Collaborative Goal Setting in Pediatric Rehabilitation

Lesley Wiart PT, PhD
Nov. 29, 2016
Children with disabilities often access rehabilitation services from a heterogeneous group of professionals. Often across service sectors and Ministries.

Goal of rehabilitation is to maximize the abilities of children to participate in the activities and roles that are meaningful to them and their families.

The involvement of professionals across environments and service sectors makes rehabilitation planning complex.
International Classification of Functioning, Disability and Health
World Health Organization (2001)
Family Centred Service

CEREBRAL PALSY: The Six ‘F-Words’ for CP

1. FUNCTION
   - Finishes dinner before I can do it, that’s ok. It’s not important. Please let me try.

2. FAMILY
   - They know me best and I trust them to do what’s best for me. Listen to them. Talk to them. Hear them. Respect them.

3. FITNESS
   - Everyone needs to stay healthy, including me. Help me find ways to keep fit.

4. FRIENDS
   - Making friends is important. Please give me opportunities to make friends with my peers.

5. FUN
   - Childhood is about fun and play. This is how I learn and grow. Please help me do the activities that I find the most fun.

6. FUTURE
   - I will grow up someday, so please find ways for me to develop independence and be included in my community.

World Cerebral Palsy Day
www.canchild.ca

World Cerebral Palsy Day
www.worldcpday.org

Funded by: The Alberta Foundation
Based on research, if I have CP, I can:

- Live independently
- Learn independently
- Walk independently
- Be part of my community

Research in pursuit of a child’s ability to move forward.
Goal setting approaches

Functional therapy for children with cerebral palsy: an ecological approach

Disability and Rehabilitation, 2009; 31(22): 1808–1816

RESEARCH PAPER

Activity focused and g palsy – Do goals make

KRISTINA LÖWING1, ANN
1Department of Woman & Child Heal Stockholm, Sweden

Accepted February 2009

OCCUPATIONAL FET
Attainment Scale

SIGRID OSTENSJÖ, ID

Effects of a Functional Therapy Program on Motor Abilities of Children With Cerebral Palsy

Background and Purpose. The purpose of this study was to determine whether the motor abilities of children with spastic cerebral palsy who were receiving functional physical therapy (physical therapy with an emphasis on practicing functional activities) improved more than the motor abilities of children in a reference group whose physical therapy was based on the principle of maximization of the quality of movement. Subjects. The subjects were 55 children with mild to moderate cerebral palsy aged 2 to 7 years (median: 5.5 years). Methods. A randomized block design was used to assign the children to the 2 groups. After a course, the physical therapy group received training in the systematic application of functional physical therapy. There were 3 follow-up assessment 6, 12, and 18 months after the program. Both groups showed improvement in motor abilities tested in 12 months. The results of the GMI scores were analyzed by the GMI in the reference group, but not in the therapy group. When examining functional skills in daily situations, as measured by the GMFM, children in the functional physical therapy group improved more than children in the reference group. (Resubmit M Vermeij A. H Bart.)

Key Words: Cerebral palsy, Children, Function, Motor abilities, Physical therapy.

Margareth Kuhnau, Adria Vermeij, Hanne H Bart, Els van Pootegem, Bob, Paul JM Holman

Novak, I.
Implementation has been challenging

- 23% of Alberta pediatric rehabilitation programs (n=59) had formalized goal-setting processes (Darrah et al., 2010).

- Parents do not always perceive optimal involvement in the process (Wiart et al., 2010)

- Rehabilitation Activities Profile (RAP) for Children Netherlands (Nijhuis, et al., 2008)
  - 23% of principal goals addressed child/family identified needs
  - 46% of principal goals were related to principal problem constructs
  - 24% of children did not have a principal goal
We need to define and evaluate a broader range of outcomes

- Increased continuity for families
- Increased efficiency of service delivery
- Engagement of children in identifying meaningful goals
- Increased motivation to participate in rehabilitation activities
- Improved child and family outcomes
Increased Continuity of Care for Families

- A collaborative assessment approach aligned team activities and goals and resulted in a coordinated plan (Berman et al. 2000; Nijhuis et al., 2007)

- Parent identified goals can enhance family-therapist collaboration (Stefansdottir & Egilson, 2015)

- Potential for enhancing inter-sectoral collaboration
Consider...

Liam is a 6 year old boy with cerebral palsy. He is in grade 1 at his community school. He drives a powered wheelchair and requires assistance with transfers in and out of his wheelchair. He is a non-verbal communicator and uses a communication device.
Increased efficiency of service delivery

- Anecdotal evidence that goal setting aligns team processes so there is a shared focus on family identified goals
The ‘Good Goals’ Project
(Kolehmainen et al., 2012)

- Project to improve access and equity to services by optimizing clinician resources
  - 1) Identify clear and specific treatment goals that are meaningful to the family
  - 2) Discussion of goals with family and educational staff
  - 3) Evaluate child’s progress towards those goals

- Mixed methods evaluation of uptake, changes in service delivery, cost of service delivery (n=46 therapists, 558 families)
Results

- Mean length of treatment ↓ by 2 months despite mediocre uptake (21-59%)

- Intensive implementation process necessary part of the process

- One of the most significant barriers was therapists’ beliefs that therapists and some parents are incapable of collaborative goal setting

- Became more open when they considered the role of feedback on goals as a strategy to improve engagement and outcomes
Engagement of Children

- Research primarily focused on parent participation in goal setting
  - If rationale includes motivation to participate then we need child involvement
- Children can identify attainable goals (Nordstrand et al., 2015)
- Children as young as 5 years old can participate in goal setting
  - Description of process is lacking
Engaging children in setting their own rehabilitation goals

(Wiart, L., Phelan, S., Andersen, J.)

- Child identifies rehabilitation goals
- Goal discussion with parent and child
- Compare parent and child goals and ratings of performance
- Qualitative interviews with children and parents about their perspectives on the goal setting process
“I want to be able to tell her in my own words what my goals are.

I: Why is it important that you tell her in your own words?

Because sometimes it’s different in the ways people explain things and tell them.

(12 year old girl with cerebral palsy)
Increased motivation to participate in rehabilitation activities

- The link between motivation and positive outcomes has been firmly established in goal setting research.

- This link has not been evaluated in pediatric rehabilitation.

- Lack of a theoretical framework for pediatrics linking process with outcomes.

![Pie chart with categories: No Theory (12%), Theory (rationale) (30%), Integrated Theory (58%).]
Improved Child and Family Outcomes

- Studies to date have compared ‘traditional’ therapy to a different intervention that included goal setting.
- Outcomes of goal setting have not yet been specifically evaluated in pediatrics.
Future Steps

- Scoping review on the theoretical basis of goal setting in pediatric rehabilitation (in progress)
- Develop theoretical framework for goal setting
- Develop process for goal setting that optimizes child engagement (in progress)
- Evaluate outcomes and process of collaborative goal setting
  - Child and family outcomes
  - Cost effectiveness and service delivery outcomes (length of treatment, waitlists, inter-professional collaboration, inter-sectoral collaboration)
Thank you!

Collaborators
- Children and Families
- Megan Bulat, OT
- Tanya Skitsko, PT
- John Andersen MD
- Shanon Phelan PhD OT
- Lyne Bourassa
  (research coordinator)