

# Lessons from Use of the Pediatric Evaluation of Disability Inventory: Where Do We Go from Here?

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**Purpose:** The purpose of this article is to review the innovations, applications, and effect of the original Pediatric Evaluation of Disability Inventory (PEDI) published in 1992 and to describe planned revisions. **Summary of Key Points:** During the past decade, the PEDI has helped to shift thinking from a developmental to a functional focus. Using the PEDI, researchers and clinicians worldwide have highlighted variations in functional skill acquisition in clinical populations, the importance of recognizing cultural differences, and the value of documenting functional progress in relation to interventions. **Conclusions:** The PEDI has had a rich tradition in helping to document functional development. New methods are proposed for the next generation of the PEDI by using item banks and computer adaptive testing. **Recommendations for Clinical Practice:** The computer adaptive testing feature and the revised and expanded content of the new PEDI will enable therapists to more efficiently assess children's functioning to a broader age group of children. (*Pediatr Phys Ther* 2010;22:69–75) **Key words:** activities of daily living, adolescent, child, computing methodologies, cultures, disability evaluation, outcome assessment, psychometrics

## INTRODUCTION

The Pediatric Evaluation of Disability Inventory (PEDI) is a comprehensive clinical assessment that samples key functional capabilities and performance in children between the ages of 6 months and 7½ years.<sup>1</sup> Much has changed in assessment practice and psychometrics since the original publication date of the PEDI in 1992. Although the PEDI continues to be a preferred clinical and

research assessment used worldwide, the very nature of how assessments are built and administered is changing.<sup>2</sup> The PEDI is keeping up with those changes, as will be described later. As we are experiencing a transition period of adoption of new approaches for building clinical assessment, such as creating item banks and developing computer adaptive testing (CAT),<sup>3,4</sup> it seems timely to look back at the innovations that were part of the original PEDI and to look forward to new assessment technology that is on the horizon.

## A LOOK BACK

The PEDI was developed to provide an alternative to traditional approaches for assessing children with disabilities.<sup>5</sup> Assessment of impairments, often the focus of clinical measures at that time, did not provide adequate information about individual functioning in the daily performance of activities. The PEDI was designed before the revised World Health Organization's International Classification of Functioning, Disability and Health<sup>6</sup> was

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presented, but it is grounded in a similar conceptual model. In particular, the PEDI was designed to examine what the child actually does in the context of daily life (activity) rather than to describe his or her impairments (body functions and body systems). This approach inherently incorporated both the environmental and the personal dimensions. The Functional Skills section of the PEDI provided summary scores that reflect the child's current repertoire of daily life skills in each of 3 domains (self-care, mobility, and social function), whereas the Caregiver Assistance section provided a summary of the extent to which the child's overall performance of complex daily tasks such as dressing or moving around is supported by help from a caregiver. Revised versions of the PEDI will follow this tradition by assessing behaviors at the International Classification of Functioning, Disability and Health component of Activity, which focuses on tasks that are part of the child's daily routines. The design of the PEDI supports both discriminative purposes such as determination of eligibility for disability related services (with norm-referenced standard scores) and evaluative purposes such as determining change following intervention (with criterion referenced scores).

### **Alternative to the Developmental Model**

Most of the pediatric assessments used by physical therapists and others in 1992 were guided by a developmental model that focused on the extent to which children with disabilities do or do not attain motor, cognitive, and social developmental milestones at the expected age. Measures typically used for this purpose were formed using items selected to provide optimal discrimination between children who are and are not performing at age-expected level. Although some developmental items in measures such as these have activities with functional value (eg, running and buttoning), most were selected because they discriminated well between normative and disability groups, not because those activities were representative of the child's engagement in daily life. As a result, the summary scores from these measures did not provide useful information about the child's repertoire of functional skills and typically provided limited or no information about the extent of the child's participation in the various contexts of daily life. For example, Case-Smith<sup>7</sup> found that for a population of children with developmental delays, measures of fine-motor developmental skills were only weakly correlated with functional PEDI items involving hand use. Studies such as this support the conclusion that traditional developmental measures do not provide adequate information about the performance of daily life activities by children with disabilities.

### **Scaling: Use of the Rasch Model**

Another innovation of the original PEDI was the inclusion of a psychometric model for item scaling that was soon to become popular in many contemporary assessments. The original PEDI was the first pediatric functional assessment to use the Rasch approach to develop best-fitting hierarchical models of functional development.<sup>8</sup> Ra-

sch methods take ordinal item response data and convert scores to an interval-like metric so that relative positions of items along a functional continuum can be modeled along with child functional scores. We used the simplest form of the Rasch model for the dichotomous Functional Skill items and a polytomous model for the Likert-type 5-point rating scale for the Caregiver Assistance scales. At the time, most pediatric assessments simply used raw scores as their basis for developing summary scores.

Rasch and Item Response Theory (IRT)<sup>9</sup> methods have now become the predominant means of scaling items for new assessments. Although there are important differences between Rasch and IRT models in terms of complexity and assumptions, both are currently popular methods for scaling new assessments in healthcare applications. For example, the Gross Motor Function Measure-66 has converted to a Rasch-based scaling approach.<sup>10</sup> See Reeve et al<sup>11</sup> for details on other applications of IRT methods in health outcome instruments. The use of IRT has had a major influence in the development of the PEDI revisions. The most relevant advantage is in the possibility of estimating an unbiased score from any subset of items in the scale.<sup>12</sup> This latter feature is why CAT programs can be constructed from sets of hierarchical items that meet the requirements of an IRT model.

## **APPLICATIONS OF THE PEDI**

### **Assessing Individual Status or Progress**

The most common application of the PEDI by therapists has been to document either functional delay or changes in a child's functional abilities over time in response to therapeutic interventions.<sup>13</sup> Two methods have been used to determine whether changes in scores are clinically significant. Distributional methods that rely on expressing the confidence intervals around change scores with an underlying sampling distribution (standard errors) and anchor-based methods, which use an external, independent standard to interpret changes in PEDI scores, have been developed.<sup>14,15</sup> These methods are discussed in detail in the section on Inpatient Outcomes and the use of clinicians as the external anchor for determining important clinical change.

PEDI item maps provide another option for interpreting change in a child's functional profile.<sup>16</sup> Six item maps are available for the PEDI, 1 for each of the Functional Skills and Caregiver Assistance scales. Items within each content domain of the PEDI are arranged along a single continuum in a hierarchical order moving from easiest to most difficult. A child's score can be placed along that continuum; thus providing a picture of a child's functional abilities. This picture helps identify areas in need of further intervention, which therapists can use to assist with goal writing and program planning.

### **Building Knowledge About Children's Functioning**

The original PEDI items were selected based on their relevance to the child's engagement in daily life tasks, including tasks in self-care, mobility, and social function domains. This feature of the PEDI has enabled therapists to

construct a much more detailed description of the child's progress in acquiring essential daily life skills.<sup>17</sup> It also enabled research to move beyond relatively gross comparisons based on aggregate scores with studies describing profiles of function across different clinical groups,<sup>18</sup> between clinical and normative profiles,<sup>19</sup> and specific functional changes across an important time period such as recovery after a brain injury.<sup>20</sup> For example, Dolva et al<sup>21</sup> used the PEDI to describe the functional performance of 5-year-old children with Down syndrome in Norway, just before beginning kindergarten. One of the issues raised in their study was at what age children with Down syndrome can be trained and expected to stay dry day and night. Only 14% of the parents in this sample reported that their 5-year-old child had mastered bladder control, and many parents were worried that they were the only ones who did not have their children toilet trained. Two years later, Dolva et al<sup>22</sup> conducted a follow-up study to document the children's developmental progression in functional skills. In the follow-up assessment at the age of 7 years, 51% of the children in the sample now stayed dry day and night. Before these studies, there were limited data for clinicians or parents to use to evaluate whether their child's progress was typical for a child with Down syndrome or not. This example illustrates the utility of the PEDI to document the progression of functional skill development in children with disabilities. Further research of this type is greatly needed to develop guidelines to help parents set reasonable expectations for children with various conditions.

The combination of Functional Skills and Caregiver Assistance Scales in the same instrument has given researchers and clinicians a unique opportunity to investigate the relationship between acquisition of discrete skills and independence in management of larger daily tasks. A significant gap between level of Functional Skills and level of Caregiver Assistance suggests that factors other than skill limitations may be affecting the performance of these tasks. Practitioners can use this information to guide further investigation into the child's current situation and plan the treatment accordingly. Farmer et al<sup>23</sup> pointed out that the combination of the Functional Skills Scale and the Caregiver Assistance Scale in the PEDI provided a comprehensive picture to document severity of disability and progress over time.

The PEDI has been used in a large number of studies of children with different acquired or congenital childhood conditions, including cerebral palsy,<sup>24,25</sup> osteogenesis imperfecta (OI),<sup>26,27</sup> spinal muscular atrophy,<sup>28</sup> acquired brain injury,<sup>19,29</sup> developmental coordination disorder,<sup>30</sup> Down syndrome,<sup>21,22</sup> and musculoskeletal disorders.<sup>31</sup> As noted by McCarthy et al,<sup>32</sup> the items in the PEDI are more concentrated at the lower end of the functional skill continuum and hence are more likely to detect subtle differences in young children or in children with slowly emerging functional skills.

The PEDI has also been used to investigate the relationship between children's functional performance and diagnosis subtype. For example, Engelbert et al<sup>26</sup> used the

PEDI to determine whether subtypes of OI were associated with differences in functional performance. In this cross-sectional study of 61 children, it was found that subtype of OI was related to activity performance, especially in mobility. However, even though OI type III is the most severe subtype compatible with life, children with OI type III in this study had self-care functional performance within the normal range. The results confirmed that the relationship between severity of underlying condition or symptoms and functional outcomes is not straightforward and must be determined empirically.

## Treatment Effectiveness

The PEDI has been identified as a valid assessment tool to investigate treatment effectiveness, particularly studies of the effects of surgical and pharmacological interventions for children with cerebral palsy. The PEDI is one of the few pediatric functional measures with demonstrated sensitivity to functional changes related to spasticity.<sup>33</sup> For example, Awaad et al<sup>24</sup> used the PEDI to describe the functional outcome of intrathecal baclofen therapy in 29 children with cerebral palsy. They reported that intrathecal baclofen therapy improved functional performance in self-care, mobility, and social function; and it decreased the assistance children received from their parents. One interesting finding in this study was that self-care and social function skills had gains that exceeded gains in the Motor Skill domain, challenging the assumption that treatment of spasticity would only lead to improved motor skills. Dudgeon et al<sup>34</sup> also used the PEDI to examine functional outcomes of dorsal selective rhizotomy treatment in children with cerebral palsy (20 children with diplegia and 9 children with quadriplegia). Results showed significant improvement in self-care and mobility functional skills in children with diplegia only.

## Inpatient Outcomes

The PEDI has been used to measure changes in functional abilities and caregiver assistance for groups of children admitted to hospital-based rehabilitation programs. Use of the PEDI has provided program managers with functional outcome data to provide feedback to staff and families about program performance.<sup>35</sup> In 1 set of studies, functional-scaled scores were converted to classification levels of self-care, mobility, and social function to aid in the description of program outcomes. When compared with scaled score changes, minimal sensitivity was lost. The levels provided a clinically meaningful analysis of recovery and an alternative to the reporting of change scores by clinicians and programs.<sup>29,36,37</sup> The PEDI has been shown to be responsive to important changes in functional recovery in self-care,<sup>37</sup> mobility,<sup>29</sup> and social function<sup>36,38</sup> during rehabilitation hospital stays and at 6-month follow-up.<sup>39</sup> The PEDI has also been used in the inpatient environment to demonstrate changes between admission and discharge for

individual diagnostic groups including children with musculoskeletal conditions,<sup>31</sup> children with traumatic and acquired brain injury,<sup>35,40</sup> and children with spinal cord injury (Choksi et al, in preparation). In addition, admission PEDI Functional Skills mobility scores were shown to be an important prognostic variable for recovery of ambulation during inpatient rehabilitation for children with traumatic brain injury.<sup>41</sup>

The minimally important difference (MID) has been estimated from clinician report for each of the 6 scales of the PEDI. The MID ranges from 6.0 to 15.6 points and in general, a scaled score change of approximately 11 points has been suggested as an important clinical change.<sup>15</sup> In a study examining the achievement of the MID in physical function during inpatient rehabilitation, the highest proportion of children achieved the MID in mobility functional skills (78%) and caregiver assistance (67%).<sup>42</sup> In a later report, intensity of intervention for children with traumatic brain injury was significantly related to achieving the MID.<sup>43</sup>

## CROSS-CULTURAL EXPERIENCES

The PEDI has been translated into multiple languages including Dutch, Norwegian, Swedish, Spanish (United States), Portuguese (Brazil), Slovene, Turkish, Icelandic, French (Canada), Hebrew, Japanese, and Chinese. Most recently, a team of Swiss researchers have begun to translate the instrument into German. A number of these international users have reported challenges applying the PEDI to their own culture.<sup>44–51</sup> Three major themes were identified: (1) language issues in translation, (2) cultural differences in valued and important functional activities, and (3) different parent expectations for a child's developmental progression. One of the major issues in translating the PEDI is finding comparable words in each country's language. For example, a Norwegian team has reported difficulty finding comparable Norwegian words for “prompting,” “fasteners,” and “item.”<sup>44</sup> Cultural differences required item adaptations and additions to the PEDI, for example, the Dutch team added “bicycling” to their mobility scale.<sup>47</sup> Three Scandinavian teams, including the Norwegian, Swedish, and Dutch teams, reported that the bathtub is not commonly used in their countries.<sup>44,47,48</sup> Different developmental paths were suggested by different item hierarchies in Norway,<sup>45</sup> Turkey,<sup>50</sup> and the Netherlands.<sup>47</sup> Some research teams suggested that differences between the American and their own normative data may be due to different parenting experiences.<sup>45,50,52</sup>

## PEDI CRITIQUES

In addition to the translation issues discussed in the previous section, several critiques from PEDI users have helped us to define new directions for the PEDI. The PEDI is a long instrument, and the administration time may no longer be feasible for routine clinical use.<sup>47</sup> The PEDI items are concentrated at the easier end of the functional continuum.<sup>32</sup> Although this results in more precise measurement of children with moderate to severe disabilities, it may not

be ideal for older children or those with less severe disabilities. The PEDI items are focused primarily on home-based activities, which create some difficulties for therapists to answer questions without parent input. The original standardization sample had some sampling error, resulting from a lack of geographical representation and small numbers of children in each age group,<sup>53</sup> which can affect the validity of interpretations made using norm-referenced scores. Finally, parents of children with disabilities have commented that it would be better to have a more positive title for the PEDI rather than one that emphasized disability.<sup>49</sup>

## PEDI UPDATES

Beginning in the early part of this decade, the health-care community began to show a strong interest in applying newer approaches (such as building item banks and creating CAT software) to the development of clinical assessments for adult and pediatric care. These methods had potential to improve scoring precision and contribute to developing shorter versions of tests. A strategy of matching items to respondents that had been used to achieve short and precise educational and psychological tests for decades,<sup>54</sup> now seemed appropriate for testing in healthcare applications.

## PEDI-MCAT

Our first experience with developing a CAT application for the PEDI was the development of the multidimensional PEDI-MCAT,<sup>55</sup> which expanded the content and norms for the self-care and mobility functional skill scales to 15 years of age. The multidimensional IRT model takes advantage of the moderate to high correspondence between the mobility and self-care domains of the PEDI and creates 2 separate but related scores for these domains.

CAT methodology uses a computer interface to administer an assessment individualized to each child. The basic notion of an adaptive test is to mimic what an experienced clinician would do. Clinicians learn most when they direct questions at the child's approximate level of functional ability. Asking questions about functional activities that are either too easy or too hard provides little information and is not an efficient use of clinical time. For example, parents who indicate that their child is able to “walk 50 feet” are not asked to respond to an item about “walking 10 feet.” In practice, this approach minimizes the number of items that are administered to an individual to obtain an estimate of functioning in any particular content area.

We found that the PEDI-MCAT was both more precise<sup>55</sup> and sensitive to changes<sup>56</sup> than a comparative unidimensional model in which separate CATs were created for the self-care and mobility scales. In a sample of patients with severe spinal impairments,<sup>62</sup> the PEDI-MCAT was more efficient than the fixed-length PEDI as evidenced by reductions of 36% in the number of items and 58% less time required by the PEDI-MCAT versus the original PEDI. The majority (70%) of parents preferred the PEDI-MCAT over the paper-based fixed-length PEDI form. The CAT allowed parents to easily complete a questionnaire when



waiting to see their child's physician or therapist. Additional studies have highlighted the promise of CAT approaches in pediatric rehabilitation assessments.<sup>55,57-61</sup>

## Full PEDI-CAT Revision

In response to the critiques of the original PEDI and experience with the PEDI-MCAT, the PEDI research team initiated a full revision of the instrument. The following revisions were made: (1) addition of new items to extend the functional content assessed by the domains of self-care, mobility, and social functioning; (2) expansion of the dichotomous capable/unable scale to a 4-point difficulty scale; (3) addition of illustrations for each mobility and self care item; (4) replacement of the previous Caregiver Assistance section with a new "Responsibility" section; and (5) creation of a CAT platform for administration of all content domains.

A literature review identified >60 pediatric and rehabilitation assessments that were examined for content, wording, and response options. This information, along with items from the PEDI-MCAT, created a potential item bank of approximately 2600 items. These items were coded into task areas to inform initial item writing. Focus groups with professionals (physical therapists, occupational therapist, and speech language pathologist) and parents of children with disabilities were conducted, and input was obtained to identify additional content for the 3 functional domains and provide feedback. Promising items underwent cognitive testing with parents of typically developing children and children with disabilities to ensure that parents could easily understand and rate the PEDI on their own (Dumas et al, in preparation).

We are currently field testing 78 mobility, 76 self-care, 64 social functioning, and 53 responsibility items. These items will expand the functional capabilities assessed by the new PEDI-CAT and assess children and youth over a broader age range. For example, the mobility scale includes the more difficult item "uses step ladder to put a heavy box on a high shelf." The self-care scale now includes gender-specific items for adolescents, including "shaves legs and underarms using either electric or safety razor" and "shaves face using electric or safety razor." The social functioning scale includes more items that assess advanced communication and social skills such as "accepts advice or feedback from a teacher, coach, or boss without losing temper." Items in the mobility and self-care section are accompanied by black and white line drawings to ensure that the specific functional task assessed by each item is clearly understood by the parent respondent. These drawings are easily incorporated into the computer delivery method planned for the revised PEDI.

The functional domains of mobility, self-care, and social functioning will be rated using a 4-point scale: "unable," "hard," "a little hard," and "easy." Additional rating category descriptors indicate the level of difficulty associated with each rating scale category. The new 4-point rating scales used with these domains will increase the precision of the PEDI-CAT and enable clinicians to document

important but subtle functional changes in children with disabilities.

The new Responsibility domain assesses the extent to which a young person with a disability is managing life tasks that enable independent living. This section/scale was created to meet the growing demand for assessments that can plan for and track a young person's successful transition to adulthood. The Responsibility items require the child to use several functional skills assessed in the other domains in combination with each other to carry out life tasks. For this reason, this is a more difficult domain and is estimated to assess children and youth beginning at the age of 6 years and extending to the age of 21 years. Example items include "fixing snacks and simple meals that do not involve cooking" and "planning and following a weekly schedule so that all activities get done when needed." This section also contains content assessing health management and literacy, citizenship, safety, and community mobility. The items are rated with a 5-point scale that indicates the extent to which responsibility for each life task has been assumed by either the parent or young person: (1) parent assumes all responsibility; (2) parent assumes most responsibility; (3) parent and the young person equally share responsibility; (4) young person assumes most responsibility; and (5) the young person assumes all responsibility. The process of obtaining national norms and disability estimates for this domain will provide a unique opportunity to enhance our limited knowledge regarding the nature of transition to adulthood responsibilities for young persons with and without disabilities.

Based on feedback from international users, we are taking several steps to enhance the cross-cultural validity of the PEDI-CAT. Invited international users were asked to give feedback on whether there were any important items missing in the initial draft of items. We are giving less culturally specific examples in the revised PEDI and have tried to simplify language whenever possible. Items are focused on describing whether children perform a task without specifying tools or procedures. We anticipate that by applying IRT principles in a CAT application, international users of the new PEDI can more readily add and calibrate new items that they consider unique and important to their cultural context. We believe that providing illustrations for the self-care and mobility domains will also allow international users to translate PEDI items more easily.

In the full PEDI-CAT revision, we will use a CAT platform because it provides us with the ability to provide good estimates of functional ability with a reduced response burden for parents and clinicians. The response burden is reduced because items are administered based on previous responses, and this should avoid irrelevant items or items too easy or difficult for an individual child. The PEDI-CAT software will be programmed to find an accurate and precise summary score for each functional domain in as few items as possible. However, the software will also provide flexibility for use of the CAT for therapists who

want to use the PEDI for a comprehensive individual assessment. For example, clinicians will be provided options of how many items they would like to administer. Some therapists may believe that administering 20 to 30 items per domain provides them with sufficient information for future treatment planning. In addition to using the internal computer scoring rules for determining the number of items, therapists will have the opportunity to balance the items across content areas within a domain. For example, therapists may want to do a comprehensive mobility assessment and have the items that are administered balanced across the subdomains of transfers, locomotion, bending and lifting, and climbing. Score reporting options will also be made available, which includes individual item maps and the identification of children who do not fit expected models of functional development. We hope to find a good balance between the efficiency gains of the CAT, while not losing the important functional detail that can be provided by the PEDI. We expect that the full revision of the PEDI-CAT will be available over the Internet, and, over time, in multiple languages. Therapists who do not have access to the Internet may choose a stand-alone CD version.

## CONCLUSIONS

The original PEDI provided therapists with a sound method of assessing functional capabilities in young children and in children with moderate to severe disabilities. We have obtained a great deal of knowledge about functional development from using the PEDI. In the PEDI-CAT, we will incorporate the initial innovations of the PEDI and extend them to include a more representative and larger sample of children across a wider age span. In the new PEDI-CAT, we will take advantage of the CAT platform with administration flexibility for clinical users and choices for score reporting. These advances will build on previous PEDI applications, making the assessment process more efficient and enhancing the value of the PEDI for clinical and research purposes for a broad age range of children both nationally and internationally.

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