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Development of the Pediatric Disability Inventory-Patient Reported Outcome (PEDI-PRO) Measurement Conceptual Framework and Item Candidates

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Abstract

Background: To address the gap in patient reported outcome measures (PROMs) of functional performance appropriate for youth and young adults with developmental disabilities (DD) we developed the Pediatric Evaluation of Disability Inventory-Patient Reported Outcome (PEDI-PRO).

Aim/Objective: We used a participatory process to: 1) Develop the measurement conceptual framework; 2) Identify discrete functional tasks to include in the PEDI-PRO; and 3) Refine item candidates.

Methods: We collaborated with eight youth with DD over 33 months. These youth and university researchers explored the construct of functional performance, developed and refined items, and collected and analysed data. We also conducted focus groups with youth with DD ($n = 62$) and rehabilitation professionals ($n = 26$), and consulted with PEDI measurement experts ($n = 3$).

Results: Youth's understanding of their functional performance is embedded in their experiences participating in everyday life situations. We developed 78 Daily Activities, 65 Social/Cognitive, and 52 Mobility item candidates that are linked to 11 everyday life situations to assess discrete functional tasks important to youth with DD and rehabilitation professionals.

Conclusion & Implications: As a result of our participatory development process, the PEDI-PRO's proposed conceptual framework and item candidates are grounded in the lived experience of youth with DD.

Keywords

Outcome Assessment (Health Care); Patient Participation; Disabled Children; Community-based Participatory Research

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Introduction

Funding agencies, advocacy groups, and human rights treaties, such as the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities, highlight the rights of all persons of any age and ability to be actively engaged in the planning and evaluation of their healthcare and rehabilitation services. This right has been increasingly operationalized in rehabilitation research and practice through the use of patient reported outcome measures (PROMs) [1,2]. A patient reported outcome measure is any instrument that provides youth with the opportunity to directly report on the status of their health condition, health behaviour, or experience with health care [1,2].

Although high quality PROMs assessing outcomes such as health-related quality of life, functional status, and symptoms are currently available for use with the general youth and young adult¹ population (e.g., PROMIS [3]), youth with developmental disabilities (DD)² have traditionally been underrepresented during the development of PROMs. As a result, these PROMs may fail to include content relevant to the unique life experiences of youth with DD [4,5]. Emerging research suggests that when youth with DD use PROMs developed for the general population, the scores cannot be interpreted in the same way as scores obtained from youth with other health conditions [6]. Proxy respondents such as parents, who are commonly relied upon when measuring outcomes with youth with DD, do not recognize or share the same concerns as youth [7]. Therefore, PROMs completed by proxy respondents may fail to reflect all relevant rehabilitation needs and outcomes. Given the growing number of youth diagnosed with DD [8], there is a vital need for PROMs that can be validly and meaningfully used with this population [9].

This paper describes the participatory research approach used over three years to develop the Pediatric Evaluation of Disability-Patient Reported Outcome (PEDI-PRO) specifically for use by youth with DDs such as cerebral palsy, autism, and Down syndrome. Functional performance of everyday activities is an important outcome of interest addressed in rehabilitation and supports participation in everyday life situations [10]. The Pediatric Evaluation of Disability Inventory-Computer Adapted Test (PEDI-CAT) is a gold-standard *parent* report of functional performance used internationally in research and practice. Aligned with the International Classification of Functioning, Disability and Health's (ICF) definition of "activity," the PEDI-CAT defines its measured construct as, "functional performance of discrete tasks or activities of everyday living." The PEDI-CAT's measurement conceptual framework operationalizes that definition through three functional performance domains: Daily Activities, Social/Cognitive, and Mobility [11].³ Designing a youth PROM would allow researchers and clinicians to obtain a more comprehensive understanding of youth's abilities and needs via the youth's lived experiences. Further, a youth PROM aligned with the PEDI-CAT could provide youth with an opportunity to contribute to evaluation and intervention planning in contexts in which the PEDI-CAT is used. However, prior to developing a new PROM, the meaning of the construct, functional performance, must be understood from the perspective of youth with DD. This understanding should inform the design of the PROM conceptual framework and items to

ensure the resulting score is a meaningful measure of functional performance for this population.

We engaged a team of youth with DD in a long term participatory collaboration to develop the PEDI-PRO [12,13]. When youth with DD engage in long term research partnerships [14], they have repeated opportunities to develop an in-depth understanding of the targeted construct and relate the construct to their everyday lives. As a result, the youth partners can provide rich ideas and insights; those emerging ideas can be further explored in a more targeted manner with a larger group of stakeholders using additional methods to elicit youths' perspectives such as focus groups [15]. We used an iterative, participatory three-phase process to: 1) Develop a PEDI-PRO measurement conceptual framework aligned with youth with DD's everyday lived experiences, 2) Identify discrete functional tasks to include in potential PEDI-PRO items (referred to as item candidates), and 3) Refine PEDI-PRO item candidates. Figure 1 illustrates this iterative, participatory process and the outcomes of each phase. This manuscript uses a non-traditional format: first, we describe our participatory approach; second, we present the participants, methods, and results for each phase; third, we integrate our results to discuss the implications of the participatory development process on the PEDI-PRO.

Participatory Development Approach

Participatory research is a process of collaborating and learning *with* youth with DD, with the aim of making changes that positively impact youths' experiences in rehabilitation [12,16]. In this study, we integrated our participatory research approach with recognized methodological best practices in PROM development [15] to design a PROM that uniquely reflects the lived experiences of youth with DD. Although the PEDI-CAT is designed for youth ages 0-21, we targeted the development of the PEDI-PRO to youth ages 14-21, as this is the mandated period of transition planning under the United States' Individuals with Disabilities Education Act (IDEA) that requires youth involvement in identifying needs and goals. We also purposefully targeted development to youth with DD and co-occurring cognitive or intellectual impairments who may have difficulty completing PROMs and have been underrepresented in the PROM literature [3]. The study was reviewed and approved by the university's institutional review board, and all participants and/or their guardians provided informed consent/assent.

Youth team members.

The youth team included eight youth with DD (Table 1) who were ages 14 years, 9 months to 21 years, 7 months at time of initial enrolment. Recruiting eight youth allowed representation of a range of personal characteristics, while ensuring our research team had the time and resources to support each youth's authentic involvement in the research process. To form the youth team, the Principle Investigator (PI, first author) used professional networks to identify youth representing a range of diagnoses, living contexts, and functional skills. Inclusion criteria were: ability to attend to a task for 15 minutes and follow two-step, accessible directions with minimal support (e.g., verbal prompts and encouragement); identification as a person with a disability; and some experience expressing

needs or goals at school, work, or the community. These inclusion criteria ensured youth had the capacity to share their ideas in a group format. Two youth were wheelchair users, and six youth had intellectual disabilities; two had Down syndrome. These youth are meant to represent the diverse experiences and characteristics of our desired target population for the PEDI-PRO.

Youth team procedures.

In keeping with a participatory approach, the youth team had intensive and long term engagement throughout the research process. The youth attended 12 group research meetings in a 33 month period (Phases I-III). Youth also met individually with university researchers to complete additional research tasks. In total, youth contributed 277 hours to the project. During months 1-9, the youth team completed activities to explore the concept of functional performance in their own lives and the lives of other youth with DD. During months 10-33, in response to findings emerging from concurrent focus groups, the youth team developed and refined item candidates to ensure they were understandable to youth with DD.

Our collaboration integrated the unique expertise and skills of the youth team and the university researchers. As is common for participatory research, each party's expertise informed the PEDI-PRO development process as appropriate for each research question or research task [17]. The youth drew their expertise from their lived experience as youth with disabilities. The university researchers brought knowledge of best practices in PROM development, research design, and an appreciation for the clinical contexts driving PROM use in practice.

Three Phase Participatory Development Process

To demonstrate the iterative nature of this study, this manuscript chronologically details each phase of the development process. In each phase, the Youth Team subheading describes the participatory processes and unique contributions of the youth collaborators. Additional subheadings describe additional participants, methods, and results within each phase.

Phase I: Development of the PEDI-PRO Measurement Conceptual Framework

In Phase I, our objective was to explicate the meaning of functional performance from the perspective of youth with DD.

Youth Team

To explore the salience of the construct of “functional performance” for youth with DD, we asked the youth team to collect data about functional tasks important to their everyday lives. Initially, the youth team generated examples of discrete functional tasks in content categories aligned with the PEDI-CAT functional domains: for example, “keeping clean” (Daily Activities) or “sharing my ideas and feelings” (Social/Cognitive). The youth team recorded examples by writing or taking photos. Using this approach, the youth team

generated 90 functional tasks aligned with the following functional domains: 41 Daily Activities, 26 Social/Cognitive, 23 Mobility. Youth generated the greatest number of tasks categorized as “Daily Activities,” including self-care and domestic life tasks [18]. These tasks did not represent the range of more difficult discrete functional tasks required to engage in everyday activities the youth team told us were important, such as advancing their vocational skills, or going places in the community. These observations implied the functional domain categories, on their own, did not evoke linkages with youth’s everyday lived experiences and failed to facilitate youth’s identification of difficult, yet crucial skills that support increased functional performance.

We subsequently explored an alternative method to elicit difficult discrete functional tasks associated with important everyday activities. Each youth team member participated in two self-selected activities at home, school, work, or the community (see Table 1). All activities were video recorded by a university researcher. The youth completed a field note to document the functional tasks completed during the activity (e.g., use a touch screen, ask a store employee for help, slide down a bench). In addition, the team watched video clips as a group and identified the functional tasks they observed each other performing. Using this combined approach, the youth team generated 179 functional tasks aligned with the following functional domains: 45 Daily Activities, 113 Social/Cognitive, 21 Mobility. Compared to the first approach, youth generated a greater number of discrete functional tasks that required cognitive and social skills. Youth also identified more functional tasks that they acknowledged were challenging to complete, such as multiplying and add[ing] to figure out how much money they needed on a train pass. This process demonstrated that youth could identify and reflect on their abilities to complete difficult discrete functional tasks while participating in everyday activities. The youth team’s experiences informed our emerging understanding of the conceptual framework. However, the youth team’s perspectives required triangulation by additional youth with DD.

Phase I Youth Focus Groups

The purpose of the Phase I focus groups was to explore youth’s conceptualization of functional performance.

Methods—Phase I focus groups ($n = 19$, 3 groups), held during months 7-9, were exploratory and informed the emerging conceptual framework.

Phase I youth focus group participants.—We recruited youth from local sites serving youth with DD (Table 2). At each site, staff identified youth with DD meeting inclusion criteria: ability to communicate simple ideas in English and attend to a task for five minutes. These inclusion criteria ensured youth could share perspectives in a small group setting and complete the data collection procedures. Phase I youth focus groups were held in a variety of settings: one residential school program (1 group, $n = 7$) and two high school/secondary transition programs (2 groups, total $n = 12$).

Phase I youth focus group procedures.—University researchers and the youth team developed and co-facilitated focus groups. We asked participants to identify important

everyday life situations and related functional skills that would allow them to be more independent at home, school, work, and the community. We selected these contexts given the literature's recognition of their relevance to adulthood [18,19]. To reduce the social, communication, and cognitive demands of the focus groups, participants worked in small groups with a university researcher and/or youth team member, who used a semi-structured interview guide to ask questions for each context. Example questions include: "Can you think of different places you go in your community?" "What activities do you need or want to do in those places?" To support participants' attention, comprehension, and communication preferences, participants could speak, write, or draw their responses, or select from pre-printed photos depicting activities in each context. The use of photos supported youth who may have had difficulty generating ideas in response to open-ended questions. Participants used these materials to create posters for each context. We video and audio recorded each group, and took field notes during and immediately following each group to ensure we captured all responses. Each individual piece of data (i.e., spoken comments, selected or drawn pictures, or written worksheet responses) was entered into an Excel spreadsheet.

Phase I youth focus group analysis.—To support the youth team's involvement in data interpretation, university researchers reduced Phase I focus group data. Data reduction is the process of transforming large quantities of data to a more simplified form [20]. First, the university researchers counted the number of times each everyday life situation and functional skill was represented in each poster across all groups. The primary goal was to accurately represent the breadth of everyday life situations and functional skills, so we sparingly grouped similar responses together (e.g., grocery shopping and clothes shopping were counted in the category "shopping" for the community context). Second, two members of the youth team reviewed the reduced data in a typed list, and created summary posters of the reduced data to present to the full youth team. Third, as described below, the youth team interpreted the data.

Results: Phase I Youth Focus Groups—The 19 youth identified a range of important activities and related functional skills that facilitate their independence at home, school, work, and the community (Table 3). In the home context, youth frequently mentioned self-care, domestic life, and social activities. In the community context, shopping emerged as highly salient. In the work context, youth shared professional and vocational career aspirations. In the school context, youth valued graduating and doing school work, along with a range of social and extracurricular activities.

Refining the Measurement Conceptual Framework with the Youth Team

Our observation that the youth team identified more functional tasks in the context of everyday life situations led to our proposed conceptual framework. In the PEDI-PRO, we propose to assess the functional performance of discrete tasks in context of "everyday life situations." Everyday life situations are "frequently occurring routines or other activities that are complex, include sequences of actions suitable in societal contexts, involve engagement and are directed towards meaningful goals" [21] (p. 1231). To prioritize the everyday life situations to include in the PEDI-PRO measurement conceptual framework, the youth team

and the university researchers reviewed reduced Phase I data. First, the university researchers generated 16 everyday life situations that captured the activities mentioned most frequently across contexts in the Phase I focus groups. Second, the university researchers recommended the inclusion of two of the 16 everyday life situations: 1) “Shopping,” as it was the most frequently mentioned everyday life situation mentioned in Phase I youth focus groups, and 2) “Getting ready in the morning,” to capture the variety of functional tasks identified as important by youth in the home context, as well as to support content validity for outcomes commonly addressed in rehabilitation. The youth team agreed with this recommendation.

Third, the youth team reviewed and interpreted the reduced data to prioritize the remaining 14 everyday life situations for inclusion in the PEDI-PRO. To reduce abstract thinking demands that are required for prioritization, we wrote each everyday life situation on a piece of paper and provided youth with three stickers they could use to “vote” for their priorities. Youth could indicate “high” priority for one situation by placing three stickers on a single everyday life situation. Alternatively, youth could place one sticker on three different everyday life situations. Each everyday life situation was given a priority ranking based on the number of stickers. “Working at a job” received the most priority votes (three total); three everyday life situations received no votes: “Playing sports and exercising,” “Going to the library,” and “Making a snack”; the remaining everyday life situations received one or two votes. We developed item candidates aligned with all 16 everyday life situations, but as we moved into Phases II and III, more item candidates were developed for the highest priority everyday life situations.

Phase II: Identification of Discrete Functional Tasks for Inclusion in the PEDI-PRO

The objective of Phase II was to identify item content that operationalized the framework and that represented meaningful and important functional performance tasks [2]. Given the potential benefits of using the PEDI-PRO in conjunction with the parent-reported PEDI-CAT, we gathered data about essential discrete functional tasks in the PEDI-CAT Daily Activities, Social/Cognitive, and Mobility functional performance domains.

Youth Team

As described in Phase I, the youth team generated content for item candidates by identifying functional tasks they performed during everyday activities. They also evaluated the relevance of PEDI-CAT items. At least two youth team members independently evaluated each PEDI-CAT Daily Activities, Social/Cognitive, and Mobility item (items for young children, such as “pulls heavy wagon with small toys” were not reviewed). The youth first indicated if the item described a functional task they needed and wanted to do. Second, they identified words that were hard to understand, suggested alternative wording, and generated an image for each item. At least one youth team member endorsed most PEDI-CAT items (Daily Activities: 85.53%, Social/Cognitive: 85.07%, Mobility: 87.88%).

Phase II Youth Focus Groups

Methods—Phase II focus groups ($n = 43$, 6 groups), held during months 24-25, were used to identify discrete functional tasks to include in item candidates and to triangulate the proposed measurement framework.

Phase II youth focus group participants.—We used the same recruitment and inclusion criteria as described in Phase I. Phase II youth focus groups were held in a variety of settings: two residential school programs (2 groups, total $n = 18$), three high school/secondary transition programs (3 groups, total $n = 21$), and one community agency (1 group, $n = 4$) (Table 2).

Phase II youth focus group procedures.—Phase II youth focus groups used the same accessible procedures as Phase I, with one addition. In addition to making posters, youth completed a picture-based worksheet designed to elicit difficult cognitive, communication, and self-care functional tasks to ensure adequate content coverage in the item candidates.

Phase II youth focus group analysis.—The university researchers content coded all responses to identify discrete functional tasks to include in PEDI-PRO item candidates. Each response was independently coded by two research staff as a Daily Activities, Social/Cognitive, or Mobility functional task, with subcategories based on the PEDI-CAT content areas. Data that did not reference a discrete functional task were not coded. Coding discrepancies were reviewed by university researchers until consensus was reached. Because youth with DD may generate less spoken content during focus groups, we conducted a retrospective analysis of Phase I data using the same procedure. Coded Phase I and II data were combined. We examined code frequencies across domains and content areas, and reviewed responses to generate item candidates.

Results: Phase II youth focus group

Youth in focus groups across both phases described a variety of discrete tasks that supported their engagement in everyday life situations (Table 4). Examples of discrete functional tasks used to develop PEDI-PRO item candidates are shown in Table 4. Few youth mentioned discrete mobility tasks. This may be because mobility tasks are embedded in the performance of functional activities (e.g., management of toileting) and participation (e.g., grocery shopping).

Professional Focus Groups—University researchers conducted in-person (year 1) and online (year 3) focus groups with rehabilitation professionals to identify discrete tasks to include in PEDI-PRO item candidates. The youth team was not involved in data collection due to logistical constraints.

Methods

Professional focus group participants. We conducted two in-person focus groups at national conferences: the first group was specific to occupational therapists ($n = 13$) and the second group included interdisciplinary professionals (e.g., social workers, special educators; $n = 7$). Inclusion criteria were: 1) licensed professional with 6 months of

experience working with youth with DD ages 8-21, 2) experience using PROMs with youth with DD. To ensure representation from physical therapists, we conducted an online focus group with physical therapists recruited via professional networks ($n = 6$).

Professional focus group procedures and analysis.: All participants completed a worksheet to identify essential discrete functional tasks that support youth with DD's successful transition from high school to adulthood. We entered each functional task into an Excel file; we used the same content coding and analytical procedures as the Phase II youth focus groups.

Results: Professional focus groups: In comparison with youth, professionals identified more discrete tasks aligned with the Daily Activities domain and the Mobility domain (Table 4). In comparison with youth, professionals identified fewer discrete tasks aligned with the Social/Cognitive domain.

Phase III: Refining PEDI-PRO Item Candidates

The phase III objective was to create PEDI-PRO item candidates for each prioritized everyday life situation; we did this in collaboration with the youth team and with feedback from PEDI-CAT measurement experts. First, the university researchers developed item candidates based on the wording suggested by the youth team during their review of the PEDI-CAT items. We also developed items based on the discrete tasks identified by the youth team during their participation in everyday life situations and those discussed by youth during focus groups. Item wording incorporated design recommendations that can enhance the comprehension of PROM items for youth with DD [22]. Whenever possible, item candidates included words that specified the everyday life situation in which the task was occurring. For example, "pay attention to my work when my co-workers want to talk about other stuff." In addition, the university researchers developed images for each item based on the youth team's drawings.

Youth Team

The youth team provided feedback on the clarity of item candidates during group meetings. Co-occurring with item refinement, the youth team and university researchers completed cognitive interviews, as reported elsewhere [23]. Items that had poor comprehension in initial interviews were further refined with guidance from the youth team.

Expert Review

Three PEDI-CAT authors (one occupational therapist, two physical therapists) reviewed all item candidates across the 16 everyday life situations. The experts endorsed our measurement conceptual framework and provided feedback on the comprehensiveness of the item candidates. We also asked the experts to identify additional discrete mobility tasks for inclusion as item candidates, given the limited number of mobility tasks identified by youth and professionals during the focus groups. During the review, the experts noted item candidates in the everyday life situations "Going to the movies" and "Going to the library" (which received 1 and 0 priority votes, respectively, from the youth team) reflected a limited

range of performance difficulty, which could lead to poor sensitivity to detect change over time and poor discrimination among youth with varying abilities. They also determined that items in the lower priority everyday life situations “Family dinner” and “Making a snack” (1 and 0 votes, respectively) were redundant with items in other situations that were more highly prioritized by the youth team or frequently mentioned in youth focus groups: “Having my own place,” and “Cooking.” We therefore decided to discontinue research on items from these situations.

The experts also provided feedback on item quality. Items that had poor comprehension in initial cognitive interviews [23] were further refined with the assistance of the expert reviewers. The experts noted concerns with content clarity for many items associated with the everyday life situation “Working on a school project.” Poor content clarity can threaten the consistent interpretation of items across respondents. Although this situation received two youth team priority votes, youth focus group data (Table 3) suggested “Playing sports and exercising,” was more salient to youth with DD. Therefore, we prioritized “Playing sports and exercise” over the everyday life situation “Working on a school project” for future research.

Triangulation of the Proposed Measurement Conceptual Framework and Item Candidates

We triangulated the salience of the selected 11 remaining everyday life situations by coding Phase II youth focus group data for references to those situations. In Phase II youth focus groups, when youth referenced participation in an everyday life situation, 76.39% of these references could be categorized into one of the final prioritized, 11 everyday life situations (Figure 1). At the end of the item development process, we retrospectively coded each functional task or skill suggested by professionals ($n = 1145$) for alignment with PEDI-PRO item candidates in the final 11 everyday life situations. The item candidates reflected 65.65%, 67.95%, and 61.04% of the recommended Daily Activities, Social/Cognitive, and Mobility tasks, respectively. Professionals’ suggestions that were not captured by PEDI-PRO item candidates: 1) described broad performance areas rather than discrete, functional tasks (e.g., “socialization”), or 2) did not align with our 11 selected everyday life situations (e.g., “ask someone to prom”).

Discussion

We completed an iterative three stage process to develop the PEDI-PRO measurement conceptual framework and item candidates in collaboration with a team of youth with DD. Our innovative integration of participatory research and accessible data collection techniques enabled us to gather data from multiple groups of youth with DD, a population that has thus far been underrepresented in the development of PROMs. Triangulation of our results across multiple groups of youth as well as professionals increases our confidence that the proposed PEDI-PRO conceptual framework and item candidates adequately capture the construct of functional performance for youth with DD. This study also demonstrates how participatory research can be used as a methodological best practice in PROM development to ensure the quality and meaningfulness of the resulting measure [1,2,15].

Our proposed conceptual framework is unique from that of the PEDI-CAT and other currently available PROMs. Many available PROMs organize the presentation of functional items using professionally-defined categories such as “upper extremity” or “self-care” [24,25]. These professional terms help researchers define the construct of measurement and develop relevant items. However, our research suggests such terms may not have the same conceptual relevance to youth with DD. While professionals acquire a shared understanding of these concepts through formal education and training, youth with DD’s understanding of “functional performance” emerges from their lived experiences. Findings from our participatory development process suggest youth with DD embed their self-evaluation of functional performance in the context of familiar and valued activities, and do not isolate the performance of discrete tasks from the broader activity in which they are engaged. Thus, the PEDI-PRO assesses the performance of discrete Daily Activities, Social/Cognitive, and Mobility functional tasks in the context of everyday life situations. The PEDI-PRO will operationalize this framework by first allowing respondents to choose one of the 11 everyday life situations. Next, youth will respond to items that assess discrete Daily Activities, Social/Cognitive, and Mobility tasks completed during that situation.

We generated a pool of item candidates of discrete functional activities recognized as important by youth with DD and professionals. These items can be conceptualized as measuring functional performance of Daily Activities (78 items), Social/Cognitive, (65 items), Mobility (52 items) tasks. In all domains, the youth team produced unique item content, such as: “Use a self-checkout machine” (Social/Cognitive item in “Shopping”), “Tap the button I want on a touch screen” (Daily Activities item in “Using a computer”), and “Slide into a booth so someone can sit next to me” (Mobility item in “Going to a restaurant”). Functional tasks identified by the youth team may be particularly relevant to the everyday lives of youth with DD. All item candidates will require further development prior to inclusion in the fully developed PROM.

Three features of the PEDI-PRO’s conceptual framework may improve the quality of information gathered from youth with DD. First, the range of everyday life situations helps ensure the PEDI-PRO is relevant to the needs and goals of youth with DD from middle school through transition to adulthood [21]. Second, youth with DD may be more motivated and attentive when completing the PEDI-PRO when they respond to everyday life situations that are important and relevant to their everyday lives [26]. Increased motivation and attention may also facilitate youth’s self-reflection, resulting in more valid responses.

Third, embedding questions about functional activity performance in the context of everyday situations may enhance youth’s comprehension and recall, which may improve the validity of PROM responses. Research on PROMs for both youth and adults with DD has demonstrated that although these populations may have difficulty assessing their performance across contexts and time [4], they may respond more accurately to questions that specify the context of performance [4,5]. Our initial item candidates include references to objects, people, and places specific to the everyday life situations. The potential benefits of item specificity are illustrated by the youth team members’ assertions that, “it’s more natural” and, “it’s common sense.” Our initial hypothesis about the relationship between the PEDI-PRO’s conceptual framework and improved comprehension is supported by findings

from our cognitive interview study that showed youth with DD understood most items in the intended manner [23].

Limitations and Future Research

Oversampling transition-age youth with cognitive disabilities and the use of a convenience sample may limit the relevance and appropriateness of the PEDI-PRO for younger youth or youth with other disabilities. While many youth had secondary mobility impairments, only a few youth in our focus groups used mobility devices. However, two members of our youth team are wheelchair users and helped identify relevant mobility tasks. Future research should include more youth with mobility impairments, along with youth representing more diverse racial and ethnic backgrounds. Additionally, our findings may not be applicable to youth with DD outside the United States. While our qualitative analytical approach did not incorporate steps to establish trustworthiness, the involvement of the youth team throughout the process helps ensure our results reflect youth's perspectives.

Finally, although we used a voting process to distribute power in decision making, the university researchers discontinued the development of three everyday life situations for which youth voted. Although the youth team did voice agreement for this decision, they may have felt uncomfortable challenging decisions made by the university researchers [16]. This situation illustrates how power imbalances can influence decision making when the unique knowledge and expertise of youth (lived experience) and researchers (measurement expertise) leads to different conclusions about the best course of action in a research project.

The PEDI-PRO domains align with the PEDI-CAT, providing an opportunity to use the PEDI-PRO in conjunction with the PEDI-CAT to explore outcomes at the domain level from both parents' and youth's perspectives. However, we first need to empirically validate if responses to PEDI-PRO items aligned with the same functional domain, but administered across different everyday life situations, coalesce to measure a common domain. Future research should examine if PEDI-PRO domain scores obtained using our proposed measurement conceptual framework maintain unidimensionality and interpretability, as well as sufficient test-retest reliability.

Conclusion

Our iterative and participatory development process affirmed the salience of functional performance of discrete tasks to youth with DD and the professionals who support them. During their long term engagement, the youth team provided data that revealed the importance of embedding the evaluation of discrete functional tasks in valued and familiar everyday life situations; this finding was triangulated during additional focus groups with youth with DD. As a result of our PROM development activities, the PEDI-PRO's conceptual framework and item candidates are grounded in the lived experience of youth with DD.

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Figure 1.
PEDI PRO participatory design process and outcomes

Table 1.

Youth team members.

Name^a	Age at recruitment	Gender	Race/ethnicity	Disability	Activities for phase I measurement conceptual framework development
Alice	17y, 10mo	F	Caucasian	Autism	• Shopping for a gift • Making cookies • Going out to eat
Brendan	20y, 4mo	M	Caucasian	Developmental Disability	• Activities at a community college • Recording a song using iPod and posting the song to YouTube
Byron	21y, 7mo	M	African American	Anxiety/depression, Pervasive Developmental Disorder	• Shopping
Devan	18y, 1mo	F	Caucasian	Developmental Disability	• Shelving books/work • Making a sandwich at home
Jacob	16y, 9mo	M	Caucasian	Intellectual disability, Developmental Disability	• Getting dressed • Taking public transportation to go a restaurant
Marianne	15y, 10mo	F	Caucasian	Spina bifida	• Going out to eat • Calling to view and visit rental apartments
Sierra	14y, 9mo	F	Hispanic/Latina, Multiple races	Cerebral Palsy	• Doing laundry • Ordering food • Using computer at school
Tristian	17y, 5mo	M	Hispanic/Latino, Multiple races	Cornelia DeLange Syndrome, Autism, Intellectual disability	• Going to the library

^aAll youth team members and their parents/guardians chose to use real names in keeping with a participatory research approach.

Table 2.

Youth focus group participants.

Youth Focus Group Participants		
	Phase I % (n) (n = 19)	Phase II % (n) (n = 43)
Average age (range)	19.6 years (17.0-22.2 years)	19.1 years (15.9-21.8 years)
Gender (%)		
Male	47.4 (9)	46.5 (20)
Female	52.6 (10)	53.5 (23)
Race		
White, non-Hispanic	78.9 (15)	86.0 (37)
African American	5.3 (1)	7.0 (3)
Other or multiple	5.3 (1)	4.7 (2)
Missing	10.5 (2)	2.3 (1)
IEP Eligibility Categories Represented (%) ^a		
Intellectual Disability	31.6 (6)	34.9 (15)
Developmental Disability	31.6 (6)	18.6 (8)
Autism Spectrum Disorder	15.8 (3)	18.6 (8)
Multiple Disabilities	21.1 (4)	7.0 (3)
Visual Impairment	10.5 (2)	20.9 (9)
Specific Learning Disability	10.5 (2)	7.0 (3)
Orthopaedic Impairment	10.5 (2)	0.0 (0)
Speech or Language Impairment	5.3 (1)	9.3 (4)
Neurological impairment/Traumatic Brain Injury	5.3 (1)	7.0 (3)
Emotional Disturbance	5.3 (1)	2.3 (1)
Hearing Impairment	0.0 (0)	2.3 (1)
Not in school-no IEP	5.3 (1)	18.6 (8)
Intellectual Disability (%)	52.6 (10)	53.5 (23)
Missing	21.1 (4)	2.3 (1)

^aYouth may be eligible for an IEP under several disability categories. For phase I focus groups, we had validated IEP data for 16 participants. For phase II focus groups we had validated IEP data for 34 participants.

Table 3.

Phase I focus groups: Activities and related functional skills that support youth's independence at home, school, work, and the community.

Frequency Across Groups ^a	Home	Community	Work	School
5 times	Cook (7) Wash/clean (6) Hang out with friends (6) Laundry (5)	Shopping (18) Go to a professional sports game (8) Money management (6) Public transportation (5)	Be a teacher (8)	(none)
3-4 times	Have a pet (4) Shop (4) Text (4) Play music (4) Put dishes in dishwasher (3) Wash your face (3) Play Frisbee (3) Use the computer (3) Watch TV (3)	Drive (4) Go to the movies (4) Basketball (3) Biking (3) Swimming (3) Take the bus (3) Go to a restaurant (3) Use the computer (3)	Work in an office (4) Cooking (4) Baking (3) Be an auto mechanic (3) Get a college degree (3)	Graduate (4) Do school work (3) Use the computer (3)
2 times	Clean the floor Vacuum Clean my room/dorm room Take out the recycling Manage a personal care assistant Have a family Play Wii	Baseball Football Walk the dog Watch fireworks Music See friends Go on dates Go to work	Driving Take out the recycling Waitress or waiter Work at a coffee shop Cashier Work at a computer	Play kickball Hang out with a friend Play games Improve social skills Talk to my teacher Read Pack bag at locker Go on field trips Go to college Go to the cafeteria Order food in lunch line

^aNumber of times the same activity or skill was identified by focus group participants across groups. This data reduction table does not include content analysis.

Table 4. Discrete functional tasks identified by youth and professionals and resulting PEDL-PRO item candidates.

Functional Domain	Phase I & II youth focus groups ^{a,b} (n = 62)	Professional focus groups ^{a,c} (n = 26)	Related PEDL-PRO Item Candidate (Everyday life situation)
Daily Activities			
Eating and mealtime <i>Example data</i>	5.87% • Cut my own food • Cooking all my meals	9.29% • Appropriate self-feeding • Prepare basic foods • Use of utensils	• Use a knife to cut hard fruits or vegetables like apples or carrots. (Cooking)
Getting dressed <i>Example data</i>	1.79% • Pull up my hair • Wear apron and gloves	10.94% • Independent with fasteners • Change clothes for gym	• Put my hair in a ponytail. (Playing sports and exercise)
Home tasks <i>Example data</i>	15.99% • Sweep and wash the floor • Wiping down everything	12.34% • Folding clothes • Make bed	• Wipe the counter or table. (Working at a job)
Keeping clean <i>Example data</i>	5.06% • Go the lady's room on my own • If it gets dirty on me, I wash my hands	10.45% • Shaving • Bathing/showering • Brushing teeth	• Wash my body. (Getting ready in the morning)
Other <i>Example data</i>	0.33% Punch in my time card.	0.00%	
Social/Cognitive			
Communication <i>Example data</i>	15.50% • Ask ... someone who works at the store can tell you how much it costs • Tell [the doctor] what is wrong	3.78% • Effectively communicate any health needs to appropriate people • Use cell phone to call, text	• Tell the doctor when I am confused and explain what is confusing me. (Going to the doctor)
Everyday cognition <i>Example data</i>	34.89% • Go the right bathroom • Follow a recipe without help	5.51% • Solving problems • Looking things up on the internet	• Find the bathroom in a new store. (Shopping)
Interaction <i>Example data</i>	7.34% • Always be polite...they're not gonna go back to a rude waitresses serving • Say hi to people and not have too long a conversation	6.74% • Apologize • Reading social cues • Gain attention appropriately	• Tell a landlord when they make a mistake. (Having my own place)
Self-regulation <i>Example data</i>	5.22% • I concentrate on what I'm doing and don't get distracted	2.55% • Cope with emotions	• Pay attention to my work when my co-workers want to talk about other stuff. (Working at a job)

Functional Domain	Phase I & II youth focus groups ^{a,b} (n = 62)	Professional focus groups ^{a,c} (n = 26)	Related PEDI-PRO Item Candidate (Everyday life situation)
Mobility			
Basic movements & transfers <i>Example data</i>	0.65% • Getting out of bed • Pick things up	10.85% • In and out of tub/shower • Sitting upright	• Sit up straight with good posture for 10 minutes when I am using the computer. (Using a computer)
Standing and walking <i>Example data</i>	1.47% • Take the [grocery carts] from outside • Carry the food	12.25% • Walking around tables in mall food court • Carries heavy items from car to house	• Carry a full drink to the table. • (School lunch)
Steps & inclines <i>Example data</i>	0.16% • Bringing down the laundry	6.50% • Go up curb or incline carrying 3.5, 10 lbs object • On and off trains, buses	• Climb up and down the steps of a bus. (Shopping)
Running & playing <i>Example data</i>	1.30% • Swimming • Run on the grass • Biking	2.06% • Dynamic balance to run/walk for leisure play/games/sports of choice	• Ride a bike. (Hanging out with friends)

^aPercentages represent the percent of focus group data aligned with each functional domain content area.

^b3.43% of youth-generated data was not codable because no functional tasks were mentioned.

^c9.74% of professional-generated data was not codable; most of this data referenced broad concepts, such as “classroom routine,” “executive functioning,” “complete tasks at work,” or “peer pressure”.