

Transforming Physical Therapy for Children with Movement Disorders

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Objectives

For children with movement disorders, participants will:

- describe a holistic framework for provision of rehabilitation services
- compare and contrast key elements of service provision to support meaningful outcomes
- understand how to use current information on developmental trajectories of children
- understand how knowledge & skills therapists possess can support children & their families.



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?



Case Scenario



Pre-Test

For the child in the case scenario:

1. What should be the focus of physical therapy?
2. How much service should be provided?
3. Where should service be provided?

Video Mari

Pre-Test

For the child in the case scenario:

1. What should be the focus of physical therapy?
2. How much service should be provided?
3. Where should service be provided?

Video Mari's Dad

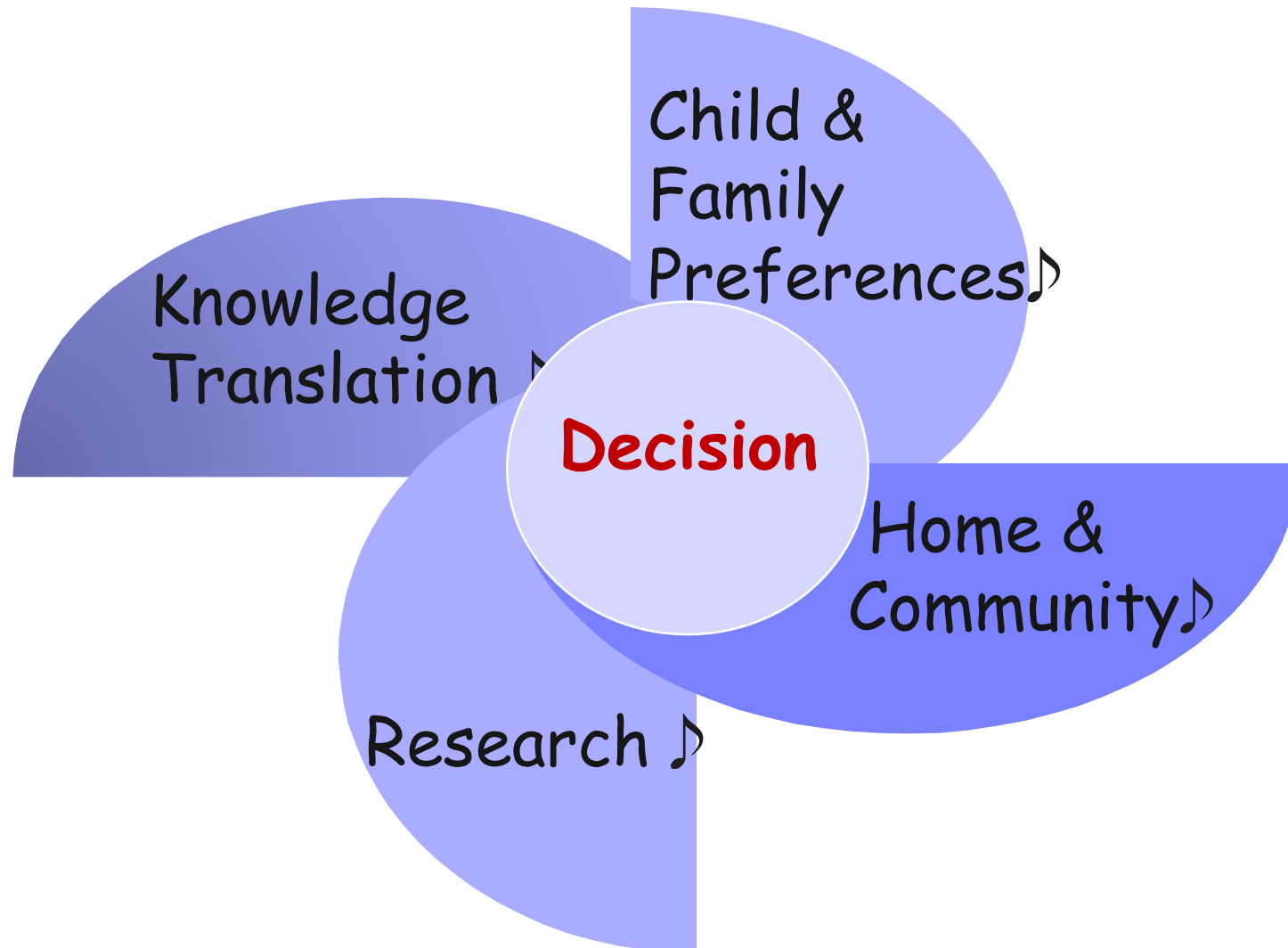
Video Mari's Mom

Pre-Test

For the child in the case scenario:

1. What should be the focus of physical therapy?
2. How much service should be provided?
3. Where should service be provided?

Evidence Informed Decision Making

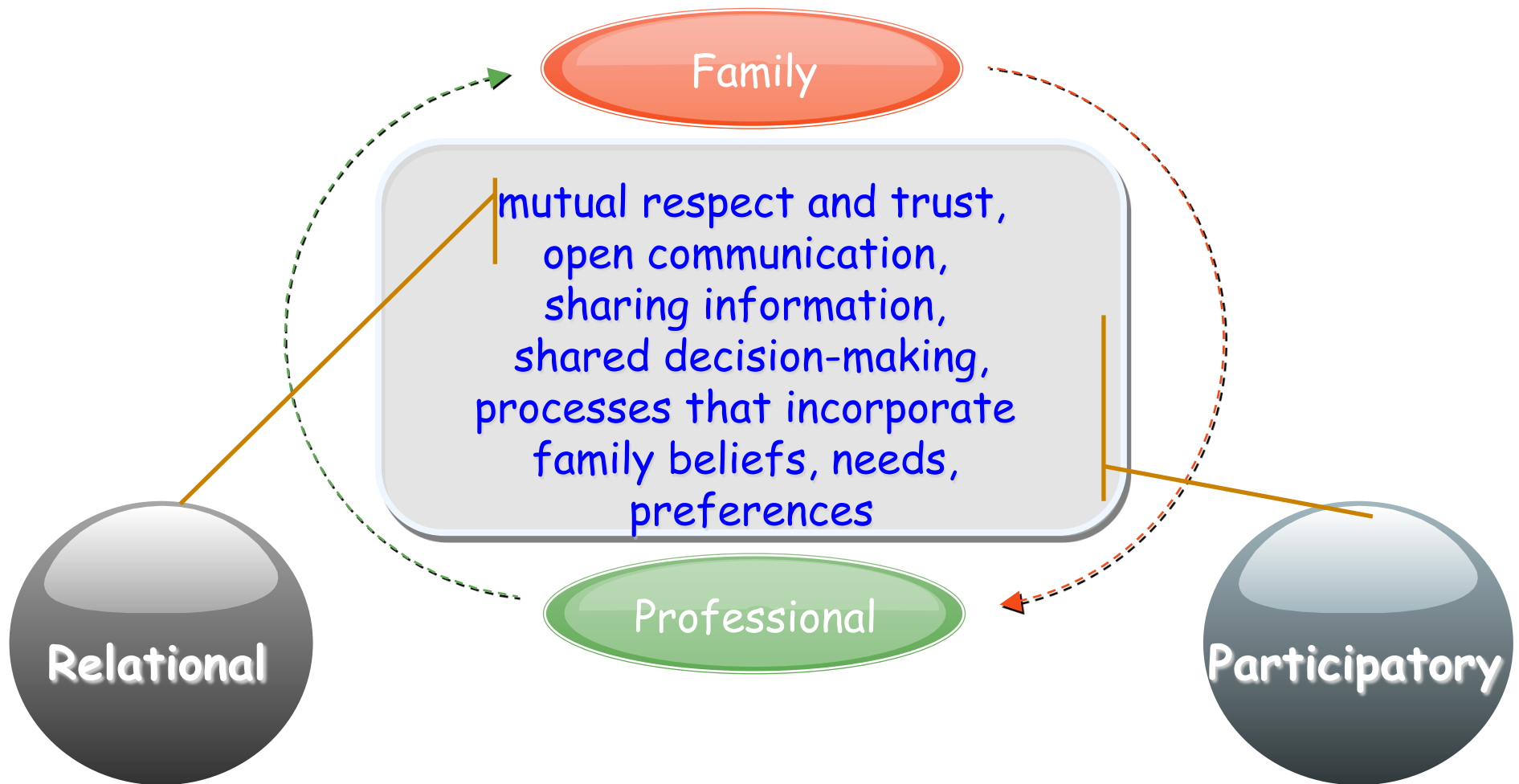


Family-Professional Partnership

- Central to ***family-centered services***, considered best practice in pediatric rehabilitation
- Essential for setting meaningful goals and planning and implementing interventions within the context of family life

(King & Chiarello, 2014; Law et al., 1998; Rosenbaum et al., 1998)

Family-Professional Partnership



Blue-Banning et al., 2004; Dunst et al., 2002; Keen, 2007; Summers et al., 2005

Participatory Practices

- Information sharing so families can make informed choices
- Family involvement in acting on those choices
- Professional flexibility and responsiveness to family requests

Trivette & Dunst, 2007

Research Evidence

When the family-professional relationship is collaborative:

- Parents more likely to seek help from professionals
- Parents more satisfied with services
- Parents perceive higher levels of individual & family well-being
- Parental stress is decreased

(Dunst & Dempsey, 2007; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Trute & Hiebert-Murphy, 2007; Van Riper, 1999)

Research Evidence

Parent involvement in setting goals & implementing intervention increased:

- Child performance & goal attainment
- Parental feeling of competency & sense of collaboration
- Parent awareness of using everyday activities as sources for natural learning opportunities, shared planning and joint actions

(Graham, Rodger, & Ziviani, 2010; Law et al., 1998; Øien, Fallang, & ØstensjØ, 2010; ØstensjØ, Øien, & Fallang, 2008)

Challenges to Parent-Professional Partnerships

- ***Participatory practices*** have been found to be more strongly related to positive outcomes than ***relational practices***, yet professionals implement participatory practices less often than relational practices
- Professionals reported difficulties collaborating with family to address their needs and concerns and engaging families in the intervention process

Dickens et al., 2011; Dunst et al., 2008; Dyke et al., 2006;
Litchfield et al., 2002; King et al., 1998

Family Perspectives on Rehabilitation Services for their Children



Parents' Experiences with Therapy for their Children with Cerebral Palsy: Mixed Methods Review

Themes supported / emerged from review:

- Each family is unique
- Importance of the broader context in which families live
- Enabling parents to make own decisions
- Providing support to families
- Time is needed to develop family-professional relationship

Kruijsen-Terpstra et al, 2013

Parents' Experiences with Therapy for their Children with Cerebral Palsy: Mixed Methods Review

Themes supported / emerged from review:

- Adapting / selecting aspects of intervention to integrate into routines
- Interventions that set short-term, realistic, & achievable goals
- Needs, preferences and perspectives change over time
- More research on experiences and perspectives of:
 - Parents of young children with CP
 - **Fathers**

Kruijsen-Terpstra et al, 2013

Experiences of Parents in Enabling Participation of their Children with Physical Disabilities

Struggles & conflicts with:

- Educational system
- Administrative procedures for accommodations & equipment
- Health care professionals regarding:
 - Supports needed for child's social participation
 - Information needs
 - Lack of inter-professional communication

Piskur et al, 2015

Experiences of Parents in Enabling Participation of their Children with Physical Disabilities

- Problems with accessibility & availability of equipment
- Attitudes of other people: feelings of frustration & pain
- Efforts to find a leisure activity:
 - limited choices
 - lack of information
 - professionals' lack of knowledge

Piskur et al, 2015

“If I Knew Then What I Know Now”: Parents’ Reflections on Raising a Child with Cerebral Palsy

- Taking time for spousal relationships & self-care
- Promoting child’s self-advocacy
- Being less protective & involving child in more activities
- Some parents found it hard to let go; others were surprised by the independence their children achieved
- Supports from extended family & friends are invaluable
- Key aspects of formal support: **Honesty, Clear Communication, & Collaboration**
- Periods of Transition: Critical Timing of Support

Reid et al, 2011

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

Transformative Services Paradigm Shift

(Doing things in new ways)

What is the motivation:

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



“F-Words”

Rosenbaum & Gorter (2012)

Ideas to guide services and supports
for children with disabilities :

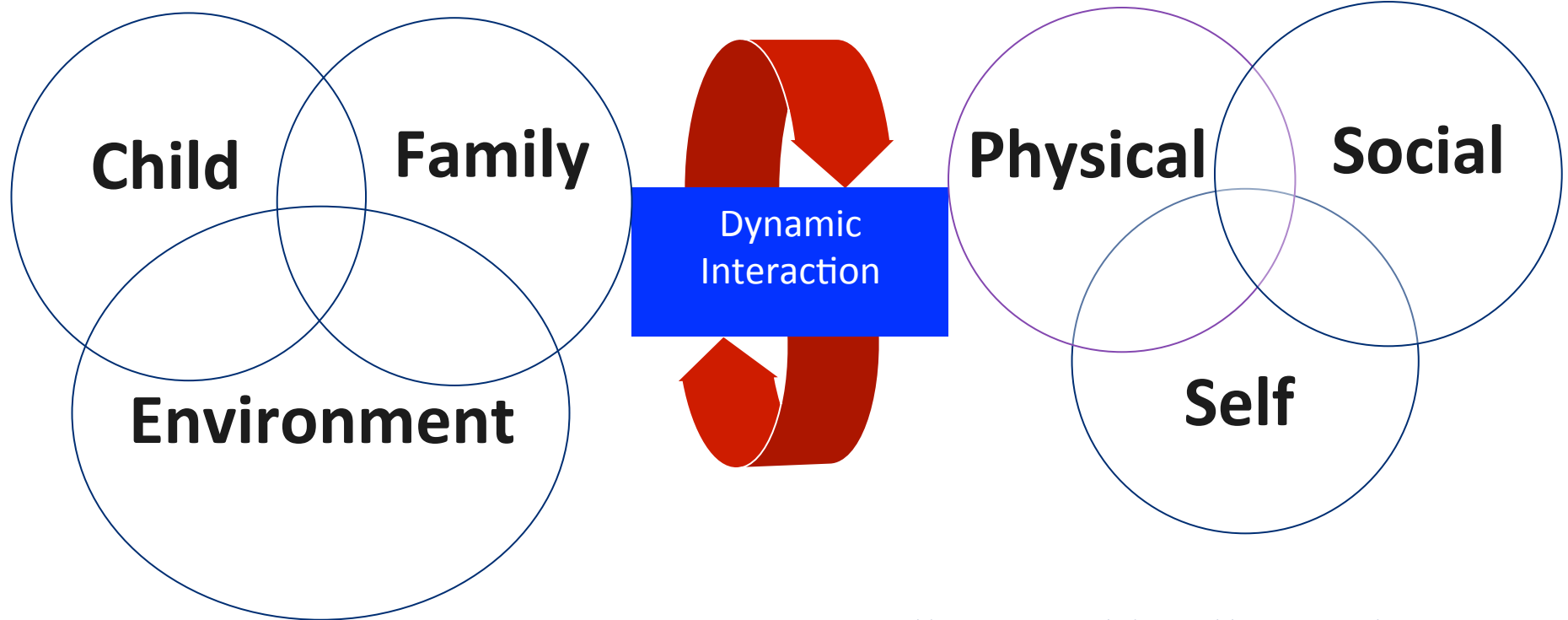
- ❖ Function
- ❖ Family
- ❖ Fitness
- ❖ Fun
- ❖ Friends
- ❖ Future



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

Partnerships

Goal oriented

Strengths
based



Solution
focused

Ecological

Palisano, Chiarello et al, 2012

Strengths based Interventions

- Build on strengths of the child, family, and community
- Build new strengths
- Strengthen the larger social environments in which children, families, and communities are embedded

Maton, Schellenbach, Leadbeater & Solarz (2004)

Implications

Do we ask / build on what the child & family do well?
(Ability Awareness!)



Solution Focused Interventions

- What needs to occur to achieve the desired outcome?
(child, family, environment)
- Person(s) responsible
 - Professional may have primary responsibility for some steps
 - Family / youth may have primary responsibility for some steps

Learning Opportunities of Natural Environments

Importance of *activity settings* that provide *natural opportunities* for children to learn social roles, cultural values, and skills

(Childress, 2004; Dunst et al., 2001; Humphry, 2002)



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?

Do We Differentiate and Consider Goals and Outcomes?

- Goals: What the child and family wants to achieve?
- 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

Services start
with the goal!

Goals and outcomes drive
activities and intervention strategies

Whose Goal?

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

**Autonomy
(Choice & Control)**

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

How Are Goals & Outcomes Identified?

Relatedness
(Connected & Supported)

- Collaborative process
 - Involvement of child, family, and other members of the team
 - Various inputs and perspectives
 - Fosters engagement of families in therapy and positive outcomes

Listen to the Family's Story

Competence
(Confidence & Efficacious)

- Supportive conversations & discussions
 - Art of goal setting
 - Approaches to goal setting
 - Person-centered planning processes
 - Discovering who the person is and what their desired future
 - Canadian Occupational Performance Measure
 - What does child need to do, want to do, and expected to do: Self-care, school/play, leisure
 - Solution-focused coaching: Visualizing a Preferred Future
 - Goal Attainment Scaling questions

How Many Goals & Outcomes?

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

Less May be Better

What Goals are Meaningful to Children and Families?



Families are unique

Parents' Perspectives on Therapy Goals for their Children with Cerebral Palsy

- 'We can't do it all': balancing therapy & everyday life
- Movement as the means to functional success
- Physical health & fitness: community sports & recreation
- Leading happy, fulfilling lives & being accepted
- Specific role of therapy: monitoring ROM, strength, posture

Wiat et al, 2010

What Might the Focus of Goals Be for Children?

Family priorities: Individualized,
within context of their family life

- 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)

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

What Might the Focus of Goals be for Families?

Family Needs Expressed by $\geq 50\%$ of Parents of Children with Cerebral Palsy (n=501)

- Information about services in the future **(68%)**
- Information about the services presently available **(60%)**
- Information on planning for future: guardianship, trust funds, and transition to adulthood **(58%)**
- Help in locating social, recreational, & leisure activities **(52%)**
- More time for self **(51%)**

Palisano et al, 2009

Family Self-Efficacy and Ease of Caregiving

- Self-efficacy: confidence and competence to nurture and care for their children
- Ease of Caregiving: parent perception of the level of physical difficulty experienced while helping their 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

Identify Family Goals for
Themselves as Parents

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

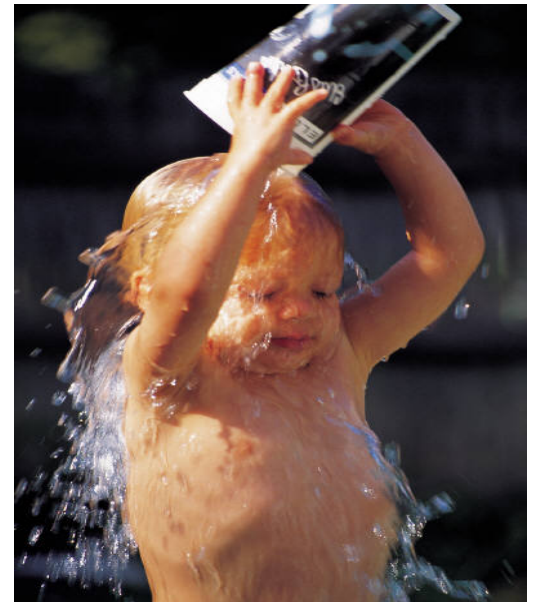
Monitor Children's Health

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:

Intrinsic motivation

Internal locus of control

Giving & receiving cues

- 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 kicks a stationary ball 5 feet.
- 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

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

Case Application and Discussion

- How would you lead the team to identify and prioritize common goals?
- How might you shape goals to support adaptive behaviors and playfulness?
- How might you support and monitor a goal related to daily life?
- How would you measure goal attainment?
- What health outcomes may be important to monitor?
- How can you begin to identify, support, and monitor parents' goals for themselves?

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!

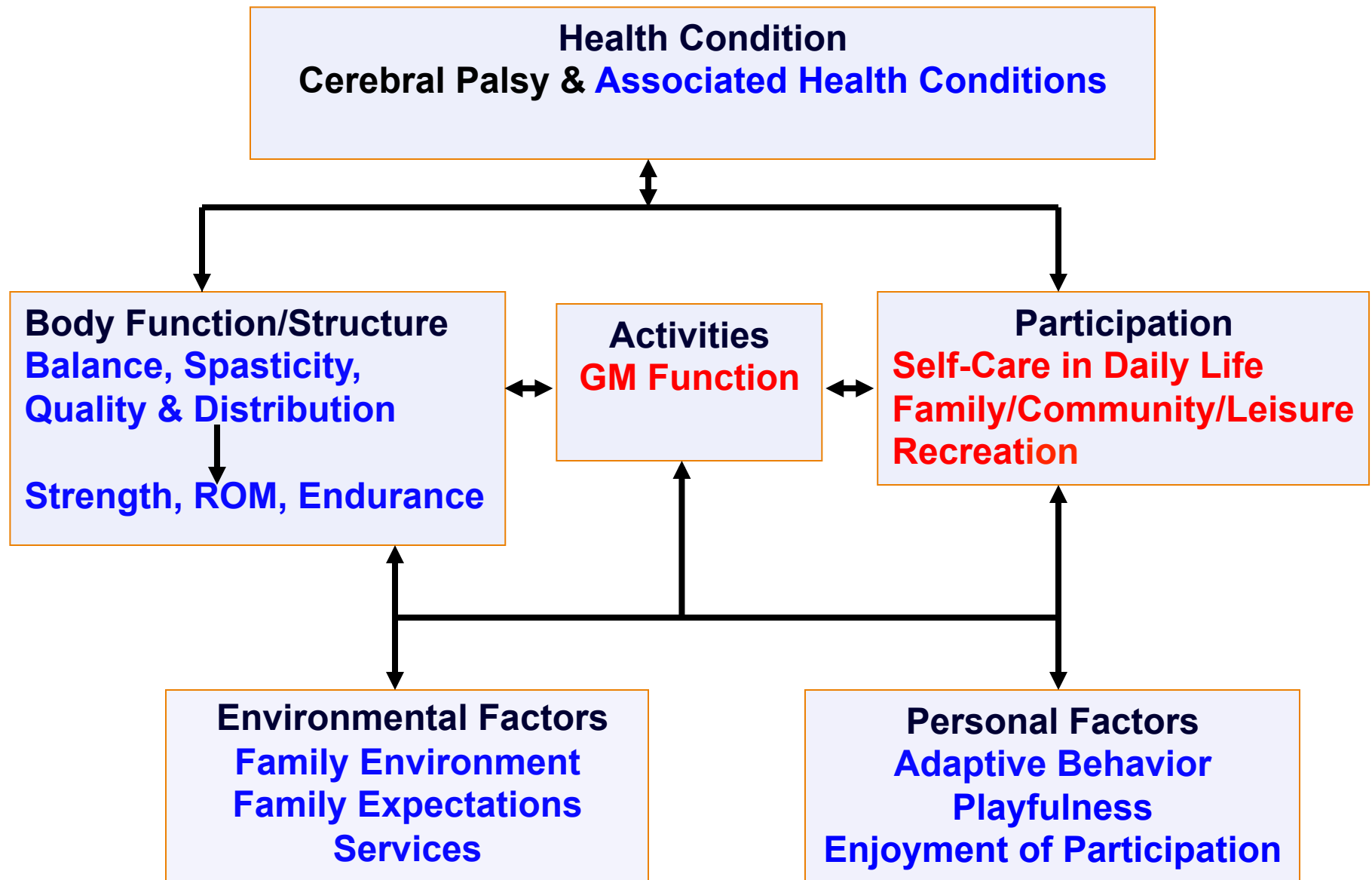
Consider theories and models for service direction

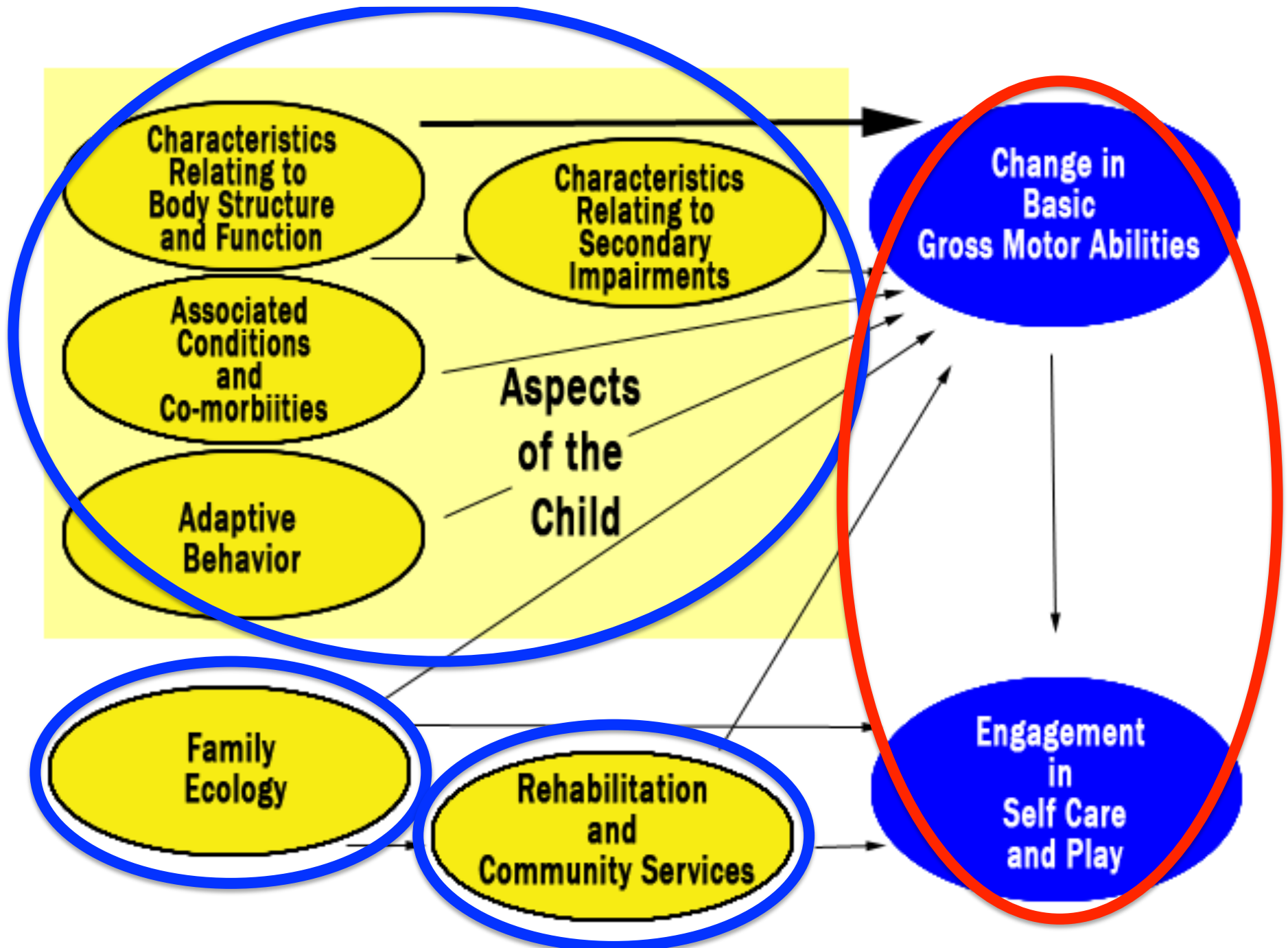
□ Theories

- 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
- Developmental growth curves





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

Using EBP to collaborate with families on focus of service

- Concept of yearly check-up/check-in on children's progress
- Tracking of progress in comparison to other children with similar issues and functional ability
- Examples of evidence to use in discussions with families about how to focus services to be efficient and effective

How should we determine the amount of service?

- Intensive intervention
 - The more the better?

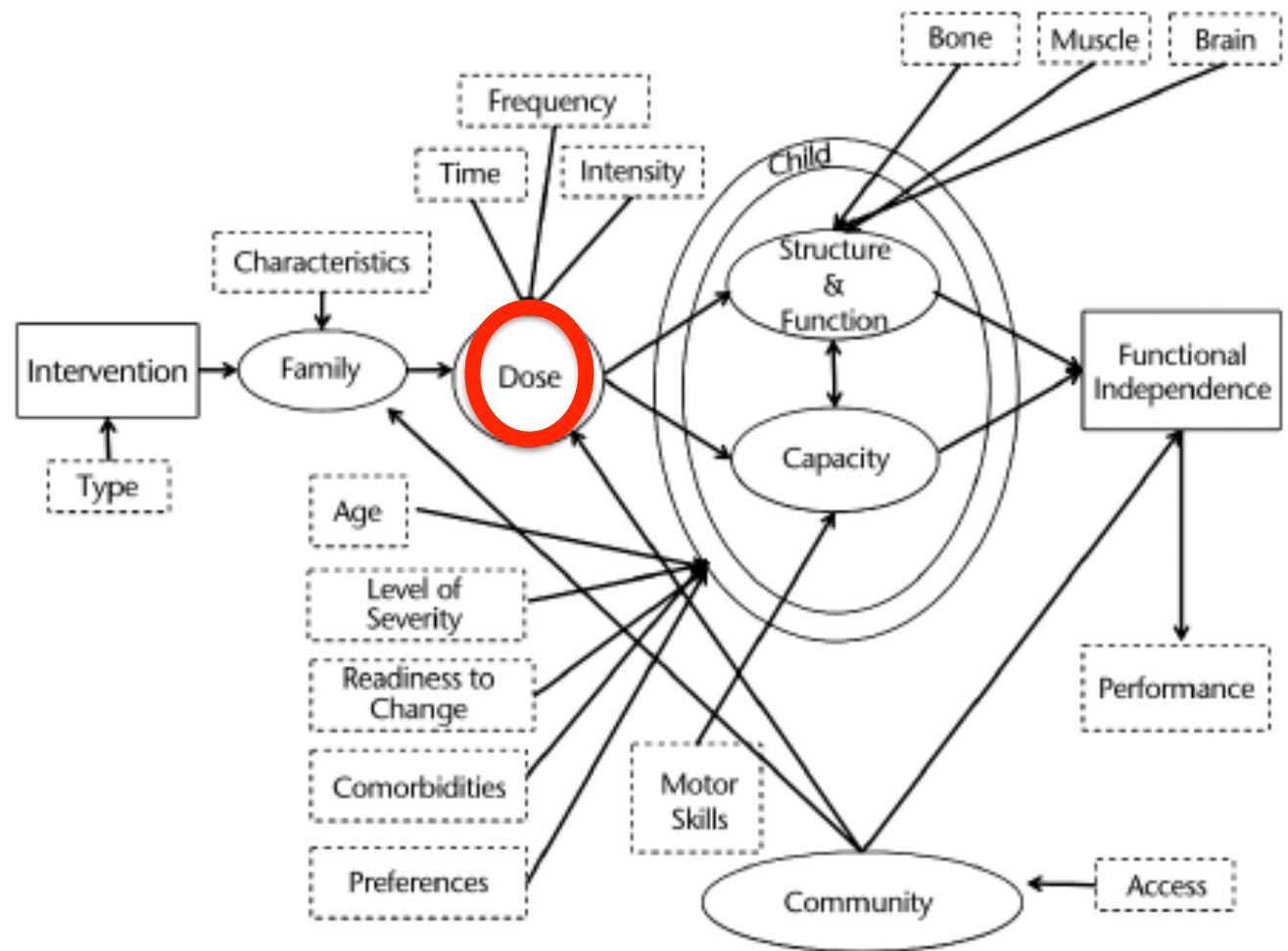


Figure 2.

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

How should we determine the amount of service?

- Gannotti et al., 2014
- Time in services?

More
practice
outside
of
services

Gannotti et al., 2014

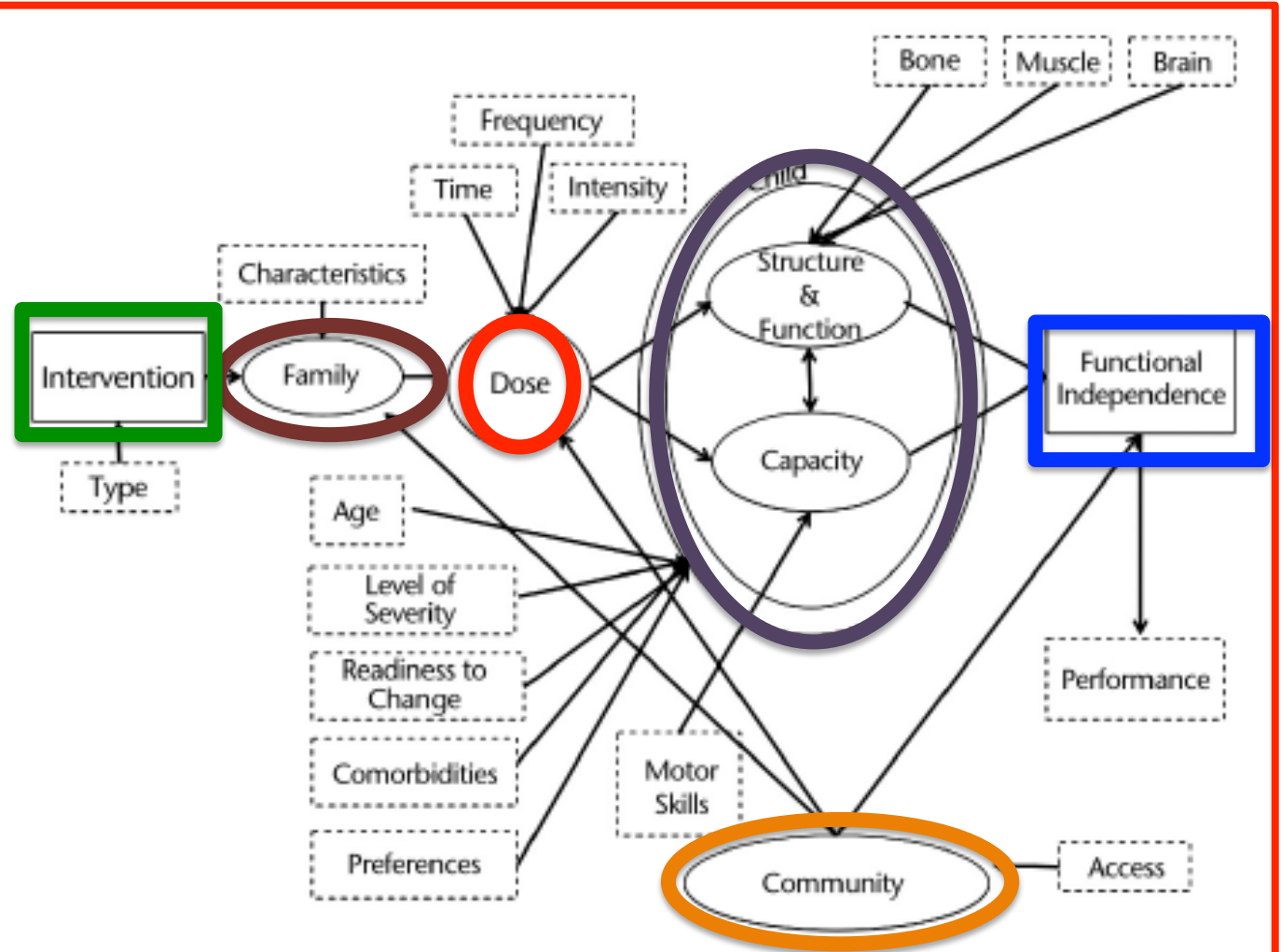


Figure 2.

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

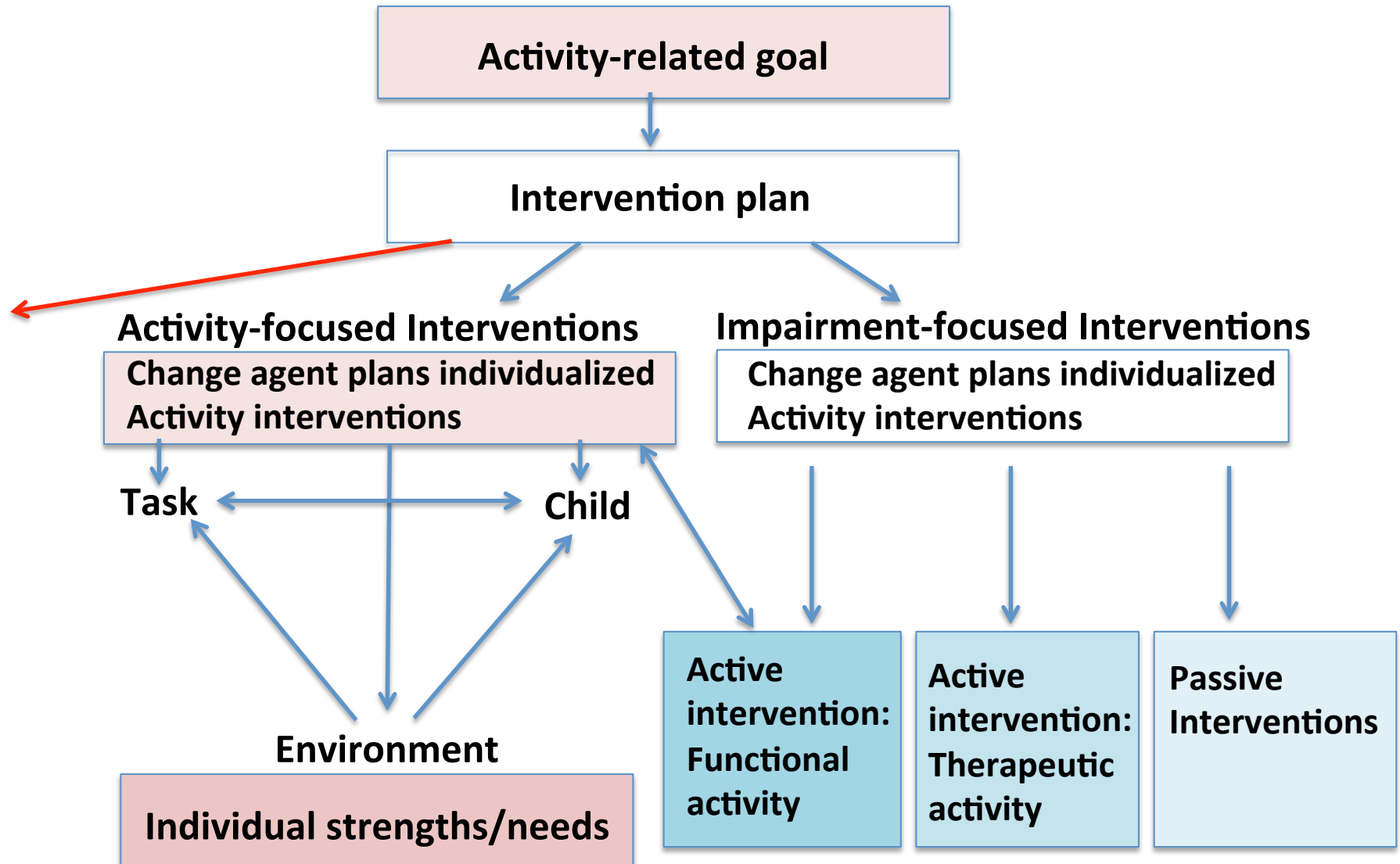
What should we focus on within intervention?

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

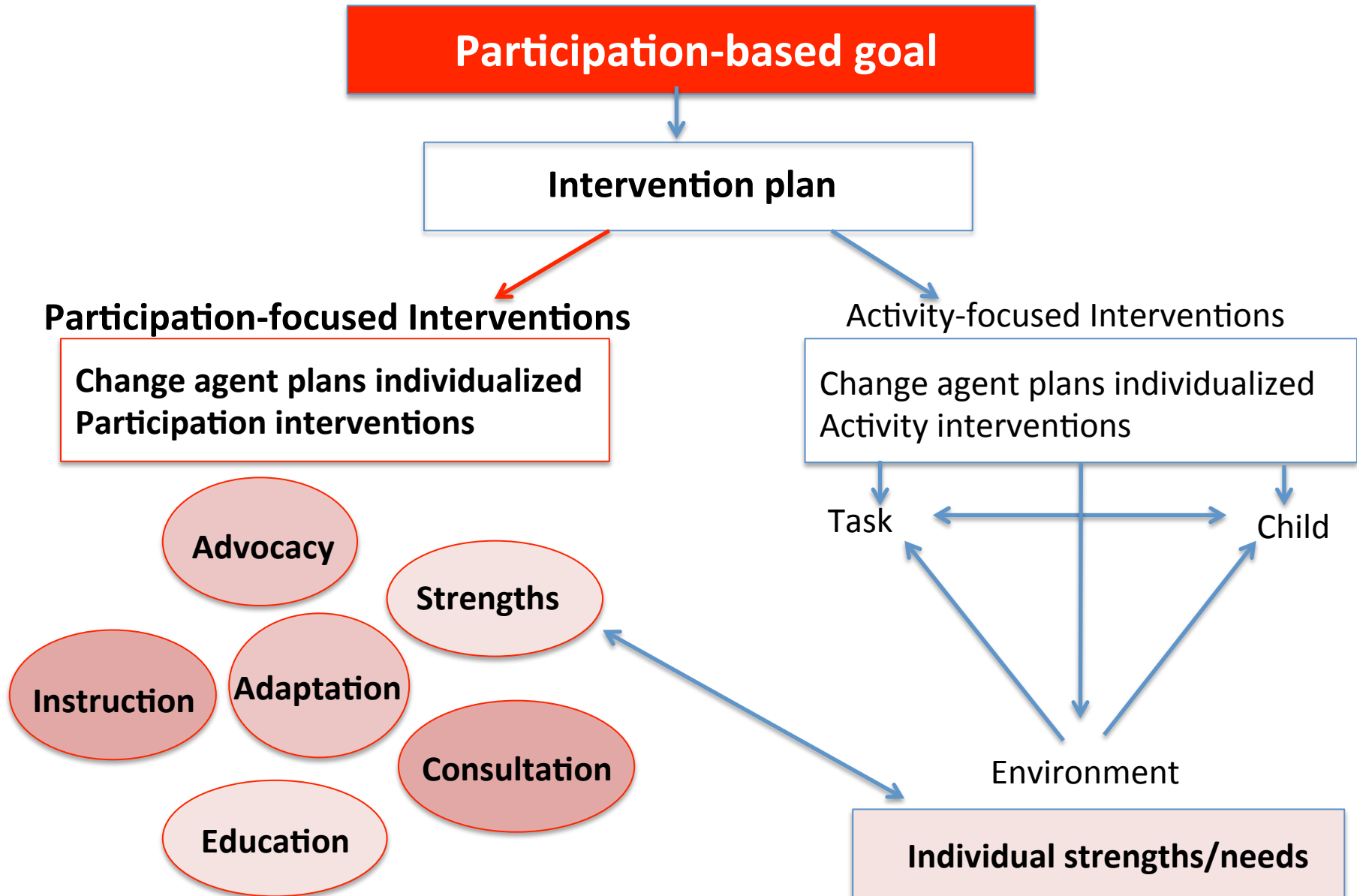


Context is Important

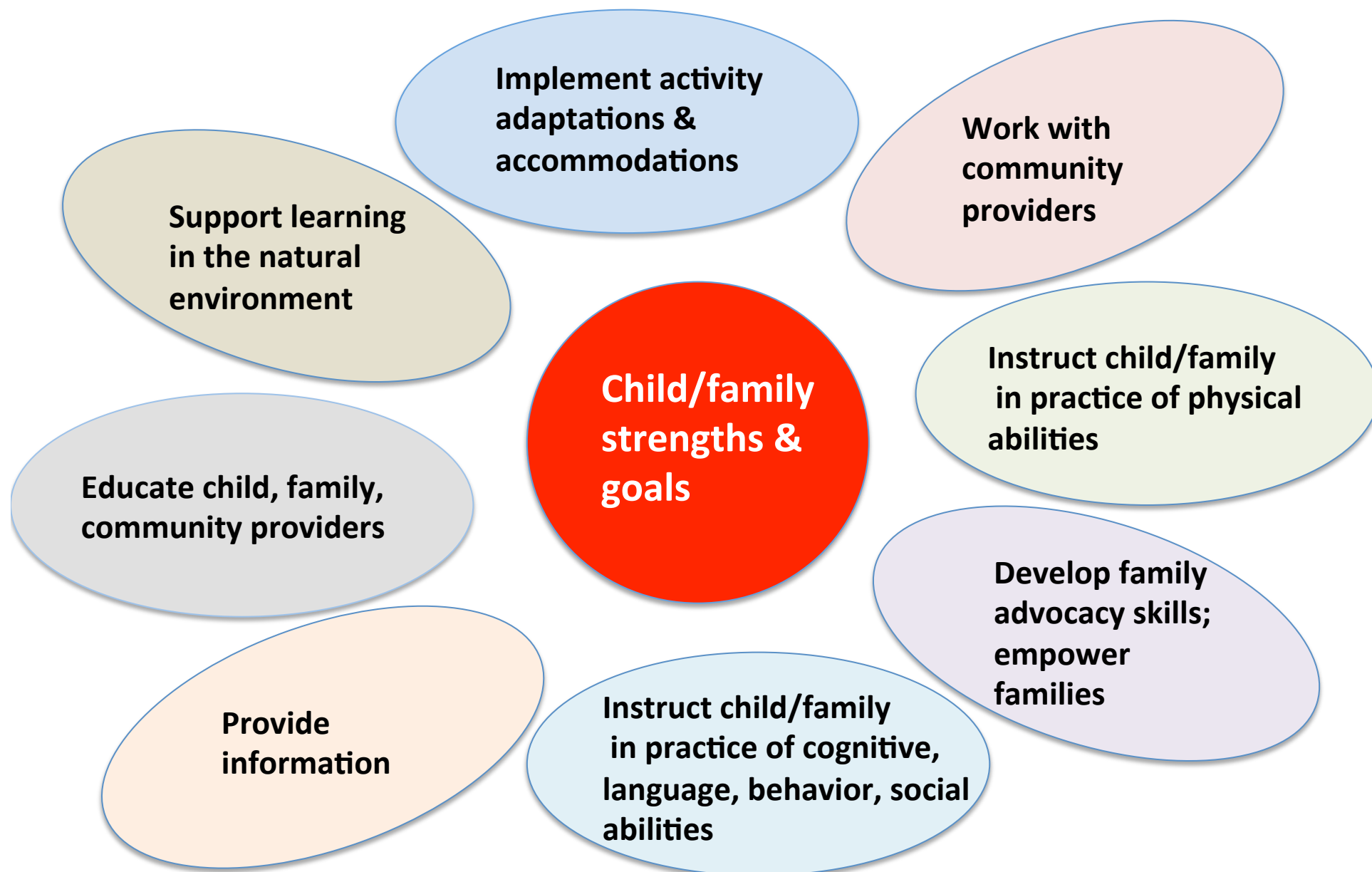
Model for Activity Focus of Intervention



Model for Participation Focus of Intervention



Participation Focused Intervention



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.”**



Case Application and Discussion

- Thinking of our child case:
- What amount of service will you provide?
- Where will you provide your intervention?
- What will you focus on within your intervention?

**What are the attributes of therapists
that facilitate transforming
physical therapy for children?**



Use of Multiple Sources of Knowledge to Inform Service Delivery

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



Structuring Knowledge and Practice

When knowledge is structured, it is accessible for use

- ❑ Using explicit conceptual frameworks improves daily practice by giving guidance on what to do and why to do it
- ❑ Structured practice enables a deeper level of understanding of the big picture

Mediators of Knowledge 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

Engagement

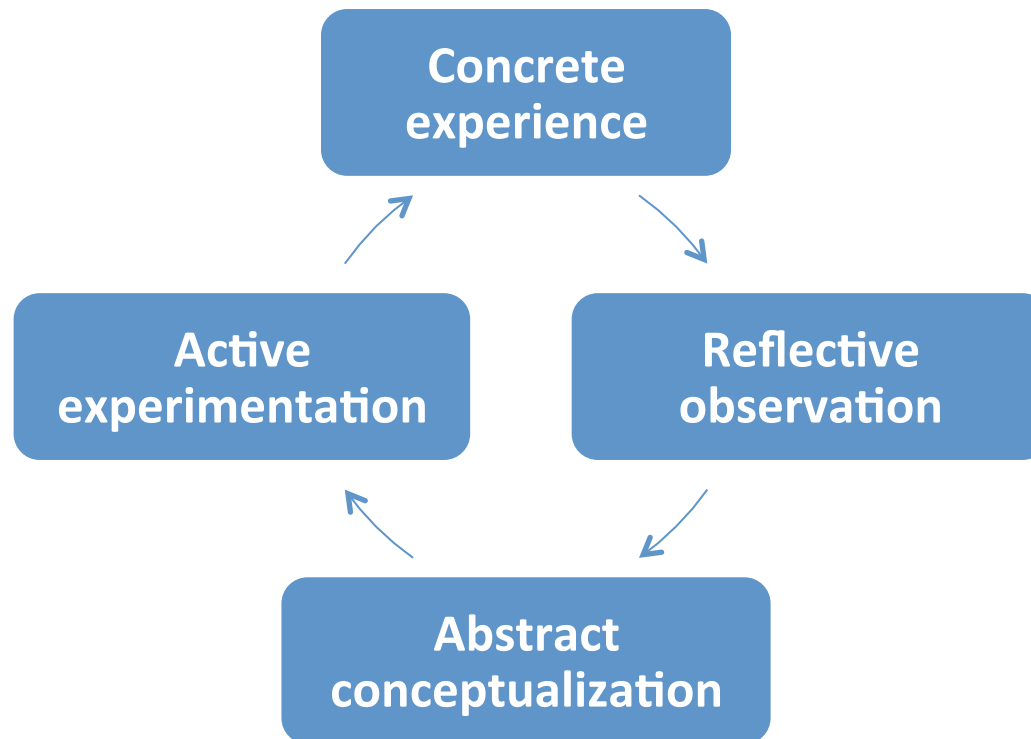
Engagement refers to the full and active investment and involvement of children and family in the intervention process

- Affectively involved: optimistic approach, trust in provider and process
- Cognitively involved: committed to the goals, believe in relevance of the intervention
- Behaviorally involved: able to implement strategies to support their goals

What skills do therapist need to foster engagement?

Practice- based Knowledge (Kolb, 1984)

Experience + **Reflection** = Knowledge



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

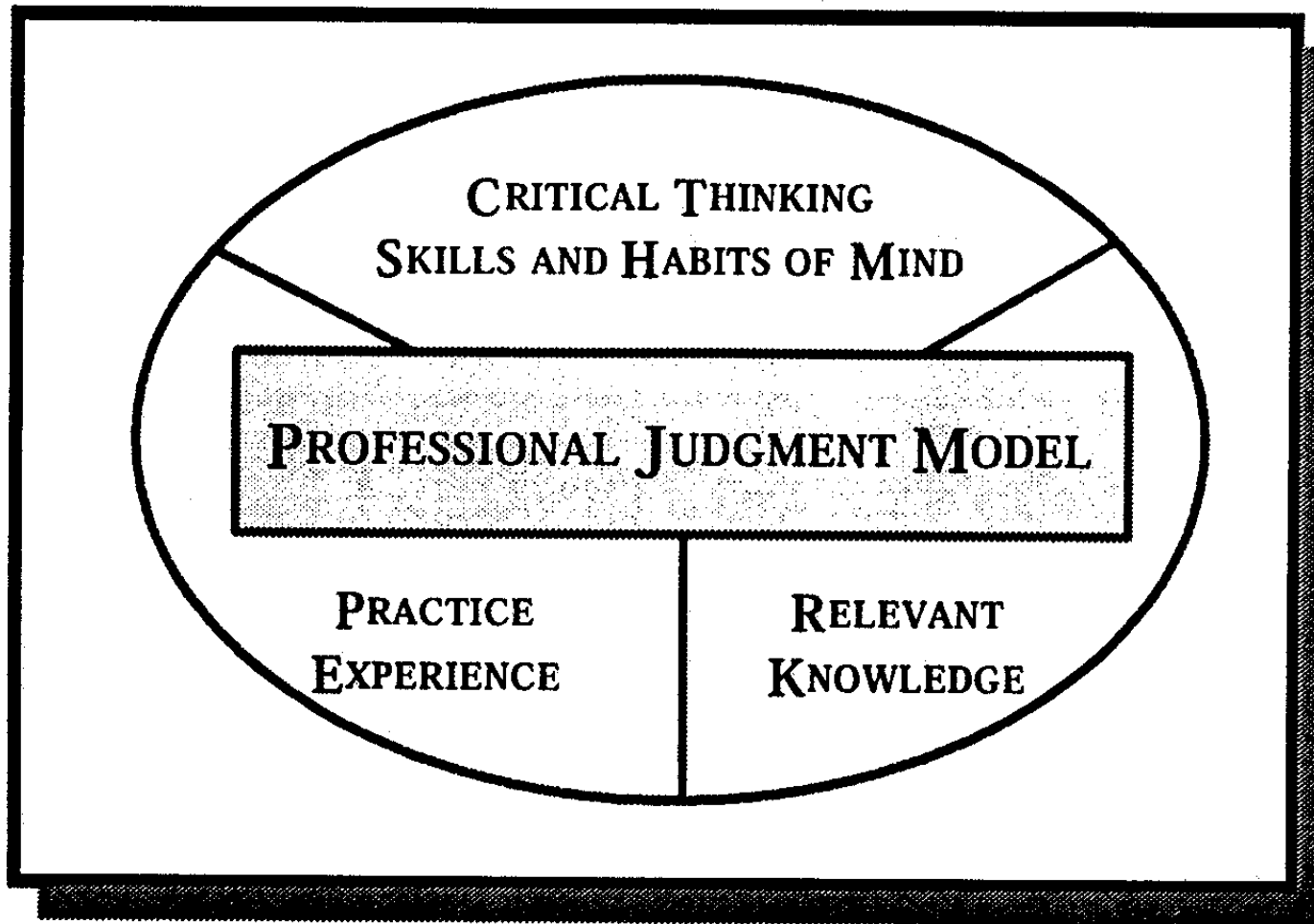
Thinking after acting

Reflection-in-Action

Thinking during acting

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

Professional Judgement



... 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 and practice
- ❑ 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

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

- ❑ Therapist
- ❑ Education and Mentorship
- ❑ Research
- ❑ Policy / Payment
- ❑ Systems of Care / Administrators of Service

Post-Test

For the child in the case scenario:

1. What should be the focus of physical therapy?
2. How much service should be provided?
3. Where should service be provided?

Final Discussion

- Can you go home and provide “transformative intervention” in your practice setting?
- What are the facilitators to doing this?
- What are the barriers?
- Other thoughts or questions?

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?



Several references

- Palisano R.J., Begnoche D.M., Chiarello L.A., Bartlett D.B., McCoy S.W., and Chang H.J. (2012) Amount and focus of physical therapy and occupational therapy for young children with cerebral palsy. *Physical and Occupational Therapy in Pediatrics*, 32(4):368-382. PMID:22954372
- Bartlett, D.J., Chiarello, L.A., McCoy, S.W., Palisano, R.J., Rosenbaum, P.L., Jeffries, L., LaForme Fiss, A., Wilk, P. (2014) Determinants of Gross Motor Function of Young Children with Cerebral Palsy: A Prospective Cohort Study. *Developmental Medicine & Child Neurology*, 56(3):275-282. PMID:24127787
- Bartlett, D.J., Chiarello, L.A., McCoy, S.W., Palisano, R.J., Rosenbaum, P.L., Jeffries, L., LaForme Fiss, A., Wilk, P. (2104) Determinants of Self Care Ability of Young Children with Cerebral Palsy: A Prospective Cohort Study. *Developmental Neurorehabilitation*, 17(6):403-413. PMID:24725221.
- Palisano, R.J., Chiarello, L., McCoy, S.W., Bartlett, D.J., An, M. (2014) Use of the Child Engagement in Daily Life and Ease of Caregiving for Children to evaluate change in young children with cerebral palsy. *Physical and Occupational Therapy in Pediatrics*, 2014 Aug 28. [Epub ahead of print] PMID: 25166344.
- Chiarello, L., Bartlett D.J., McCoy, S.W., Palisano R.J., Fiss, A.F., Wilk P. (2016) Determinants of Participation in Family and Recreational Activities of Young Children with Cerebral Palsy. *Disability and Rehabilitation*, Feb 15:1-14. [Epub ahead of print] PMID:26878416
- Email: Sarah Westcott McCoy: westcs@uw.edu ; Robert Palisano: robert.j.palisano@drexel.edu ; Lisa Chiarello: lisa.chiarello@drexel.edu
- Move & PLAY and On Track websites:
 - <https://canchild.ca/en/research-in-practice/current-studies/move-play-study-understanding-determinants-of-motor-abilities-self-care-and-play-of-young-children-with-cerebral-palsy>
 - <https://canchild.ca/en/research-in-practice/current-studies/on-track>