A Collaborative Model of Service Delivery for Children With Movement Disorders: A Framework for Evidence-Based Decision Making

Models of physical therapist service delivery provide a framework for integration of knowledge, research, and assumptions in a clinically relevant context that facilitates evidence-based decision making. In this perspective, a collaborative model of service delivery for children with movement disorders is presented. The focus is on services that address child and family priorities and preferences in settings where children live, learn, and play. The International Classification of Functioning, Disability and Health (ICF) is applied to identify relationships among the components of functioning, environmental, and personal factors that are important for the plan of care and achievement of outcomes. An assumption of the model is that physical therapists use multiple types of evidence to guide decision making. Application of the model and how child and family priorities change over time are illustrated through a longitudinal case report of a child with cerebral palsy. [Palisano RJ. A collaborative model of service delivery for children with movement disorders: a framework for evidence-based decision making. Phys Ther. 2006;86:1295–1305.]

Key Words: Children, Cerebral palsy, Clinical decision making, Evidence-based practice, International Classification of Functioning, Disability and Health, Movement disorders.

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On a daily basis, pediatric physical therapists interact with children, their families, educators, physicians and other health care professionals, and third-party payers to make decisions about patient or client management. Clinical decision making is a process in which information is shared, options are identified, and a choice is made. Evidence-based practice refers to the use of the best available knowledge and research to guide decision making within the context of the individual client, a process that involves integrating individual clinical experience with research evidence. To what extent is physical therapist practice evidence-based? In health care, current knowledge and research often are not applied or transferred into practice is slow, suggesting that dissemination of knowledge and research is a necessary, but not a sufficient, condition for evidence-based practice.

Practice models provide a framework for application of knowledge and research. The perspective presented in this article is based on the assumption that models of physical therapy service delivery facilitate evidence-based decision making. I propose that, at the level of the individual practitioner, models are useful for articulation of a rationale and assumptions about interventions and outcomes. At the level of the health care organization, models of service delivery facilitate standards of care, coordination of services, quality assurance, and program evaluation. At the level of the profession, models of service delivery facilitate outcomes research.

In this perspective, a collaborative model of service delivery for children with movement disorders is presented. The International Classification of Functioning, Disability and Health (ICF) is applied to identify relationships among components of functioning that guide the plan of care and environmental and personal factors that are determinants of outcomes. Application of the model is illustrated through a longitudinal case report of a child with cerebral palsy.

Collaborative Model of Service Delivery

The collaborative model of service delivery is presented in Figure 1. The model is adapted from a model developed for early intervention by Lisa Chiarello, PT, PhD, PCS, Margaret O’Neil, PT, PhD, MPH, and myself with input from community partners as part of the research activities in the Hahnemann Programs in Rehabilitation Sciences at Drexel University. Development of the model was supported, in part, by a Leadership Training Grant, US Department of Health and Human Services, Bureau of Maternal and Child Health. The model is based on the assumptions that effective service delivery: (1) is family-centered, (2) incorporates instruction and practice into daily activities and routines, and (3) promotes outcomes that are meaningful to the child and family in daily life.

Family-centered service is an approach to service delivery that is considered best practice in pediatric rehabilitation. The focus is on services that address child and family needs, priorities, and preferences in settings where children live, learn, and play. Collaboration between the family and service providers is integral to establishing goals and the plan of care. Service providers respect and support the family. Interventions build on child and family strengths and are acceptable to the family. As illustrated in Figure 1, identification of family needs, priorities, and preferences occurs prior to development of the plan of care.

The components of physical therapist intervention have been adapted based on principles of family-centered services. The components of intervention interact in an iterative manner. Communication and coordination are essential for effective collaboration. Communication is the process of passing on knowledge and information to families and other team members. Service coordination is based on the assumption that integrated services will minimize stress and maximize outcomes for children and families. Sharing information is a reciprocal process. The family and therapist share information about the child, the family discusses their needs, priorities, and preferences, and the therapist provides information, recommendations, and instruction in formats that are useful to the child and family. Through information sharing, interventions are implemented to achieve the outcomes that are meaningful to the child and family. The third component, natural learning environments, is based on the assumption that motor
Learning is optimized by frequent and varied practice within the context of daily activities and routines.¹³⁻¹⁶ In a home-based, family-centered model of physical therapy in which services were provided within the context of motor play using toys and materials available in the home, mothers reported high levels of satisfaction with the intervention and indicated that their needs were addressed.¹⁷

The ICF model⁴ is presented in Figure 2. The ICF was developed to provide a scientific basis for understanding health and health-related states, outcomes, and determinants and a common language to improve communication among health care providers, researchers, policy makers, and people with disabilities. The ICF consists of components of functioning, disability, and health and of contextual factors. The 3 components are: body structures and functions (body system level), activities (person level), and participation (person-environment interaction). The 2 contextual factors are environmental and personal.

Body functions are physiological and psychological functions of body systems. Body structures are anatomical parts of the body. Impairments are problems in body functions or structures. Impairments in skeletal alignment, range of motion, sensory processing, muscle performance, balance, and endurance are associated with movement disorders in children. Activities are the execution of a task or action by an individual. Activities represent the integrated use of body functions and vary in complexity. Activities limitations are difficulties an individual may have in performance of age-appropriate tasks or actions. Children with movement disorders often have limitations in activities that require maintaining and changing body positions, moving around, manipulating objects, and self-care. Participation refers to an individual’s involvement in life situations. Most children participate in home life, education, community activities and organizations, and social relationships with friends. Participation restrictions are problems that individuals experience with involvement in life situations.

Environmental and personal factors influence the relationships among body functions and structures, activities, and participation. Environmental factors are the physical, social, and attitudinal features of the settings in which children live and conduct their lives. Personal factors are characteristics of the individual that are not part of a health condition or health state. The following is an example of how contextual factors might influence a child’s participation at school: The distance from the classroom to the cafeteria and encouragement from other students (environmental factors) and the child’s
fitness and motivation (personal factors) are determinants of whether the child walks with classmates when going to the cafeteria (participation).

Figure 3 presents the full collaborative model of service delivery that incorporates the ICF. The ICF framework is used when making decisions about:

1. relationships among impairments, activity limitations, and participation restrictions that are relevant to child and family outcomes,

2. environmental and personal factors that are most likely to influence achievement of outcomes, and

3. the plan of care.

Decisions on the plan of care also are informed by:

1. knowledge of the movement disorder (health condition),
2. prognosis,
3. principles of motor learning, and
4. evidence of the effectiveness of specific interventions. As will be illustrated in the case report, relationships between components of functioning, disability, and health and contextual factors change over time.

**Evidence-Based Decision Making**

An assumption of the model is that physical therapists use multiple types of evidence to guide decision making. This perspective is consistent with the definition of evidence-based practice. Knowledge of the needs, priorities, and preferences of children with movement disorders and their families is obtained through needs assessment, satisfaction measures, and participatory research in which families of children with movement disorders are members of the research team. In clinical practice, information on child and family needs, priorities, and preferences is obtained through interview. The Canadian Occupational Performance Measure (COPM) is a semistructured interview instrument in which the child or parent identifies self-care, productivity, and leisure activities that the child wants, needs, or is expected to perform and is currently having problems performing.

For this perspective, *evidence* is broadly defined and includes experimental research, nonexperimental research, expert consensus, expert opinion, and personal experience based on systematic observations. The *randomized control trial* (RCT) is generally considered the design that provides the strongest evidence of cause-effect influences between interventions and outcomes. Subjects are randomly assigned to an experimental or control group. The intervention is defined by the investigators and provided in the same way to all subjects in the experimental group. Outcomes provide evidence of efficacy of the intervention. Findings, however, may not directly transfer into clinical practice. A challenge for therapists is application of findings to clinical settings where patient characteristics are not identical to those of subjects in the experimental group, conditions are not controlled, and exact replication of the intervention is not feasible.

In *nonexperimental research*, group assignment is not randomized and interventions are provided under typical conditions using observational, predictive, and qualitative designs. Nonexperimental research is useful for determining optimal processes of care and identifying factors that enhance or restrict outcomes. Outcomes provide evidence of the effectiveness of an intervention. Although the RCT is often referred to as a “gold standard” for outcomes research, Grossman and Mackenzie contend that, depending on the internal validity of data obtained during an RCT and the clinical question, the results of nonexperimental designs may provide stronger evidence.
Expert consensus, expert opinion, and individual experience are types of evidence that are based on judgment and reasoning rather than research. 

**Expert consensus** involves extensive discussion of evidence by a panel knowledgeable on the topic. The criterion for consensus is established beforehand and following discussion a formal vote is taken. Consensus is typically defined as agreement by 75% to 90% of the panel. **Expert opinion** reflects the perspective of an individual who is knowledgeable on the topic. Textbooks typically reflect the expert opinion of the authors. **Expert opinion** and **individual experience** should be generated from systematic observation, documentation, and program evaluation.

Haynes et al21 presented a model of evidence-based decision making that involves the simultaneous consideration of research evidence, patient preference, patient status, and clinical expertise. In applying the collaborative model of service delivery, physical therapists use research evidence together with child and family preferences, child prognosis, and personal experience to inform decision making.

**Case Report**

The case report illustrates application of the collaborative model of service delivery to clinical decision making and how child and family needs, priorities, and preferences change over time. In part 1, the child is 17 months of age. Parents’ concerns centered on prognosis for walking and services. In part 2, the child is 4 years of age. Her parents shared with the therapist their desire for her to walk at school when she begins kindergarten. In part 3, the child is 10 years of age and experiencing difficulty in physically keeping up with classmates at school and friends during leisure activities.

**Part 1**

Teresa Spataro (a pseudonym) is a 17-month-old twin born at 31 weeks gestational age with a birth weight of 1,570 g. Her stay in the neonatal intensive care unit was notable for several episodes of apnea. She lives in a single-family home with her parents, twin sister, and 4 older siblings. Mr Spataro works most days until 7 pm. Mrs Spataro manages the household. The home environment is “child oriented” with toys, books, and school projects visible. Interactions among family members are positive, and the children’s accomplishments are praised. Teresa was referred for physical therapy by her pediatrician. She has hypertonia in her leg muscles. Gross motor development is delayed (unable to stand or walk).

**Examination, evaluation, and prognosis.** During the initial interview, Mrs Spataro identified the following needs and priorities: (1) information on when Teresa will walk, (2) concerns about leg stiffness, and (3) recommendations for what to do. Although Teresa did not have a medical diagnosis of cerebral palsy, the therapist’s neuromuscular findings and Teresa’s patterns of movement are consistent with this condition. Teresa is classified at level II on the Gross Motor Function Classification System (GMFCS).22 She crawls on hands and knees with leg reciprocation and is beginning to pull to stand and cruise. Figure 4 presents gross motor development curves developed from a population-based longitudinal study of 656 children with cerebral palsy.23 The 66-item version of the Gross Motor Function Measure (GMFM-66) was used to create the curves.24 The Gross Motor Function Measure measures capability (what the child “can do” in a standardized situation) rather than performance (what the child “does do” in daily life). Children with cerebral palsy demonstrate a greater rate of gross motor development during infancy, with a leveling of scores at 3 to 5 years of age depending on GMFCS level. Logistic regression was used to estimate that children with a score of 56 have a 50% chance of walking 10 steps unsupported (represented by horizontal line). On average, children at level...
II achieve a score of 56 at age 3 years. Teresa was administered the GMFM-66 and achieved a score of 48. Figure 5 indicates that her score is slightly above the average score predicted for children at level II at 17 months of age. The therapist shared this evidence with Mr and Mrs Spataro when addressing their question, “When will Teresa walk?”

**Plan of care.** Figure 6 presents the relationships between components of functioning and contextual factors that are most important for Teresa at 17 months of age. Impairments in skeletal alignment, range of motion, and muscle performance were hypothesized by the therapist to contribute to activity limitations in sitting, standing, and movement transitions. The communication and coordination component involved meeting parent information needs, the therapist contacting the pediatrician to discuss a medical diagnosis of cerebral palsy, the parents sharing the family’s daily activities and routines, and discussion of how the family will participate in therapy. King et al reported that families of children with developmental disabilities rated service providers lower in meeting information needs than other aspects of family-centered services.

One strategy for the component of sharing information is the family routine and outcome matrix. As indicated in the Table, play in a long-sitting position and play in a standing position were 2 activities that were identified by the family and therapist to practice at home (natural learning environments component of the collaborative model of service delivery). These tasks involve integration of impairment- and activity-focused interventions and addressed the Spataros’ concerns about leg stiffness. Mrs Spataro identified 2 times during the day and Mr Spataro identified 1 time during the day for practice.

As Teresa progressed, Mrs Spataro and the therapist identified simple ways to adapt the home environment to encourage practice of pull-to-stand, standing, and supported walking. Two picnic benches were moved indoors to provide a stable surface of appropriate height for pull-to-stand, play in standing, and cruising. Some days, the benches were positioned in parallel, enabling Teresa to practice walking forward without adult assistance. Placement of toys at a distance was a strategy used to motivate Teresa to pull-to-stand and walk. In supported standing, hip and knee extension and weight shift were facilitated by the demands of the task (reach in different directions to poke soap bubbles, hitting a balloon suspended overhead by a string). The therapist demonstrated several methods of supported walking (varied hand placement, use of walking poles) based on the premise that each method provides a different task demand.

**Procedural interventions** for maintaining hamstring muscle length and improving ankle-foot alignment in standing were important for the plan of care because these impairments were hypothesized to limit floor sitting, standing, and movement transitions. The therapist performed a literature search, appraised the research, and formulated 3 summary statements that were shared with Mr and Mrs Spataro:

- Prolonged positioning is required for muscle/tendon adaptation.
- Serial casting and botulinum toxin have been reported to improve ankle range of motion in children with spasticity.
Evidence of whether one intervention is more effective than the other is inconclusive.\textsuperscript{30–35} The family’s decision was serial casting.

\textbf{Outcome measures.} Ankle range of motion and hamstring muscle length were measured with a goniometer and documented monthly. Goal attainment scaling (GAS)\textsuperscript{36} was used to measure outcomes for sit-to-stand, standing, and supported walking within the context of daily activities and routines. Goal attainment scaling is an individualized measure that uses 5 possible outcomes (the expected level of attainment, 2 outcomes that are less favorable, and 2 outcomes that exceed expectations). A T-score ($X=50, SD=10$) for multiple goals is computed to measure change. For the first 3-month period, Teresa achieved a T-score of 59 (she achieved the expected level of attainment for 2 goals and achieved the most favorable outcome for the goal involving sit-to-stand). The GMFM-66 was readministered every 6 months to measure change in gross motor capability. Research provided evidence that GAS is responsive to change in infants and children receiving therapy services and that GAS complements results of standardized measures of motor development and function.\textsuperscript{37,38}

\textbf{Part 2}

Teresa is 4 years of age. She has a medical diagnosis of cerebral palsy, with spastic diplegia. Cognition and language are areas of strength. Teresa will begin kindergarten next year and will attend a neighborhood parochial school with her twin sister and older siblings.

\textbf{Examination, evaluation, and prognosis.} Mr and Mrs Spataro’s priorities for intervention were: (1) improvement in Teresa’s ability to walk without falling, especially when outdoors, (2) improvement in her ability to walk up and down stairs at home (Teresa’s bedroom is in a renovated basement), and (3) improvement in her ability to walk when she attends kindergarten. Teresa continues to be classified at level II. She walks indoors and short distances outdoors. She has difficulty with initiation of walking, changing directions, and stopping. The GMFM-66 was readministered at 4 years 3 months, and Teresa achieved a score of 58. Her GMFM-66 score is comparable to the average score predicted for children at level II at 4 years of age (Fig. 7). Individualized outcomes for walking and stair climbing were identified with the family and measured using GAS.

\textbf{Plan of care.} Figure 8 presents the relationships between components of functioning and contextual factors that were most important for Teresa at 4 years of age. Emphasis has shifted to the relationship between limitations in activities and participation restrictions. Limitations in standing and walking were hypothesized by the therapist to restrict Teresa’s self-care, independence, and safety at home and potentially full participation when she begins kindergarten. Figure 8 lists features of the school environment and personal factors that were important considerations for the plan of care.

The communication and coordination component of the plan of care included the therapist: (1) visiting the school that Teresa will attend to meet the principal and kindergarten teacher, (2) performing an environmental assessment of the school (including distances between the school entrance, kindergarten classroom, and playground; the classroom layout; class routines; and accessibility of the restroom and playground equipment), and (3) scheduling therapy sessions outdoors, including at the school playground. The sharing information component involved: (1) recommendations for strengthening and fitness (riding a tricycle, participation in a community swimming program), (2) instructing Mr and Mrs Spataro in how to supervise and provide verbal and touch cues when Teresa practices walking up and down

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\* Figure 6. Relationships among components of functioning, environmental, and personal factors that were important for Teresa at 17 months of age (represented by thick lines).

\* Figure 7. Individualized outcomes for walking and stair climbing were identified with the family and measured using GAS.

\* Figure 8 presents the relationships between components of functioning and contextual factors that were most important for Teresa at 4 years of age.
stairs, and (3) the recommendation that Mr Spataro play games with Teresa and her siblings that involve starting, stopping, turning, and bending down (Simon Sez, obstacle courses) 3 nights per week. The therapist's rationale for the later recommendation is that anticipatory postural adjustments are important for mobility and best learned within the context of functional activities.39

Teresa’s impairments in force production and timing of muscle activation illustrate why knowledge of the health condition is important for the plan of care and how impairments can often be addressed within the context of activities and participation. The disorder in motor control in children with cerebral palsy is characterized by poor central regulation of intensity and timing of motor unit recruitment, secondary changes in muscle, and poor joint alignment, placing muscles at a biomechanical disadvantage.40,41 The therapist identified a systematic review on strength training in children with cerebral palsy42 and a more recent literature search where the authors discussed implications for clinical decision making.43 Of the 10 studies included in the 2 articles, 8 reported increased force production following strength training. Only 4 studies measured activity, and the effect of strength training was smaller.42,43

Based on the parents’ priority of preparing Teresa to walk at school and the motor learning principle of specificity of learning,44 the decision was made to incorporate strengthening into functional tasks (natural learning environments component of the model). The principle of specificity of learning states that learning is optimized by practice that approximates the target skill and environmental conditions in which the skill will be performed.44 A study on functional strength training by Blundell et al45 provided support for the decision. Children with cerebral palsy who participated in a circuit training program demonstrated improved stride length and speed in walking and improved performance on sit-to-stand and step-up tasks.45 Recommendations for children’s adherence to a home-based strengthening program by Taylor et al46 were useful in formulating the plan of care. Recommendations for walking included: practicing in contexts that are meaningful for Teresa, varying task and environmental demands, and encour-

Table. Activities and Times Identified by Family for Practice at Home

<table>
<thead>
<tr>
<th>Play in Long-Sitting</th>
<th>Play in Standing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position Teresa between your legs, with her back and knees straight</td>
<td></td>
</tr>
<tr>
<td>Position Teresa at picnic bench with her feet shoulder width apart and her heels contacting the floor</td>
<td></td>
</tr>
<tr>
<td>Late morning</td>
<td>Activities while listening to music or watching Sesame Street on TV (singing, clapping hands)</td>
</tr>
<tr>
<td>Squatting down to pick up a toy and coming back to stand</td>
<td></td>
</tr>
<tr>
<td>Early afternoon</td>
<td>Play with a toy placed between Teresa’s knees</td>
</tr>
<tr>
<td>Reaching for toys beyond arms length</td>
<td></td>
</tr>
<tr>
<td>Bedtime (father)</td>
<td>Read bedtime story</td>
</tr>
<tr>
<td>Poking soap bubbles</td>
<td></td>
</tr>
<tr>
<td>Taking steps sideways to obtain toy</td>
<td></td>
</tr>
<tr>
<td>Taking steps sideways to obtain toy</td>
<td></td>
</tr>
<tr>
<td>Play games such as rolling ball or car with an older sibling</td>
<td></td>
</tr>
</tbody>
</table>

Figure 7. Gross motor development curve for children at level II with Teresa’s Gross Motor Function Measure (GMFM-66) scores at 17 months and 4 years 3 months of age (indicated by asterisks). Adapted and reprinted with permission of the American Medical Association from: Rosenbaum PL, Walter SD, Hanna SE, et al. Prognosis for gross motor function in cerebral palsy: creation of motor development curves. JAMA. 2002;288:1357–1363. Copyright 2002, American Medical Association. All rights reserved.
aging Teresa to “solve” problems encountered when walking.

Part 3
Teresa is 10 years of age. She is in grade 4 of a regular education program. Teresa actively participated in identification of goals and the examination through completion of the COPM and the Activities Scale for Kids (ASK). The ASK is a self-report measure designed for completion by children 5 to 15 years of age with musculoskeletal disorders who are experiencing limitations in physical activity. On the performance version of the ASK, children indicate how often they performed each activity by themselves during the previous week. On the COPM, Teresa identified keeping up with classmates at school and friends during leisure activities and play as her priorities. Teresa’s priorities were consistent with her responses to the ASK items “I walked in crowded areas,” “I got around outside without anyone to help me,” and “I did activities I usually enjoy for a long time without getting tired” where she responded “sometimes” or “most of the time.” Over the past 6 months, the therapist observed reduced pelvic rotation, decreased ankle and foot mobility, and a narrowed base of support when Teresa walked.

Figure 9 presents the relationships between components of functioning and contextual factors that were most important for Teresa at 10 years of age. The therapist hypothesized that activity limitations contributed to secondary impairments in skeletal alignment and range of motion. Increased environmental demands when walking at school and in the community (farther distances to travel, more time demands, crowds) and personal factors were identified as important considerations when addressing Teresa’s concerns about going places and doing things with classmates and friends. A recommendation for the communication and coordination component of the plan of care was referral to an orthopedic surgeon to address skeletal alignment and range of motion. A particular concern of the therapist was the “balance” between interventions designed to improve walking speed and endurance and the potential for excessive biomechanical forces during walking to contribute to secondary impairments, including early joint degeneration. In preparation for the orthopedic consultation, Teresa, her parents, and the therapist discussed options for exercise, fitness, conditioning, and joint protection. An article...
that addresses issues relevant to physical fitness requirements for walking in people with cerebral palsy was shared with the Spataros (sharing information component of the plan of care).

Summary
Models of service delivery provide a framework for evidence-based decision making. The collaborative model of service delivery is based on the assumptions that effective service delivery for children with movement disorders is family-centered, encourages opportunities for motor learning as part of daily activities and routines, and promotes outcomes that are meaningful to the child and family in daily life. The focus is on services that address child and family needs and priorities in settings where children live, learn, and play. The components of physical therapy intervention have been adapted to reflect the focus of the model (communication and coordination, sharing information, and natural learning environments). The ICF is applied to identify relationships among the components of functioning, environmental, and personal factors that are important for achievement of child and family outcomes. Decisions on the plan of care are informed by knowledge of the movement disorder, prognosis, principles of motor learning, and evidence of the effectiveness of specific interventions. For this perspective, evidence is broadly defined and includes experimental research, nonexperimental research, expert consensus, expert opinion, and personal experience based on systematic observations. In addition to evidence, feasibility and acceptability are important considerations for decision making. As illustrated in the case report, relationships between components of functioning and contextual factors change over time.

References
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