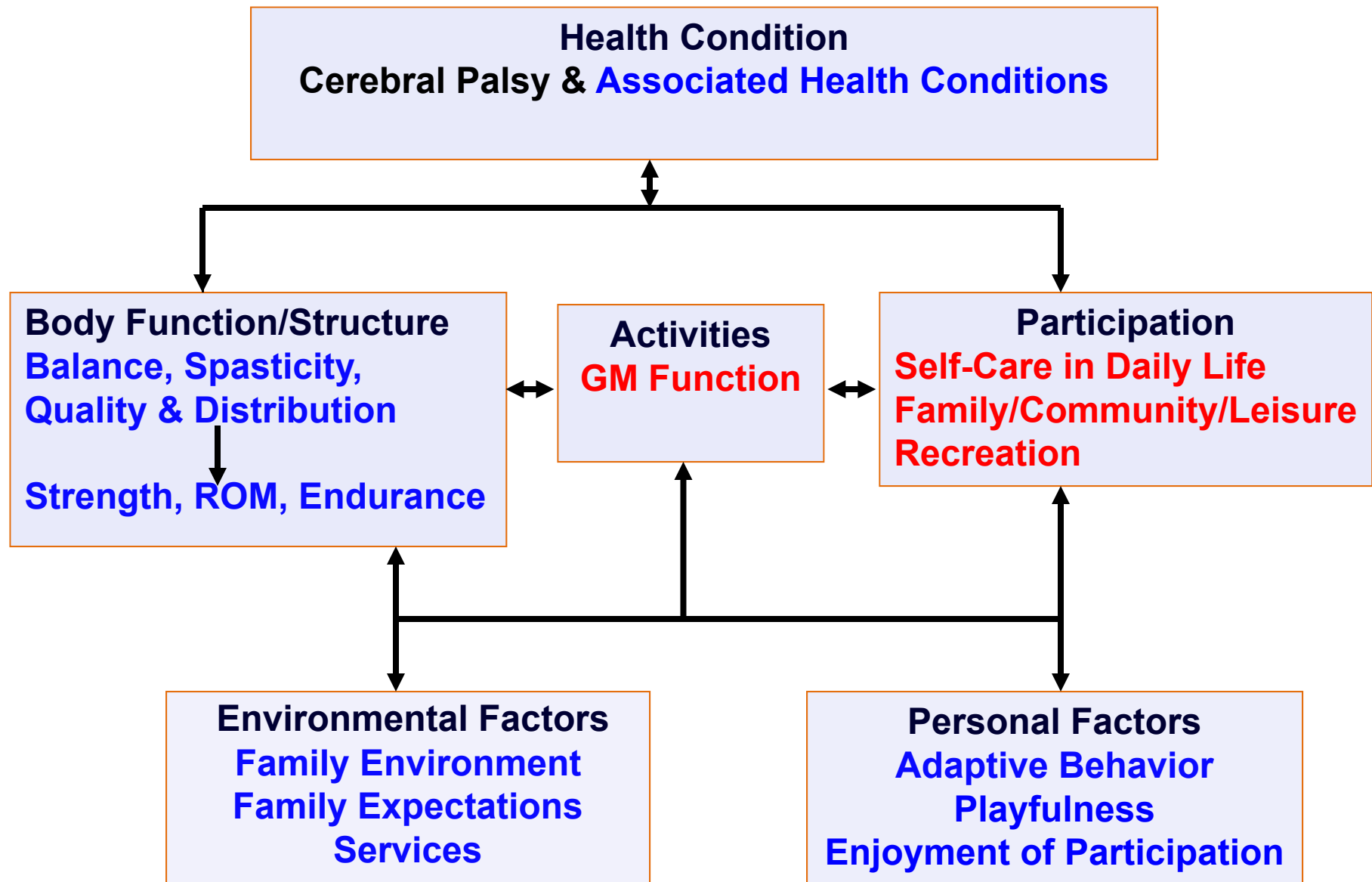
Consider theories and models for service direction

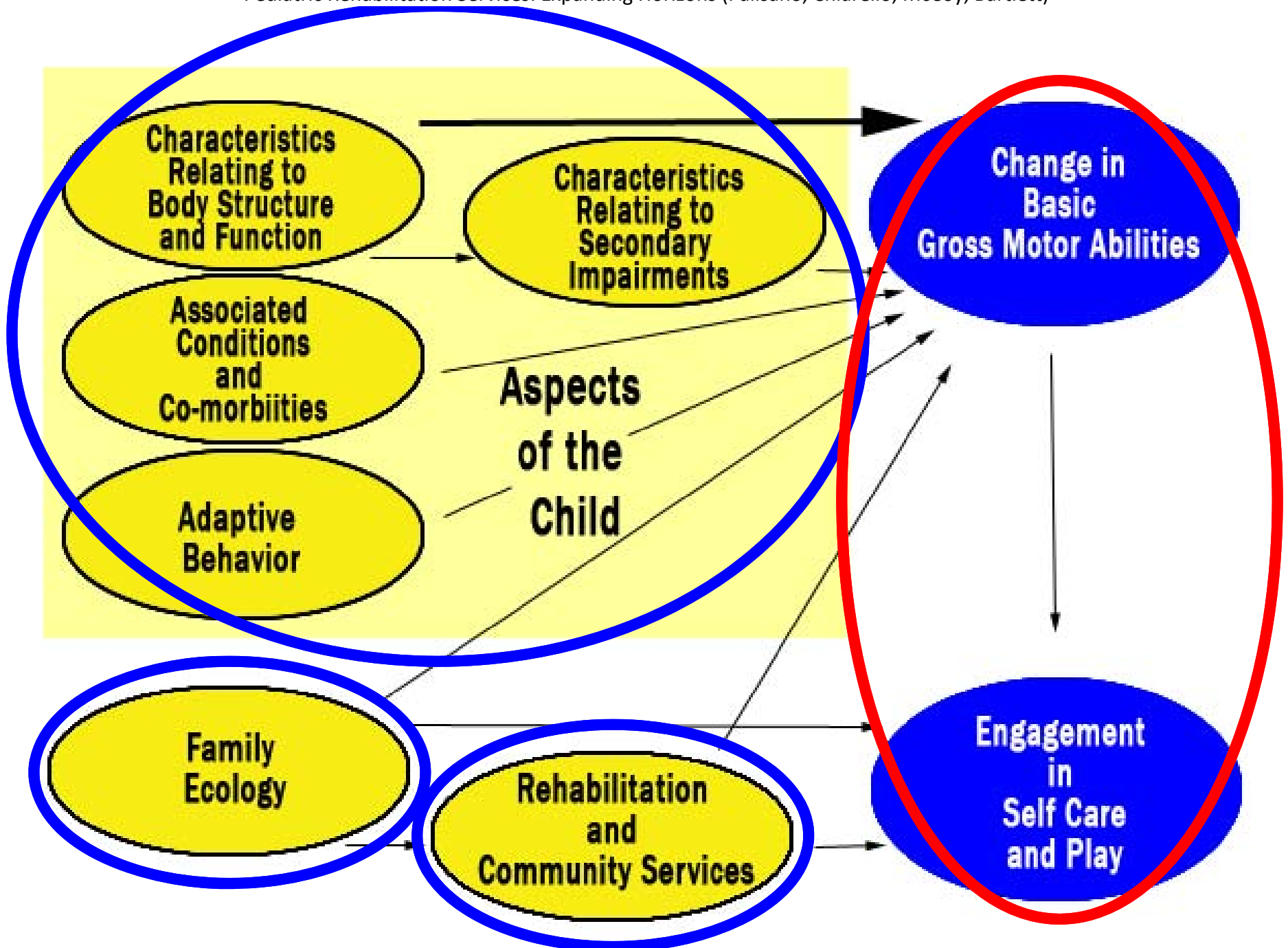
□ Theories

- motor control & development, motor learning, motor recovery

□ Models

- International Classification of Functioning, Disability and Health (ICF)
- Determinants of motor and participation ability for children with disabilities





Chiarello et al. 2011, 2016; Bartlett et al. 2014A, 2014B

How should we determine the amount of service?

- Intensive intervention
 - The more the better?

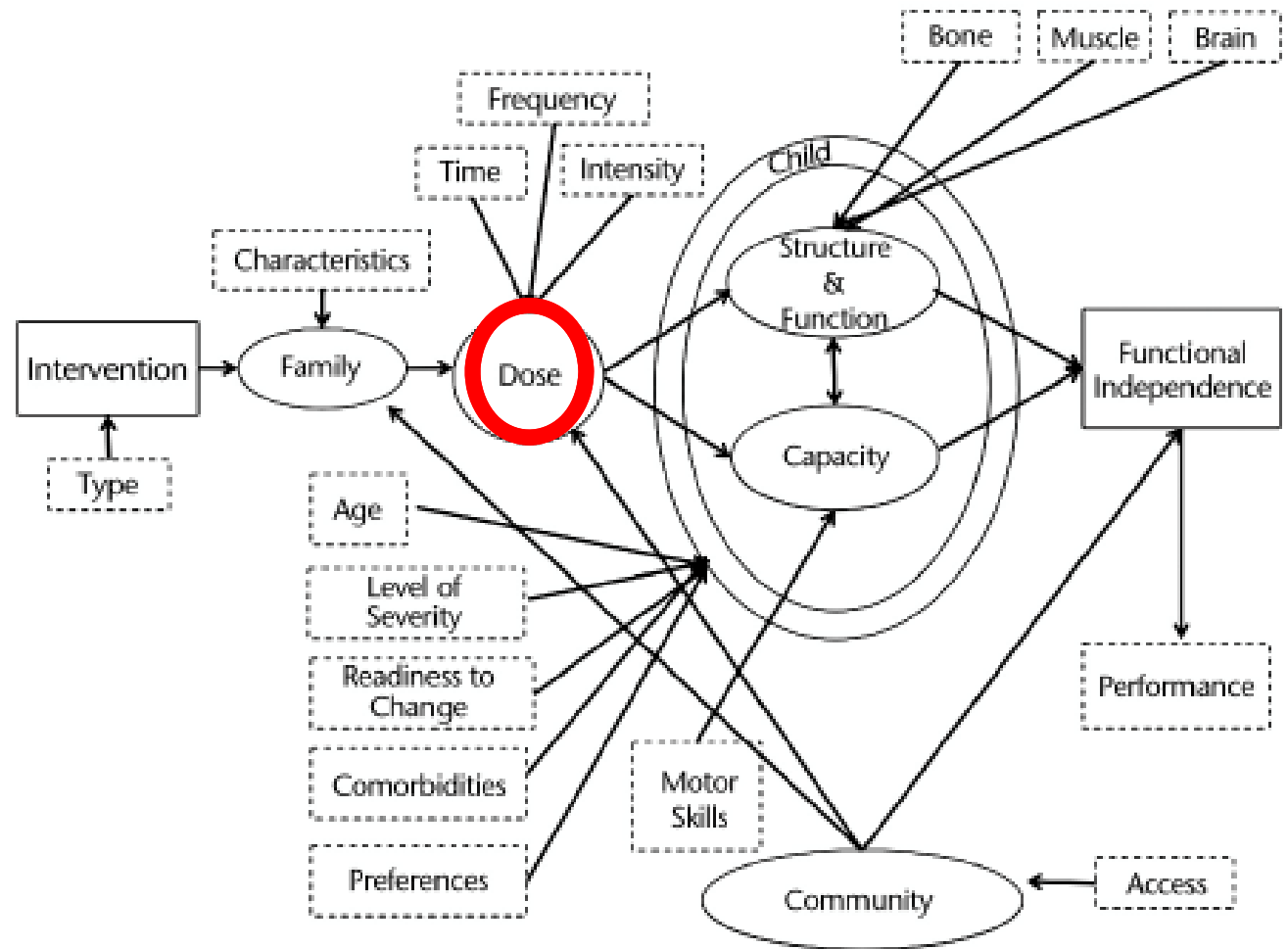


Figure 2.

Path model for evaluating dosing parameters for children with cerebral palsy. Dashed boxes represent characteristics of the constructs that warrant consideration.

Gannotti et al., 2014

- More
practice
outside
of
services

Path model for evaluating dosing parameters for children with cerebral palsy. Dashed boxes represent characteristics of the constructs that warrant consideration.

How hard should we ask children to work within practice?

- ❑ Focused task-oriented services
 - Studies of focused intense intervention do change focused outcomes

- Ex. CIMT

Need to assist children to be active & sweat!

- ❑ Intense service may not work for all families

Home activities can be effective

Novak et al. 2013; Novak & Berry 2014; Kruijsen-Terpstra et al. 2016

What should we focus on within intervention?

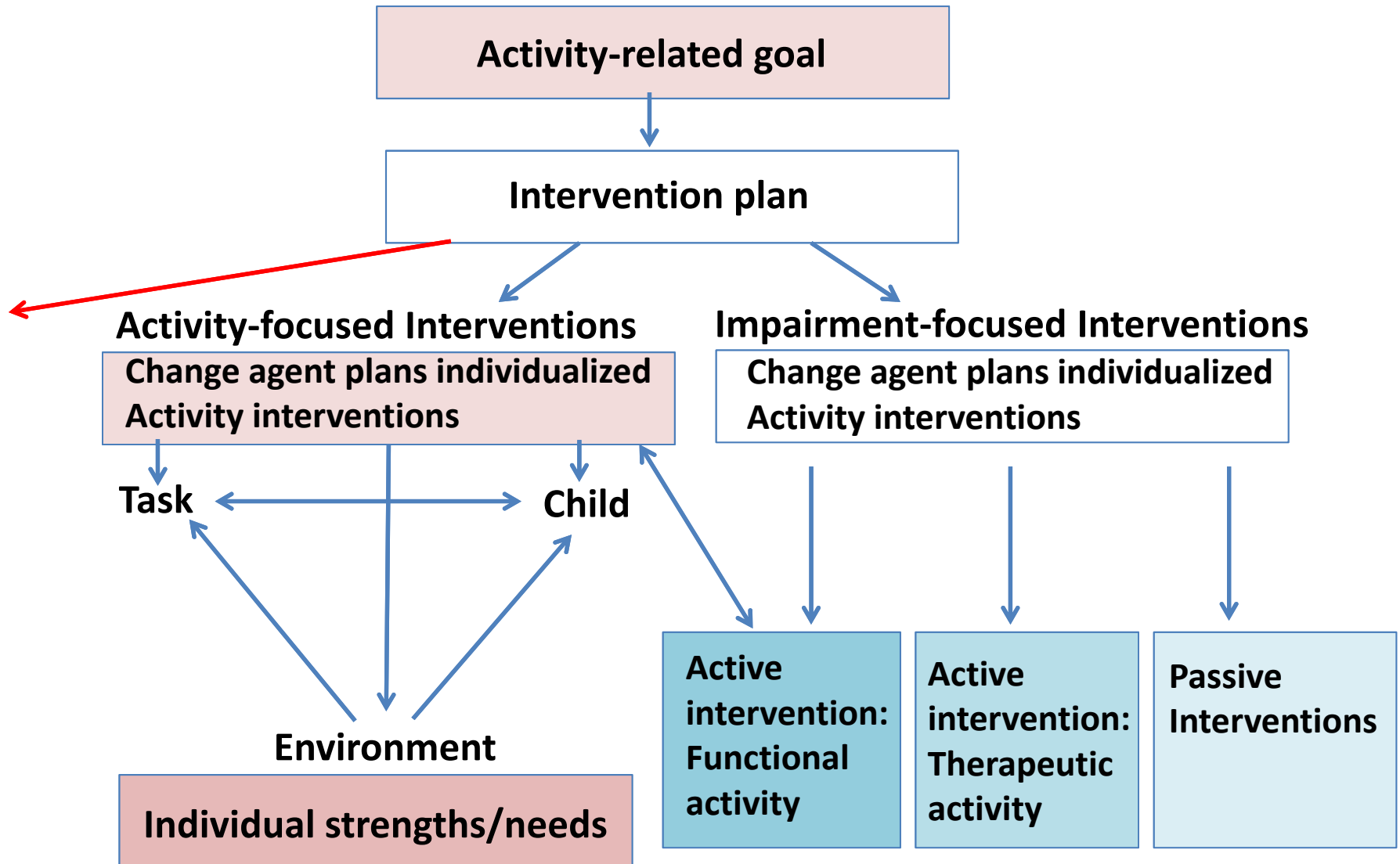
- ❑ Based on Research to date:
 - Motor learning
 - Activity practice
 - Aerobic conditioning
 - Assistive devices/environment
- ❑ Need research on:
 - Participation based intervention
 - Home activities



Context is Important

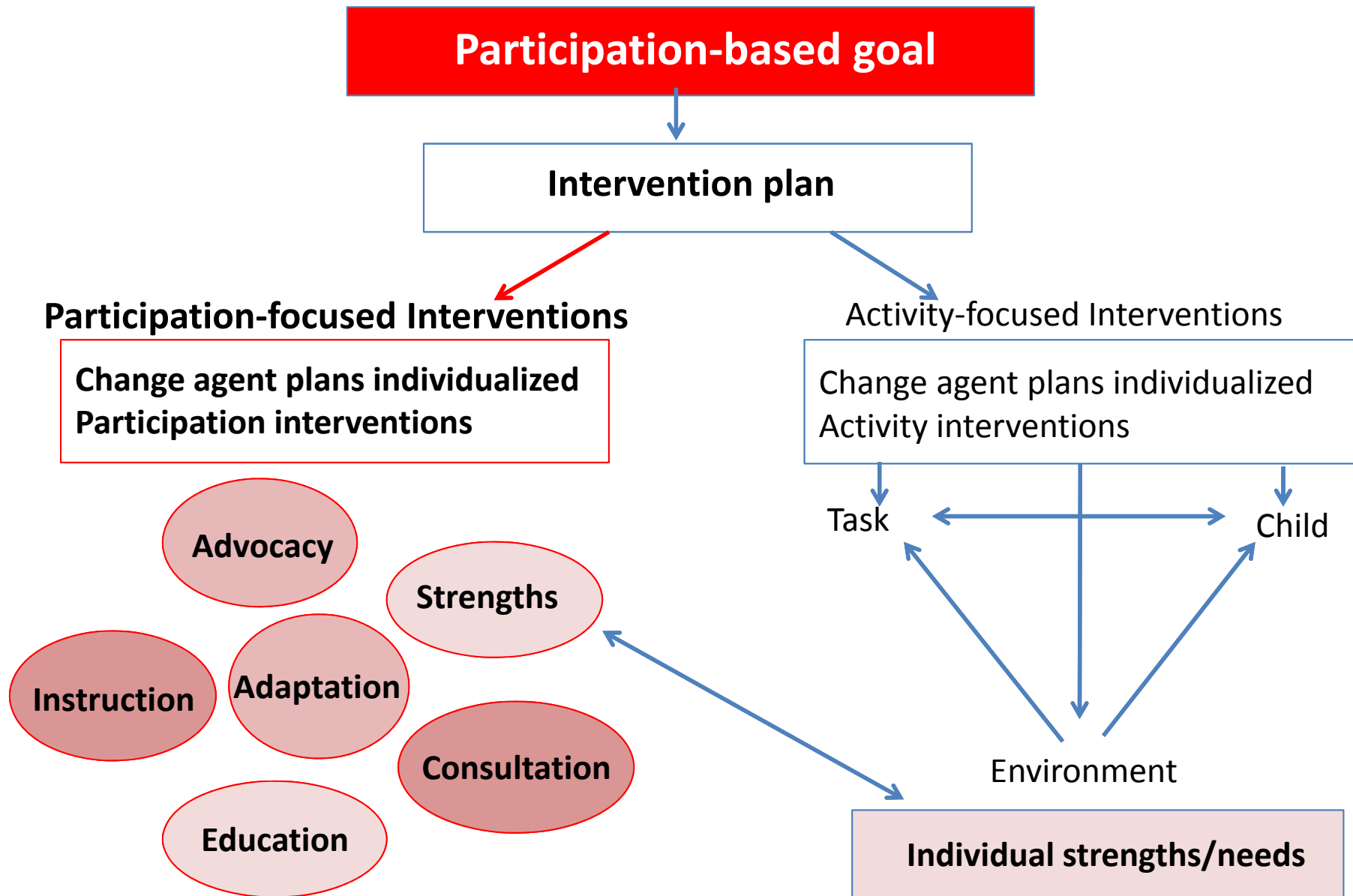
Morgan et al. 2016; Novak et al. 2013, 2014; Tinderholt Myrhaug et al. 2014

Model for Activity Focus of Intervention

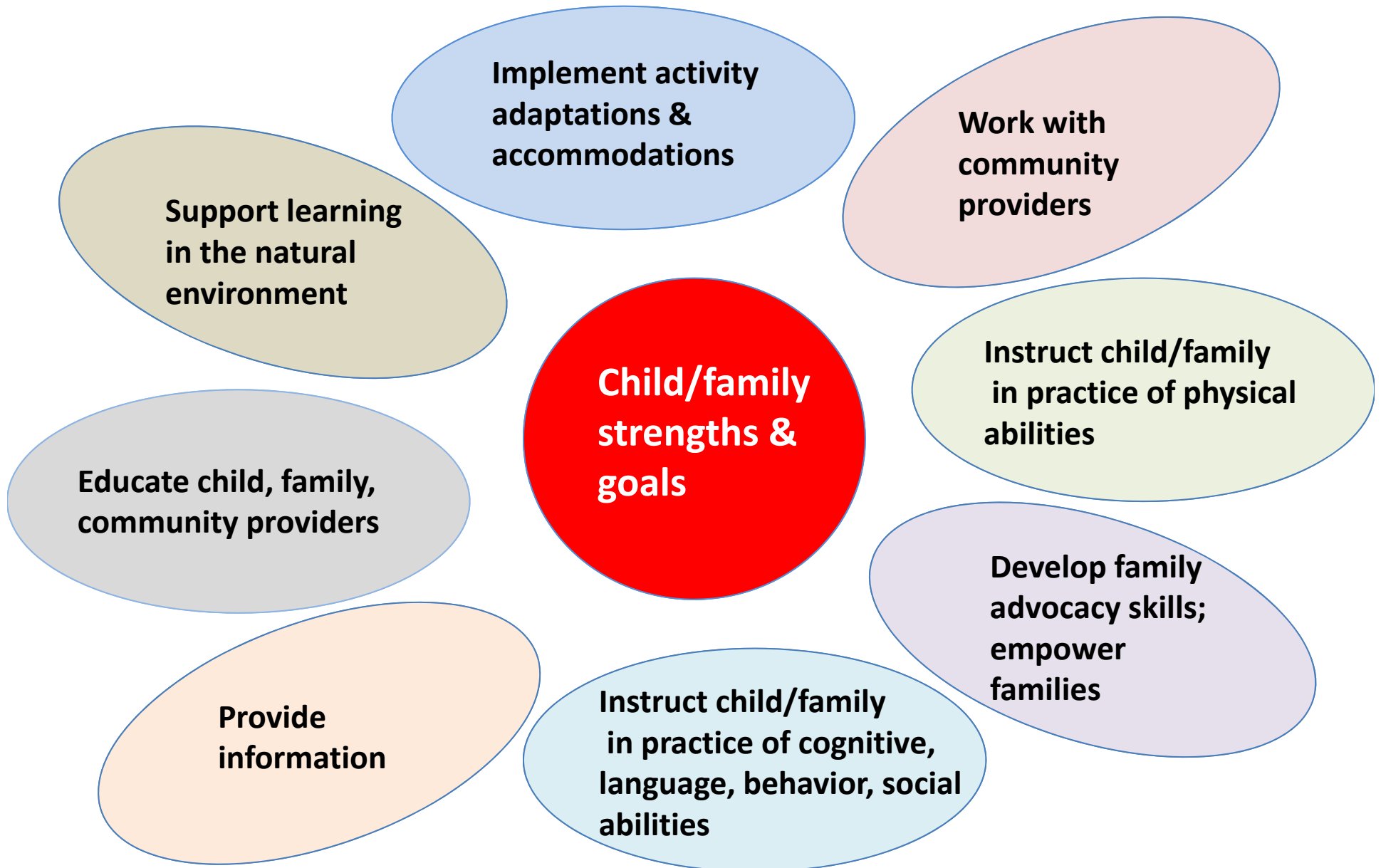


Valvano, 2004

Model for Participation Focus of Intervention



Participation Focused Intervention



Palisano et al. 2012; Kruijsen-Terpstra et al. 2016

Where should we provide our intervention?

- Clinic??
- Home, School, Community
 - Child/family goal directed for motivation
 - Integrated for real life carry-over
 - Real life practice for chance of intensity



Environment is Important

Law & Darrah 2014; Palisaon et al. 2012

New Horizons for Service

- ❑ **“Charlotte will participate in a 3 minute dance routine during her dance class without falling.”**



What are the attributes of therapists that facilitate expanded horizons?



Multiple Sources of Knowledge to Inform Service Delivery

- ❑ Research evidence
- ❑ Theory-based knowledge
- ❑ Practice-based knowledge
- ❑ Philosophical approaches to care



Research Evidence

Evidence-based practice is the integration of

- ❑ **best research evidence:**
 - ❑ clinically relevant, patient-centred
- ❑ **clinical expertise:** ability to use one's knowledge and clinical skills and past experience to rapidly identify each person's uniqueness and to tailor examination and intervention accordingly
- ❑ **patient values:** unique preferences, concerns, and expectations each patient brings to the clinical encounter (Sackett et al. 2001)

15%

85%

**How much of practice is
informed by research?**

Theory-based Knowledge

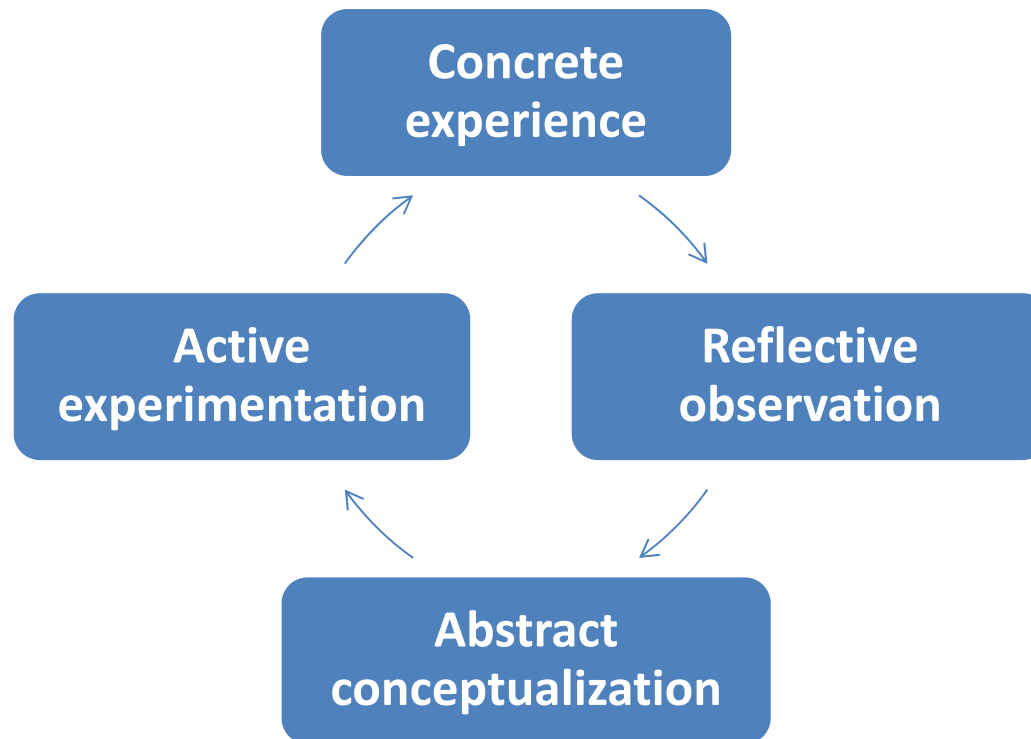
“there is nothing so practical as a good theory”

Kurt Lewin

- ❑ Dynamic systems theory
- ❑ Motor learning theory
- ❑ Self-determination theory

Practice- based Knowledge (Kolb, 1984)

Experience + Reflection = Knowledge



Experiential learning is enhanced and made possible by reflection

Benefits of Structuring Knowledge

When knowledge is structured, it is accessible for use

- ❑ Structured practice enables a deeper level of understanding of the big picture
- ❑ Using explicit conceptual frameworks improves daily practice by giving guidance on what to do and why to do it
- ❑ Students, novices, and mentees can better understand the apparent “mind leaps” of their clinical instructors and mentors with explicit use of conceptual models

Mediators of Sources of Knowledge: Essential Skills to Optimize Service Delivery

Expertise

Reflective Practice

Professional Judgement

Expertise (King et al. 2007)

- ❑ Supportive, educational, holistic, functional, and strengths-based approach
- ❑ Self-knowledge, including heightened comfort and humility, as well as a “quiet self-confidence”
- ❑ Realistic and refined expectations for changes that could occur with interventions
- ❑ Understanding of how to facilitate and support client change and adaptation using principles of engagement, coherence, and manageability

Reflective Practice

“the higher order intellectual and affective activities in which [health care practitioners] engage to critically analyse and evaluate their experiences in order to lead to new understandings and appreciation of the way they think and operate in the clinical setting”

(Higgs and Jones, 2000, page 6)



Metacognition: thinking about one's thinking

Reflective Practice

Deliberate cognitive process

Anticipatory Reflection

Thinking before acting

Reflection-on-Action

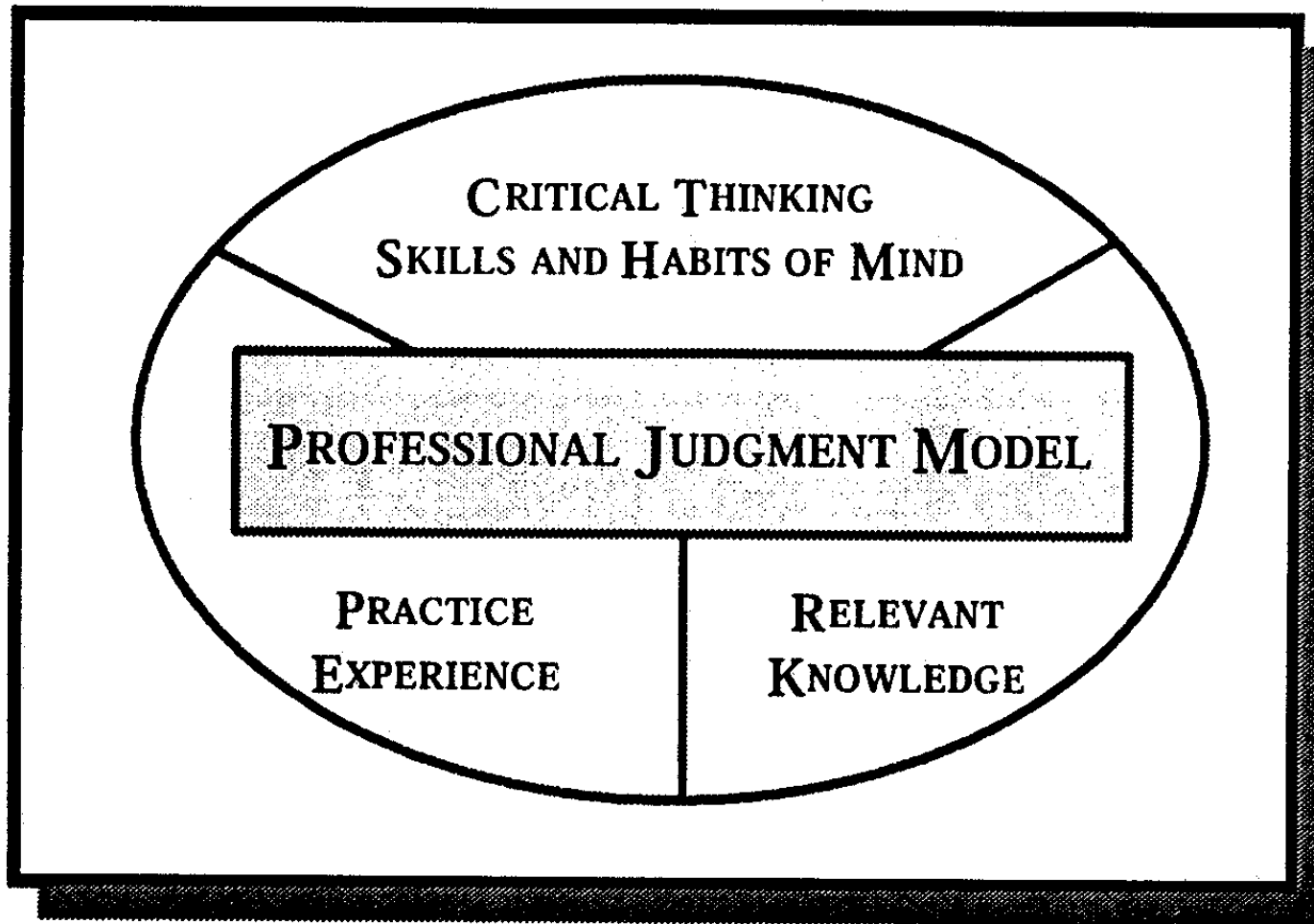
Thinking after acting

Reflection-in-Action

Thinking during acting

**With development of expertise>
in-the-moment, seamless**

Professional Judgement



Facione et al. 1998

... supported by critical thinking

Critical Thinking (defined, Facione et al. 1996)

The ideal critical thinker is habitually inquisitive, well informed, trustful of reason, open-minded, flexible, fair-minded in evaluation, honest in facing personal biases, prudent in making judgments, willing to reconsider, clear about issues, orderly in complex matters, diligent in seeking relevant information, reasonable in the selection of criteria, focused in inquiry, and persistent in seeking results which are as precise as the subject and the circumstances permit.

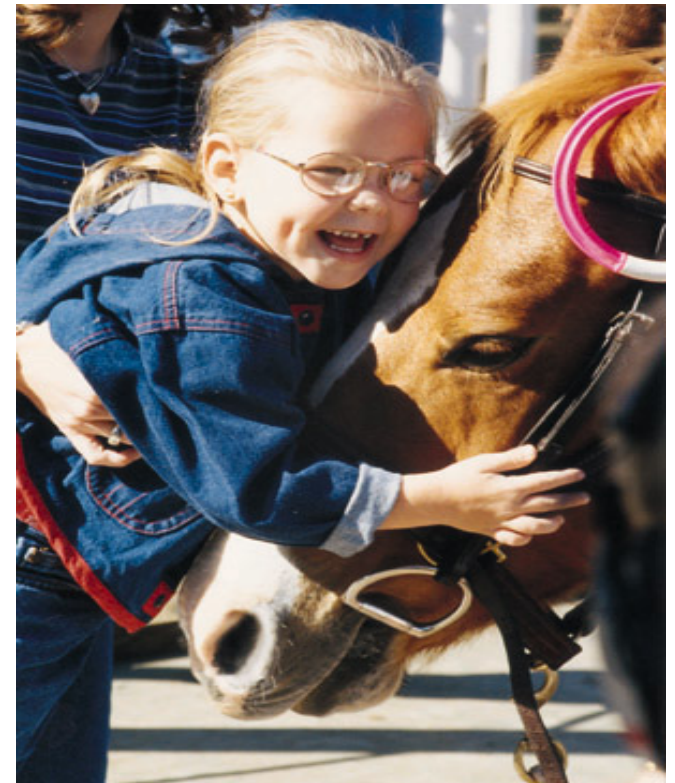
Recommendation: Service Providers should **STRETCH THEMSELVES** by

- ❑ Recognizing the unique nature of each child and family
- ❑ Acknowledging that knowledge from research, theory, practice and philosophical approaches all inform decisions
- ❑ Structuring knowledge to support decision making
- ❑ Optimizing one's own level of expertise and self-knowledge, reflective capacity, and professional judgment skills, supported by strong critical thinking abilities

To appropriately individualize services to optimize outcomes for children and families

NEW HORIZONS ABILITIES NOT disabilities

How can professionals partner with
children, families & communities to
not only
support children's participation
but also
enable children to be healthy and
ready to live, work, and enjoy life in
their communities as adults?



What needs to change? How should we change? Your thoughts?

- ❑ Therapist
- ❑ Administrators of Service
- ❑ Educators
- ❑ Research
 - Are we asking the right question?
 - Are we partnering with families and youth

Thank you!

