

## Supporting people with Disabilities across the lifespan: Practical steps to Partner with Families

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### Introduction: Top 10

- ▶ Thank you:
  - ▶ Acknowledge Biripi elders, past, present and future
  - ▶ Ministry of Children & Family Development
  - ▶ The families who have agreed to share their stories
- ▶ Context: Following an early presentation... (Dolby et al)
- ▶ Strategy : Top 10 Key points to consider/ further learning
  - ▶ The first visit sets the stage: Interview
  - ▶ Listen
  - ▶ Coach
  - ▶ Share your knowledge
  - ▶ Keep solutions simple
  - ▶ Feedback
  - ▶ Pace
  - ▶ Team
  - ▶ Equipment
  - ▶ Move across the lifespan

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### Introduction: Top 10

- ▶ What is gained Over the lifespan?
  - ▶ You will learn and grow as a therapist (Ayani)
  - ▶ Minimize severe deformities
  - ▶ Support relationships (Circle of security)
  - ▶ Support Communication: Support making wants and needs known; increases self esteem
  - ▶ Minimize behaviours of concern: Empathy (Totsika, 2014)
  - ▶ Families become great problem solvers




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### #1. First things first: background

- ▶ Your first visit sets the stage
  - ▶ Early diagnosis interview research (Martin & Planta, 1996)
  - ▶ First introduction influences way in which parents see their role
- ▶ Clear your mind
  - ▶ leave all your thoughts in the car or at your desk
- ▶ Start with introductions:
  - ▶ I am X, I would like to get to know more about you and your child today, so I can learn who you are and how I might be able to assist you.
  - ▶ I would like to start with a few questions to help guide our work together..

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### #1. First things first: strategies

- ▶ Open questions, body language
- ▶ Start the interview....my favourite questions (Meade, Partners in Movement ch. 8)
  - ▶ What is most enjoyable
    - ▶ Positives from talking about yourself
  - ▶ What is your child's best skill (any area of development)
    - ▶ Strengths based
  - ▶ What is most difficult for you right now? ( family or parenting or the child?)
    - ▶ A good start
  - ▶ What would you like to see happen next?
    - ▶ Short and long term goals
  - ▶ How do you organize a typical day?
    - ▶ Rhythms and routines provide context and opportunity

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### #1. First things first: A story

- ▶ Build Rapport
  - ▶ Take the TIME
  - ▶ Emailed the interview
  - ▶ Started 'what most difficult'
  - ▶ How this affected our relationship over his lifetime
  - ▶ What we both gained
    - ▶ Learnings




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### #2. Listen, listen, listen: Strategies

- ▶ Listen between the lines
- ▶ The art of the conversation...
  - ▶ The volley: find the balance
  - ▶ Everyone is an expert on something
    - ▶ and has so much to share
  - ▶ Ayani: Collaborate to each contribute our special talents to the wider society (Porter & Mondard 2001)




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### #2. Listen, listen, listen: Background

- ▶ Listen between the lines
- ▶ The most important skill
- ▶ Whose goals?
  - ▶ The therapists or the families?
- ▶ The family as expert
- ▶ Sets the stage to share




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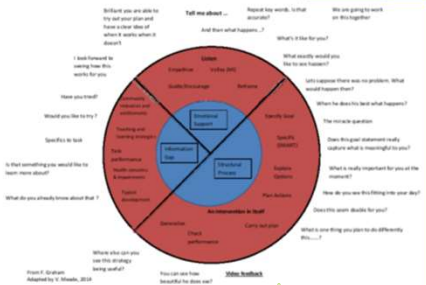
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### #3. The red circle of coaching

- ▶ What is coaching?
  - ▶ Best reference
    - ▶ Graham et al., 2013
- ▶ Three phases
  - ▶ First listen...
  - ▶ Second: create the goals together
  - ▶ Talk through what may have already been tried
  - ▶ Allow possible solutions to emerge first




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### #3. The red circle of coaching: A story

- ▶ Solutions emerge
- ▶ What you gain
  - ▶ Example Christian and his future
  - ▶ You will learn so much
  - ▶ Energizing



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### #4. Share your thoughts: Strategies

- ▶ Your main role is a coach (framework, context)
- ▶ When the family has their goal
  - ▶ May get stuck on a solution
- ▶ Begin to share
- ▶ Listening for 'yes, I can do this'
  - ▶ What is am observing is....
  - ▶ An idea we could start with is...
  - ▶ What do you think?
  - ▶ We can use it as a test
  - ▶ Monitor

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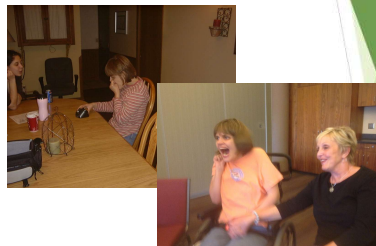
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### #4. Share your thoughts: Strategies

- ▶ The Big picture
- ▶ Choice, Voice, Control for families
- ▶ Independence
- ▶ Daily Routines
- ▶ Choices for individual



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### #4. Share your thoughts: Strategies

- ▶ M. Began Age 13
  - ▶ PEDI interview; taught many
- ▶ At Age 26
- ▶ Family Forum Reflections
  - ▶ Mom: Just teach us... any and all no matter how unskilled we are
- ▶ Ayani 13 years
  - ▶ Minimized deformities
  - ▶ Decreased behaviours of concerns



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### #4. Share your thoughts: the lifetime

- ▶ Age 33
- ▶ Touching base; asking for an opinion on surgery
- ▶ Lives with caretaker family
- ▶ Post surgery
  - ▶ Walks 20 minutes in Pool
- ▶ Uses medicinal cannabis for control of Epilepsy
  - ▶ 'waking up'




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### #5. Keep the solutions simple

- ▶ The Kinesiological Framework
  - ▶ Based on muscles working together to create efficient, pain free movement (Sarhmann, 2014)
  - ▶ Combined with 'Dynamic Systems' perspective of person, task and environment (Perry 1997, Kiem 2016)
- ▶ Has worked to create a problem solving focus for me
  - ▶ Use the interview questions to start
  - ▶ "What did the family want to happen next?"
  - ▶ Problem solve together
  - ▶ Embed in the typical day
    - ▶ 'How do you spend a typical day?'



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#5. Keep the solutions simple: strategies

1. Develop a balance between muscles groups for efficient movements
2. 'Must haves' in lateral plane
  1. Focus on Shoulder girdle stability as a basis for moving
  2. Develop 'core' abdominal obliques in lateral plane
3. Work for independent transitions to use all of the 'must have' muscles
4. Keep all of the 'nasty' muscles elongated through everyday movement opportunities



see 'Partners in Movement' Chapter 8,11,12

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MUST HAVE



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#5. Keep the solutions simple: strategies

Adding the lateral plane of movement

Abdominal Oblique Muscle

- ▶ Biomechanics and alignment
- ▶ F.100% abdominal obliques
- ▶ vs. 30% sit ups
  - ▶ (Konrad et al. 2001)



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#5. Keep the solutions simple: strategies  
Five Nasty Muscles: Create Torsion

1. Sternocleidomastoid
2. Rhomboids
3. Iliopsoas



**NAME THE NASTY...**

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#5. Keep the solutions simple: strategies

- ▶ 4. 'Nasty' Tensor Fasciae Latae
  - ▶ Flex, abduct, internally rotate when hip flexed
  - ▶ The 'deltoid' of the hip
  - ▶ Partners in Movement (page 85)
- ▶ 5. Adductor Magnus
  - ▶ When hip flexed
  - ▶ Internally rotates




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#5. Keep the solutions simple: strategies

- ▶ Effects of the 'Nasty' Muscles on alignment of the Ankles
  - ▶ Optimal: muscle support for longitudinal arch
  - ▶ Difficulties: medial strains lead to pronation
  - ▶ Eventual collapse of longitudinal arch due to weakness



see 'Partners in Movement' Chapter 7 pg 88

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### 6. Keep the solutions simple: a story

- ▶ Penny; background
- ▶ 'I CAN DO'
- ▶ Know a person's strengths and interests
  - ▶ Prevents Behaviours of concern
- ▶ Families become great problem solvers
  - ▶ focus on one small step at a time; math

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*I: Interview C: Collaborate using guided participation DO: Practice in daily routines*

#### The Case 15 months

**Interview:** Parent info  
 • Twin, Fourth Child  
 • First concern sucking at 4 months, told 'Grew out of it'  
**Collaborate:** Want sitting  
**DO:** Practice move to sit



#### The Case 2.5 yrs.

**Interview:** Want walking  
**Collaborate:** Demonstrate  
**DO:** Practice bearwalk up slide. (walks alone age 3)



#### The Case 5 yrs.

**Interview:** Parent Concerns:  
 • Riding a bike, Running  
 • Hand skills  
**Collaborate:** Strengthen core; referrals OT, speech  
**DO:** Practice 'Rolling like a Ball' game' for siblings



#### The Case 11 yrs.

**Interview:** Keeping up when family hiking  
 Math in Middle School  
**Collaborate:** Hip, ankle-strength  
**DO:** Ankle balance ex



#### The Case 18 yrs.

**Interview:** Concerns: Vulnerability, Independ  
**Collaborate:** Lifeskills  
**DO:** Practice \$ manage



#### The Case 25 yrs.

**Interview:** Living I; traveled alone to visit twin in Cambodia  
**Collaborate:** Lifelong fitness ideas, What for work? Grown out of 'Sheltered' workshop  
**DO:** Run, Find new job



[www.sickmeade.com](http://www.sickmeade.com) 'Partners In Movement: A Family centered approach to pediatric kinesiology'

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### 6. Feedback

- ▶ Total, non judgemental acceptance,
- ▶ Careful of your thoughts
  - ▶ Thoughts become words
  - ▶ Words become actions
  - ▶ Actions become routines
  - ▶ Routines become character (anonymous)

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### 6. Feedback: Strategies

- ▶ Second visit:
  - ▶ Show me what you have been doing
  - ▶ Use pictures for home programs
  - ▶ Use video to assist understanding
  - ▶ Stop motion to 'make big'
  - ▶ Focus on what want to do more of

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### 6. Feedback: Monitor

- Don't give up...  
Monitor progress
- ▶ H: Began during school program:
  - ▶ Monitored progress using Gross Motor Function Measure: (Palisano et al 1997)
  - ▶ At start age 4: 20%
  - ▶ At age 5: 35.1%
  - ▶ At age 6: 47%
    - ▶ Could move from prone to sit independently and started to move to sit throughout each day..
  - ▶ Also started crawling
  - ▶ Pulled to knees, then stand.
  - ▶ Parents reported him doing all of this at home independently during his day.



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### #7. PACE: Don't wear people out

- ▶ The Power of Routines:
  - ▶ Easy or difficult (McWilliams 2001)
  - ▶ 'The typical day'
  - ▶ In the home
  - ▶ Across all environments
- ▶ Examples: backyards, parks
- ▶ Family feedback;
  - ▶ "keep it doable, include the whole family"



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### #7. PACE: Routines support repetition

- ▶ What is the evidence?
  - ▶ From studies of brain plasticity (Kliew, 2008)
    - ▶ 1. Intensive task repetition
    - ▶ 2. Progressive challenges to the learner with increased difficulty
    - ▶ 3. Presence of motivators and rewards
  - ▶ COPA
    - ▶ Testing a tool to capture what clinicians do during treatment sessions (Blauw-Hospers et al. 2010)
      - ▶ Focus on family centered practices
      - ▶ Found that clinicians were surprised to learn only 4% of session focused teaching parents
      - ▶ Majority time spent how to change child
    - ▶ RCT: (Hammer et al. 2017)
      - ▶ Compared Family Centered and Typical PT for infants
      - ▶ Found that actions of therapist made a difference: coaching versus teaching
  - ▶ YET.. Families reported too stressful to learn how to change; easier if staff did this (Scales et al. 2007)

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### #7. PACE: WHO has Opportunity???

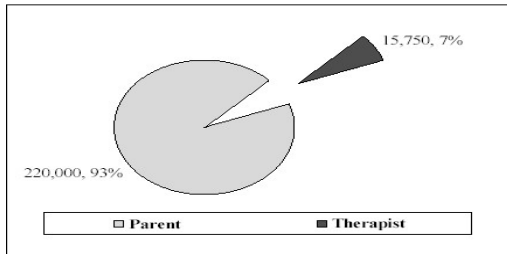


Figure 1. Who has the greatest potential to maximise children's motor experience?

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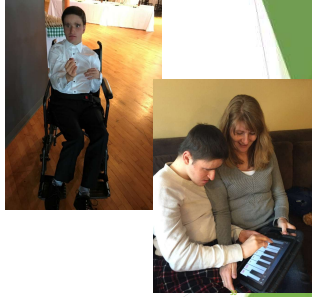
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### #7. PACE: A story

- A lifetime is a very long time
  - ▶ Small steps
  - ▶ Understand where they are at
  - ▶ Use the interview question:
    - ▶ 'what do you want to have happen next?'
  - ▶ Collaborate and plan together
  - ▶ Do: "Yes I can do this"




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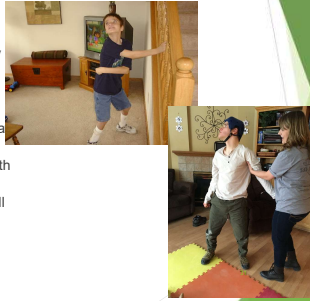
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### #7. PACE: Don't wear people out: A story

The Power of small steps during daily routines:

- M at 1 year: 58/63 on MAI
- At 3 years: Rolled onto tummy to play
- At 5 years: pushed into sitting through sidelying
- At 9 years: pulled onto knees at furniture.
- At 11 years: pulled to stand with assist
- At 13 years: sidestep, treadmill training
- At age 21: independent sit to stand and took first step




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### #7. PACE: A story

- ▶ What you gain
  - ▶ Across the lifespan
  - ▶ Relationships
  - ▶ Continuing active problem solving
  - ▶ Therapists come and go.. but families are forever




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### #8. Team: Accept and Include all

- ▶ Total, non-judgemental acceptance of the whole family
  - ▶ The family will be the most important resource for that person: keep them central to your team
  - ▶ Include everyone from siblings to grandparents to babysitters
  - ▶ Create your 'virtual team'
- ▶ Transdisciplinary Model of service delivery: 2 key tenants, 4 phases
  - ▶ Parents central to the team
  - ▶ One lead team member based on relationship with family
- ▶ **Assessment:** team members (including person and family) participate in interviewing, observing, recording and discussing results across disciplines. Discipline specific assessments may or may not be required
- ▶ **Support Plan Development:** The person, their support network and professionals develop the plan together. Goals are based on their priorities and resources. Each person identifies their role in supporting the goals
- ▶ **Implementation (Delivery):** Team members share responsibility and are accountable for how the plan is implemented. One team member has lead role with the family to implement the support plan
- ▶ **Evaluation:** Process of report writing, reflection on outcomes, what is working, reflections on reflections, sharing stories, recommendations

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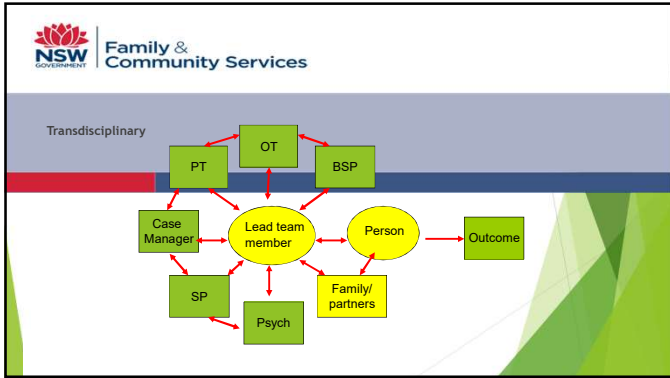
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### #8. Team: Accept and Include all

Lead Team member as coach  
 Coaching parents to provide secure base for exploration  
 Coaching Staff to Support Parents and clients  
[www.circleofsecurityinternational.com](http://www.circleofsecurityinternational.com) for excellent videos

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### #8. Team: Accept and Include all; story

- ▶ 48 year old gentleman: severe autism; minimal language
- ▶ Resided group home
  - ▶ Began self injurious behaviour (scratching arms and face)
  - ▶ Unable to go swimming; his favourite activity for calming
- ▶ Behaviours of concern increased
- ▶ Team met to create plan
  - ▶ All (GH, Day program, Physio, OT, Speech, Behaviour) assessed situation
  - ▶ Lead taken by group home team leader
  - ▶ Goal: "to get back to swimming"
  - ▶ Strategies all goal driven:
    - ▶ GP to determined constipation and seasonal scratching; started medication
    - ▶ Group home staff assisted to help with healing
    - ▶ Swim routines with communication and behaviour strategies introduced

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### #9. Equipment

- ▶ Part of typical daily Routine
  - ▶ 'Support for the child's efforts each day'
  - ▶ Use little; start with the least support possible
- ▶ Time wisely
- ▶ Normalize if possible first
  - ▶ Sitting: everyday opportunities first
  - ▶ Orthotics
  - ▶ Standing
  - ▶ Mobility

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### #9. The place for Equipment

- ▶ Standing Supports
  - ▶ Supportive Shoes
  - ▶ Orthotics
  - ▶ Extended SMO's
  - ▶ [www.dafo.com](http://www.dafo.com)



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### #9. The place for Equipment

- ▶ Orthotics
  - ▶ Extended SMO's
  - ▶ Two Pieces
  - ▶ Case A: age 4



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### #9. The place for Equipment

- ▶ Standing Opportunities
  - ▶ Immediate from 6 months of age
  - ▶ 45-60 min. 4X week
    - ▶ (Paleg, 2013)
- ▶ Support Knees:
  - ▶ O'Connell Taping
  - ▶ Ref. in book




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### #9. The place for Equipment

- ▶ Management focus
  - ▶ Use technology
  - ▶ Family plan and goal
- ▶ Repeated assessments
  - ▶ Orthotics
  - ▶ Wheelchairs
  - ▶ Assistive Devices




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### #9. The place for Equipment




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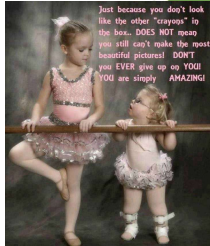
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### #10. A lifetime of moving: anticipatory guidance

- ▶ By decade: transitions, transitions, transitions
- ▶ The first year: In the caregiver's arms
- ▶ Toddlers: Bearwalk, animal walks, climbing
- ▶ School age: Upright orientation
- ▶ Teens: Plan for growth
- ▶ Young adults: Keep moving
- ▶ Adults: Teaching daily routines
  - ▶ Home program better than nothing (Novak, 2014)
- ▶ Plan for Aging with a disability




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### #10. A lifetime of moving: Infant

- ▶ In the parent's arms
- ▶ Traditional cultures
  - ▶ Less than 2 months
- ▶ Always held by family member
- ▶ Often sleeps in arms
- ▶ No equipment!!
- ▶ No prolonged supine




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### #10. A lifetime of moving: The Infant

- In the Parents Arms:
  - Immobile Infant/Child: Activating the 'Must Haves'
  - Core stability for function
  - Lift, carry, setdown routine
  - Transitions: in daily routines
    - ▶ Sidelying
    - ▶ Half-sidelying
    - ▶ Half-sitting
    - ▶ Half-all-fours
    - ▶ Half-kneel
    - ▶ Half-stand



see 'Partners in Movement' page 95

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#10. A lifetime of moving: Toddler

Crawling and Climbing Programs



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#10. A lifetime of moving: Toddlers

Animal walks




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#10. A lifetime of moving: School

Sitting: Bench

- Feet Flat
- Free use of arms

► P. Mullens, 2005



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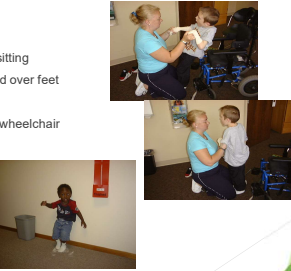
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#10. A lifetime of moving: School

- ▶ Sit to Stand
  - ▶ Weight bearing
  - ▶ Trunk extension in sitting
  - ▶ Move weight forward over feet
  - ▶ Lean forward
  - ▶ Feet flat on floor or wheelchair
- ▶ Stand: Wall dancing



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#10. A lifetime of moving: School

Upright orientation



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#10. A lifetime of moving: School

Upright Orientation (Mullens, 2004)

- ▶ Communication
  - ▶ Head vertical/ midline/ eye contact
  - ▶ Minimize lip retraction
  - ▶ Looking appropriately while reaching



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### #10. A lifetime of moving: School

#### Use of the arms

- ▶ (Mullens, 2004)
  - ▶ Reaching (freedom of movement)
  - ▶ Support
  - ▶ Sustained grasp with arm extension



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### #10. A lifetime of moving

- ▶ Management focus
  - ▶ Keep moving
  - ▶ Treadmill training
    - ▶ Mixed evidence to date
    - ▶ Level III spinal cord
    - ▶ Level II Down Syndrome



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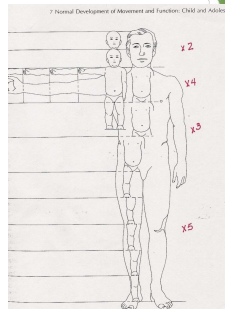
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### #10. A lifetime of moving: Teens

- ▶ Head X 2
- ▶ Trunk X 3
- ▶ Arms X 4
- ▶ Legs X 5



Campbell et al. 2006

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### #10. A lifetime of moving: Teens

- ▶ Muscle Changes
  - ▶ Adaptations
  - ▶ Size
  - ▶ Force Production
    - ▶ Bone strength more important than weight
    - ▶ Bone molded by muscles
    - ▶ Due force of muscles in child (Schoenau et al.2008)



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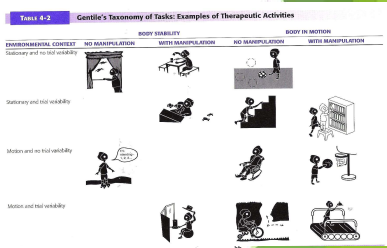
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### #10. A lifetime of moving: Teens

- ▶ Optimal challenge
  - ▶ Child is an active learner
  - ▶ Must be motivated
  - ▶ Complex exploration of their own body in different environments
- ▶ Larin, Campbell, 2010



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### #10. A lifetime of moving: Teens

- ▶ K: 16 year old high school
- ▶ GMFMCS III
- ▶ Rehab: Patella surgery
- ▶ Concerns
  - ▶ No more surgery
  - ▶ Pain
- ▶ Practical skills of independence: ADL
- ▶ "You know I can live on campus and get away with eating out of a can, but I can't get away with going outside without my pants on!!"

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### #10. A lifetime of moving: Teens

- ▶ Transitions
- ▶ Self-care
- ▶ Independence
- ▶ Decision-making



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### #10. A lifetime of moving: Adults

- ▶ Therapy Challenges
  - ▶ Home Health Aids
    - ▶ Personnel changes
  - ▶ Stability (Mullens, 2004)
    - ▶ Weight bearing
    - ▶ Trunk extension in sitting  
Move weight forward over feet
    - ▶ Feet flat on floor for wheelchair
    - ▶ Sit to stand



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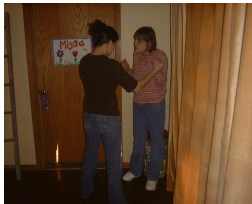
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### #10. A lifetime of moving: Adults

Home Program effectiveness for Adults (Novak, 2011)

1. More effective than no intervention at all
2. Equally effective to expert-provided therapy, except when therapeutic modalities were used
3. Different instruction formats produced similar outcomes.



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### #10. A lifetime of moving: Adults

Successful Home Programs (Novak, 2014)

1. involve the patients in establishing the programme
1. intervene on the person, task and environment
3. provide feedback about progress.

Dose did not appear to be related to outcome.



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### Summary

- ▶ What can we accept?
  - ▶ Strengthen families knowledge and skill
    - ▶ For Voice, Choice, Control
  - ▶ Creating a common language helps share visions
- ▶ What can we change?
  - ▶ Invest in partnering with families
    - ▶ Listening using open ended questions
    - ▶ Define the family goal
    - ▶ Support natural environment opportunities
- ▶ What should we be asking?
  - ▶ Need future Research to include 'fidelity'
    - ▶ (what parents really use) (Barton, 2013; Carr, 2016)

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### Summary

- ▶ Expect parents to 'join in': Use the interview!
- ▶ Help parents create the 'structure' of goals with you THE POWER OF ROUTINES
- ▶ Share the experience through feedback: 'Show me'
- ▶ Encouraging parents to take control
- ▶ Successful partnerships takes practice and TIME! Be patient

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**Summary**

- ▶ Shared 10 key points
  - ▶ 'I' :
    - ▶ The first visit sets the stage: Interview
    - ▶ Listen
    - ▶ Coach
    - ▶ Share your knowledge
  - ▶ 'Can'
    - ▶ Keep solutions simple
    - ▶ Feedback
    - ▶ Pace
    - ▶ Team
  - ▶ 'DO'
    - ▶ Equipment
    - ▶ Move across the lifespan

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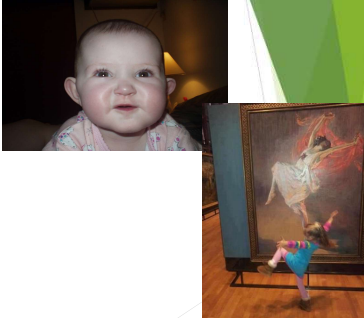
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**Thank You!**

- ▶ And don't forget to enjoy and be energized by each family and what you learn




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