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Puerto Rican understandings of child disability: methods for the cultural validation of standardized measures of child health

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Abstract

Validating the cultural context of health is important for obtaining accurate and useful information from standardized measures of child health adapted for cross-cultural applications. This paper describes the application of ethnographic triangulation for cultural validation of a measure of childhood disability, the Pediatric Evaluation of Disability Inventory (PEDI) for use with children living in Puerto Rico. The key concepts include macro-level forces such as geography, demography, and economics, specific activities children performed and their key social interactions, beliefs, attitudes, emotions, and patterns of behavior surrounding independence in children and childhood disability, as well as the definition of childhood disability. Methods utilize principal components analysis to establish the validity of cultural concepts and multiple regression analysis to identify intracultural variation. Findings suggest culturally specific modifications to the PEDI, provide contextual information for informed interpretation of test scores, and point to the need to re-standardize normative values for use with Puerto Rican children. Without this type of information, Puerto Rican children may appear more disabled than expected for their level of impairment or not to be making improvements in functional status. The methods also allow for cultural boundaries to be quantitatively established, rather than presupposed. © 2002 Elsevier Science Ltd. All rights reserved.

Keywords: Puerto Rico; Disability; Standardized instruments; Culture; Validity; PEDI

Introduction

This paper describes the application of ethnographic triangulation for the cultural validation of a measure of childhood disability widely used by rehabilitation professionals, the Pediatric Evaluation of Disability Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992). Like other standardized instruments such as the Dartmouth COOP Function Charts/WON-CA, the EuroQol, the Nottingham Health Profile, the

SF-36 Health Survey, the Sickness Impact Profile, and the WHO Quality of Life Assessment (see Wasson et al., 1992; Anderson, Aaronson, & Wilkin, 1995; Tarlov, 1997; Coons, Rao, Keininger, & Hays, 2000), the PEDI measures the impact of disease and health intervention on quality of life. Potentially, these instruments provide critical information that health care professionals, policy makers, and international organizations can use to evaluate the efficacy of interventions, the impact of public health programs, and public health policy. Cultural diversity, found increasingly within as well as between national populations, means that the validity of standardized instruments developed for one population cannot however be assumed for others (AERA, APA, & NCME, 1985).

Adapting existing health assessment tools for use with people from different ethnic groups or from different parts of the world saves valuable resources, because

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instrument development costs much time and money. It also makes possible global comparative studies and the study of people with rare conditions. To this end, many researchers have sought to adapt and validate standardized measures of health for cross-cultural application (for examples see Gonzalez, Stewart, Ritter, & Lorig, 1995; Escalante et al., 1996; Arguedas, Andersson-Gare, Fath, & Porras, 1997; Badia, Podzamczer, Garcia, Lopez, & Consiglio, 1999; Fantini et al., 1995; Goycochea-Robles, Garduno-Espinosa, Vilchis-Guizar, Ortiz-Alvarez, & Burgos-Vargas, 1997). The PEDI, as well, has been translated for use in research with children with osteogenesis imperfecta in the Netherlands (Engelbert, van der Graaf, van Empelen, Beerner, & Helders (1997). Characteristically, however, these efforts establish the psychometric properties of an instrument and provide little or no information on the culture that shapes health behavior and gives meaning to test scores. We propose that proper application of standardized instruments and interpretation of test scores in cross-cultural contexts requires cultural validation of the kind we describe here.

The recurrent patterns of behavior that constitute culture shape the individual behavior and influence health because they establish environmental parameters to which individuals must respond. Dressler and Bindon (2000), for example, demonstrate effects on hypertension that originate most immediately in deprivation relative to regionally and historically specific cultural models of material well-being and the behavioral patterns they rationalize. The theoretical framework of childhood disability employed by the authors of the PEDI recognizes the importance of culture for understanding and working with childhood disability. The PEDI is based on Nagi's model of disability (Nagi, 1991), which defines disability by reference to the ability of people to function in their cultural environment, not by reference to specific diseases or pathological conditions. Cultures shape the dimensions and severity of particular conditions or diseases through the socially constructed meaning of the condition or impairment to the individual, to other social actors in the individual's life (for children this would mean their parents, siblings, teachers, therapists, and friends), and the presence of barriers to independence within the physical and cultural environment. For example, the birth of a congenitally deaf child may be viewed more positively by a couple who are also deaf or have a large network of friends who are also hearing-impaired, than by a couple who has no experience with the deaf community or lives in a community that is not supportive of people who are hearing-impaired (Groce, 1985). Often, attitudes, perceptions, and support systems present or not present in families and communities impede or facilitate the ability of children and adults with disabilities to reach their maximum potential (Albrecht & Higgins, 1977; Asch, 1989; Edgerton, 1988; Ferguson, 1987).

Systematic attempts to specify and measure cultures and their effects on children have evolved out of the integrated behavioral science approach developed at Yale's Institute of Human Relations in the US during the 1930s and 1940s, and the work of the Whittings and their colleagues in the 1950s, 1960s, and 1970s (e.g., Whiting et al., 1966). More recently, students of the Whittings have developed increasingly specific and sophisticated models of the environmental properties of culture and of culture-individual interaction (e.g., Harkness & Super, 1994; Super & Harkness, 1980; Weisner, 1984; Worthman, 1994). Super and Harkness's "developmental niche" conceptualizes "... the immediacy of cultural forces in the environment of an individual" (Super and Harkness's, 1999, p. 284) and consists of three subsystems: (1) the physical and social settings of the child's daily life; (2) the culturally regulated customs of child care and child rearing; and (3) the psychology of the caretakers. The latter consist of the emotional orientations and cognitive models for understanding the first two subsystems.

This ecocultural framework or "developmental niche" has proved useful in the study of family adaptation to children with developmental delays. Gallimore, Weisner, Kaufman, and Bernheimer (1989) describe how families socially construct their child's disability, and propose that for these families whether "ecocultural features are positive or negative [for these families] is influenced by family constructed themes." An assessment tool of family adaptation based on an ecocultural model provides, in comparison to traditional measures, different information about families—primarily, how families reorganize their lives based on their children's disabling condition (Nihira, Weisner, & Bernheimer, 1994). Without such information on families' understandings, emotions, attitudes, and patterns of behavior concerning their children with developmental delays, we cannot optimally assess, diagnose, design, or implement effective interventions (e.g., see Pachter & Harwood, 1996).

This paper describes procedures for the construct validation of developmental niche cultures. We illustrate these procedures with the steps taken to validate the PEDI for children living in Puerto Rico (Gannotti, Handwerker, Groce, & Cruz, 2001; Gannotti & Cruz, 2001). The PEDI was developed and standardized in the continental United States. It is designed to measure childhood functional skill capability and level of disability for children between the ages of six months and seven and a half years. It consists of two scales: the *Functional Skills* and the *Caregiver Assistance Scales*. The Functional Skills Scale measures a child's ability to perform 197 skills in the areas of self-care, mobility, and social function. The Caregiver Assistance Scale measures a child's level of independence in the same three domains. Although the test is based on a universal principle (as children age, they can perform more skills

with less assistance), the skills evaluated and the timing and pattern of skill mastery reflect the developmental niche culture of children living in mainland United States (Table 1).

We (1) outline procedures for an ethnographic triangulation of the construct validation of cultures, which integrates both text and numerical data and modes of analysis; (2) describe and document the culture that forms the behavioral ecosystem bearing on childhood disability; and (3) evaluate the correspondence between that culture and the instrument—and, by implication, the culture for which the instrument was built and on which it was normed. We show that the PEDI exhibits cultural biases in test design and item selection. This finding suggests culturally specific modifications to the PEDI, provides for the proper interpretation of test scores, and points to the need to

re-standardize normative values. We conclude by proposing that cultural validation procedures become a standard addition to the procedures that assess the psychometric properties of standardized measures of child health.

Methods

Construct validation of cultures

Discordance between cultures and the social identities of the cultural participants (see Handwerker, 1997a, 1999, 2001; Handwerker, in press) validates Keesing's (1994) claim that culture is not bounded in ways many people have long assumed. "Igbo," "Chinese," or "African American" may not accurately designate the pertinent cultural group. The pertinent cultural group might correspond instead to gender, or age, or to life experiences, the significance of which we have not yet recognized. Discordance between cultures and the social identities of the cultural participants also highlights the conceptual error implicit in otherwise laudable admonitions to look at similarities as well as differences between and among families of different cultural groups. Without explicit construct validation of the cultures, one cannot know which groups to compare. If one divides one's data by identity (ethnicity, class, gender, age, etc.), counts the responses for each, and compares the results, one imposes cultural differences by assumption, not evidence. To avoid this error, one must ask "who shares what with whom" and look for similarities and differences among all informants. Appropriate forms of multiple regression can then test hypotheses bearing on plausible antecedent life experiences that produced observable intracultural or intercultural variation.

Data collection techniques

Ethnographic triangulation uses multiple lines of evidence from informal, semi-structured and structured interviews and observations to describe and to evaluate the construct validity of cultures. It uses data collected from relatively small, carefully selected samples of informants that take advantage of the case dependence integral to cultural data (Handwerker, 2001; Handwerker & Wozniak, 1997). Its sampling frames are designed to search out cultural variation that may reflect specific forms of variation in life experiences that may vary with gender, age, or class. Sample size varies primarily with the number of contrasts built into the sampling frame and the degree of agreement among informants (e.g., Handwerker & Wozniak, 1997; Weller, 1987). To detect cultural variation among parents, teachers, and clinicians, for example, we would select a minimum of 12 informants, four from each group.

Table 1
Skills used by the PEDI to evaluate disability and function

Self-care skills

Eating different food textures
Use of utensils
Use of drinking containers
Tooth brushing
Hair brushing
Nose care
Hand washing
Washing body and face
Pullover/front opening garment
Shoes/socks
Toileting tasks

Mobility skills

Toilet transfers
Chair/wheelchair transfers
Car transfers
Bed mobility/transfers
Method of indoor locomotion
Pulls/carries objects
Distance/speed outdoors
Outdoor surfaces
Upstairs
Downstairs

Social Skills

Comprehension of word meanings
Comprehension of sentence complexity
Functional use of expressive communication
Complexity of expressive communication
Problem resolution
Social interactive play
Peer interactive play
Self-information
Time orientation
Household chores
Community protection

Text data collected through informal observations and interviews along with historical data, reviews of newspapers, magazines, and television programs provided us insight into the assumptions that people use to understand and respond to children and children with disabilities, the components of Puerto Rican children's developmental niche, and how those components are organized into behavioral ecosystems. Once informal interviews failed to turn up new questions, corrections to old questions, or domain boundaries that had remained hidden, we used semi-structured interviews to reach larger numbers of informants efficiently so we could find the limits of variation for specific cultural domains. Structured interviews provided the data necessary for making the comparisons among informants necessary for the construct validation of cultures.

Data analysis techniques

Construct validation of cultures employs the same tools as those used for the construct validation of standardized measures of child health. Measurement of multidimensional constructs like "disability" requires specific observations of a set of items, each of which constitutes an independent and imperfect measure of the otherwise unseen, underlying variable. As Campbell and Fiske (1959) point out, items that measure the same theoretical construct should correlate highly. Items that measure a second construct should not correlate as highly with the items that measure the first. If there exists such a variable as *disability*, for example, and if the items one chooses measure that variable, one will see it as a large intersection shared by the entire set of items, any one of which measures *disability* imperfectly.

Standard construct validation of standardized measures of child health use factor or principal components analysis (e.g., Rummel, 1970) to test directly the hypothesis that a specific set of scale items constitutes an independent set of imperfect measurements of one and only one otherwise unseen, underlying variable. Principal components analysis constructs a small set of variables (*factors* or *principal components*) from additive combinations of existing similarities among variables. Each factor thus identifies the existence of otherwise unseen variables that lie at the intersection of observed similarities among variables measured. The size of the intersection indicates the importance of the factor. Factor *loadings* (Pearson's coefficients) measure the size of the intersection. The square of a loading (r^2) indicates how much variance a specific item shares with the unseen variable identified by each factor. Important measures of this unseen variable show loadings at or above 0.500 (25% shared variance). The sum of squared loadings for a factor (its *eigenvalue*) indicates how much variation *all* the cases or variables share with a factor. A factor's eigenvalue divided by the sum of eigenvalues for

all factors indicates the overall size of the shared intersection identified by the factor.

The first factor or principal component identifies the largest shared intersection among a set of variables. The second factor accounts for the largest shared intersection that remains. Subsequent factors account for the largest shared intersection among the variance unaccounted for by previously extracted factors.

Principal components analysis yields one factor for every variable. Ten items will form a 10×10 similarity matrix and will yield ten factors, for example. Evidence of a *single* valid factor consists of: (1) a first factor with an intersection that accounts for 50% of the variance in the matrix (or more); (2) a sharp scree fall between the eigenvalue for the first and second factor;¹ (3) the eigenvalue of the second factor lies at the top of the scree; (4) no (or inconsequentially small) negative loadings exist on factor 1, and no (or inconsequentially small numbers of) high (± 0.50) loadings on factor 2.²

Construct validation of cultures constitutes an extension of Romney's cultural consensus procedures (e.g., Romney, Weller, & Batchelder, 1986), and differs from the construct validation of multidimensional variables only in that we analyze transposed matrices to take advantage of the unique point of view that ethnography offers—its focus on similarities and differences among informants rather than among variables (e.g., Handwerker, 2002). Principal components analysis and the minimum residuals analysis employed in consensus analysis procedures yield equivalent output. However, only the software Anthropac (Bogartti, 1992) makes Minres analysis available commercially; principal components analysis is available in all the major statistical software packages, like SAS, SPSS, and SYSTAT.

¹ Scree refers to the jumble of rocks and soil that accumulates at the bottom of cliffs. A scree plot shows the size of the eigenvalues for all factors beginning with factor 1. Just by chance, sample items may show great similarity. Factor analysis of matrices filled with random data will find some eigenvalues over 1.0 and some high loadings just by chance. Matrices that contain no real factors will generate random distributions of eigenvalues and loadings. Half the eigenvalues will be over 1.00, half will be under 1.00, and you will see no perceptible scree. Matrices that contain one real factor will exhibit a dramatic scree fall between the first and second eigenvalues; the first eigenvalue will be approximately 3 or more times larger than the second.

² This last condition gives important diagnostic information. As Rummel notes (1970, p. 373), because the procedure fits the first factor to the data to account for the maximum variance, when there exist two independent clusters of interrelated variables, factor 1 may be located between them. All variables may load highly on factor 1. However, the variables will also load highly on factor 2, and the variables that comprise each independent cluster will exhibit different signs on factor 2.

We learned the content of Puerto Rican children's developmental niche culture from informal and semi-structured interviews and observations. We assessed the construct validity of that culture with principal components analysis of data from a series of structured interviews that examined specific dimensions of the culture. We measured the similarity among our informants' responses with simple matching coefficients. The size of the similarity matrices subjected to a principal components analysis corresponded with the number of informants for specific issues. Our largest sample of 391 people, for example, produced a 391×391 similarity matrix for analysis. Factor loadings produced from these analyses constituted explicit measures of intracultural variation. Multiple regression models that used factor loadings as the dependent variable tested for plausible antecedents of intracultural variation. The Spearman–Brown Prophecy formula applied to the average factor loading yielded reliability and validity coefficients (Weller, 1987). All tests reported below are consistent with the existence of a single Puerto Rican developmental niche culture. Intracultural variation is minor and not explained by reference to gender, age, education, rural or urban residence, or time spent on the US mainland. As part of the triangulation process, we reviewed findings from these analyses with our key informants in informal interviews.

Participants

Data for the present study come from 12 months of research in Puerto Rico between June 1996 and June 1997. We employed sampling frames designed to search out variation in cultural models and behavioral patterns bearing on childhood function and disability in Puerto Rico children's developmental niche. Specifically, we interviewed parents, other caregivers, teachers, and clinicians of children with and without disabilities who were from different regions of the island, of different socio-economic status, of religious and non-religious backgrounds, of different ages and gender, and who had different degrees of exposure to the mainland United States. When data analysis indicated that people with certain characteristics may have different cultural models of disability, we expanded our sample to test for these potential sources variation. For example, initial analyses raised the possibility that age, gender, or time spent in the United States might contribute to cultural variability. By increasing our sample size and targeting these informant characteristics, we gathered a sample large enough to test for effects from these life-experience markers.

The primary research site for the study was the Centro Espina Bifida (ESPIBI), a rehabilitation center in Mayagüez, Puerto Rico. However, fieldwork was performed all over the island in a variety of settings—at

the Medical Sciences Campus in San Juan, Puerto Rico, at the pediatric hospitals in Arecibo and Ponce, and in more remote schools and homes in Jayuya, San German, and Las Marías. Our primary sample consisted of 44 children with and without disabilities between 6 months and 8 yr of age recruited from the staff and patients at Centro ESIPBI. We matched 22 children with disabilities with 22 children who were developing in a typical manner on age, gender, parental education level, occupation of the father, and geographic region. It was from observations, and informal and semi-structured interviews of these children, their parents, other caregivers, clinicians, and teachers that we developed structured questions concerning the disability-related dimensions of Puerto Rican children's developmental niche. The specific characteristics of all participants in the study are described in detail elsewhere (Gannotti & Cruz, 2001; Gannotti et al., 2001).

Important components of the physical and cultural environment included macro-level forces such as geography, demography, and economics. These factors influenced how, where, and with whom children with and without disabilities spent their days and played a role in risk factors and prevalence of childhood disability, the type, quality and availability of rehabilitation services, and physical barriers to independence. Additional components of the physical and cultural environment included information on specific activities children performed and their key social interactions on a daily basis. Information was gathered by review of historical information, information from newspapers, magazines, television programs, and interviews with health officials and program directors. Additional information was gathered by observations and informal interviews with children, families, therapists, and teachers. A structured questionnaire was adapted to evaluate the content of the Spanish translation of the PEDI (Feldman, Haley, & Coryell, 1990; Gannotti & Cruz, 2001). Participants for structured questions concerning the specific activities of children included expert rehabilitation professionals from the island of Puerto Rico ($N = 15$) (Gannotti & Cruz, 2001).

Important customs of childcare included expectations of caregivers for children to perform functional skills independently and the beliefs, attitudes, emotions, and patterns of behavior surrounding independence in daily activities by children of different ages. In addition to observations of the children in our primary sample, data was collected from a large number of people with a structured questionnaire. Participants for the structured questions concerning these aspects of childrearing included people recruited from all over the island of different ages, educational status, gender, and time spent in the United States ($N = 391$) (Gannotti et al., 2001).

Questions and observations bearing on parental emotional orientations and cultural models provided

data on the psychology of the parent and yielded the definition of disability, importance of independence in activities of daily living for children with disabilities to their parents, and the beliefs, attitudes, emotions, and patterns of behavior surrounding interactions with children with disabilities. Observations and informal interviews with the children, families, teachers, and therapists in our primary sample provided the basis for structured questions. Participants for structured questions concerning these aspects of childhood disability included parents of children with disabilities, teachers, and members of the community from different parts of the island ($N = 67$; $N = 218$) (Gannotti & Cruz, 2001; Gannotti et al., 2001).

Results

The physical and cultural environment

Geography, demography, and economic factors shaped parental interactions with children and played a role in risk factors for disabling conditions. The 35-mile by 100-mile island is one of the most densely populated regions in the United States with over 3.5 million people (1000 people per square mile), the majority living in one of the island's four metropolitan areas. The island's terrain varies from steep mountainous areas and rainforests to desert plains, but a large portion of the island's interior is mountainous. Although Puerto Rico is one of the more industrialized and wealthy islands in the Caribbean, its inhabitants still earn considerably less than their mainland counterparts, and many live in poverty (Rivera-Batiz & Santiago, 1996). The island's economy is based on pharmaceuticals, sugar, rum, coffee, and tourism, and its commonwealth status provides access to the United States's market for drug traffickers from Latin America. In addition, the island's rates of crime, violence, and drug abuse are among the highest in the nation (Rivera-Batiz & Santiago, 1996). Rates of domestic violence, child abuse, and mental illness are also significantly higher than those on the mainland (Santiago-Borrero & Valcarcel, 1994). Public health problems faced by Puerto Rican children include high rates of acquired immunodeficiency syndrome (AIDS), congenital diseases, neural tube defects, poor nutrition, obesity, diabetes, asthma, and low birth weight (Martorell, Mendoza, Baisden, & Pawson, 1994; Santiago-Borrero & Valcarcel, 1994; Zorrilla, Diaz, Romaguera, & Martin, 1994).

Women—mothers, grandmothers, aunts, cousins, and nieces—provide the primary care for children in Puerto Rico. In the Caribbean, women play important roles in both household and in public domains (Berleant-Schiller & Maurer, 1993). In Puerto Rico, the high number of female heads of household combined

with high rates of teenage pregnancy create a dependency on female members of the extended family for childcare (Coll, 1989; Santiago-Borrero & Valcarcel, 1994; Steward et al., 1956). Because of the importance of the role of motherhood for women, women find a source of social recognition in perceptions of how well their children are raised (Harwood, Miller, & Irizarry, 1995; Besson, 1993; Coll, 1989).

Although Puerto Rico is mandated by the United States Federal Government to provide educational and rehabilitation services to infants, toddlers, and children with disabilities by the Individuals with Disabilities Education Act, the island has a shortage of qualified professionals, accessible buildings, equipment, and transportation (Millan Pabon, 1996; Mulero & Font, 1997). Likewise, services for adults with disabilities are not adequate, and there is a shortage of appropriate vocational rehabilitation programs and opportunities for adults with disabilities (McCahill, 1971; Rivera, 1983; McLaughlin, 1986). The mountainous roads, steep terrain, lack of sidewalks in many areas, lack of ramps into many public buildings, and heavy traffic pose formidable barriers to people with mobility impairments. Adaptive equipment, such as walkers, braces, wheelchairs, or computers for communication are available for purchase in Puerto Rico. However, the cost of this equipment is often prohibitive due to a Federal Medicare cap on durable medical equipment to Puerto Rico at the time of the study, which is an important consideration in the capability of children with disabilities. These factors all contribute to the fact that there are a large number of children with severe mobility impairments who receive home schooling and rarely leave their homes rather than attend school. (Gannotti et al., in press).

Most houses in Puerto Rico are built from cement blocks with tiled floors. Many perch on hillsides or at the bottom of hills. The interior design of the homes may include doorways, bathrooms, and hallways that do not accommodate the width of a wheelchair (Gannotti & Cruz, 2001), although the “ducha” (shower) in many bathrooms is more accessible than a bathtub. Again, the location and designs of many homes make physical independence difficult for children who need to use a wheelchair to move around. These children may never have the opportunity to learn transferring onto the toilet or bed, or to learn to propel themselves in or outside of the house.

Observations of children with and without disabilities in their homes, schools, and communities revealed that the daily activities of these children did, in fact, include the items included on the PEDI. Differences did exist in how and when children performed these activities. For example, use of a fork by children varied greatly. It is customary to eat with a spoon on the island, and it was not uncommon for children of any age, as well as adults,

to use spoons to eat all or any of their meals. Moreover, children in kindergartens received spoons to eat their lunches; forks were not provided at this age. The ability for children to solve problems without parental assistance was also of interest. Children at various ages often times would have difficulty waiting for help when they had a problem (e.g., a lost toy, not being able to get the television to work) because parents characteristically provided them with immediate assistance to avoid emotional upsets. Many children younger than 8 yr of age had never had the opportunity to perform chores independently. Parents did not expect independent performance; indeed, parental behavior taught dependence. Additionally, many children did not know the address of their home. This is because homes were traditionally organized by neighborhoods or streets, not addresses. Addresses have only recently become important because of the postal system. However, children were able to state their neighborhood and phone number.

Fifteen native Puerto Ricans who worked in academic and clinical centers involved in the training of rehabilitation professionals and the development of programs for children with disabilities in Puerto Rico responded to a structured questionnaire concerning the items included on the Spanish translation of the PEDI and its characteristics. Experts rated, on a scale of one to five (five being excellent) the items with regard to the following: (1) the ability of the Spanish translation of the PEDI to measure function and disability for children living in Puerto Rico; (2) comprehensiveness of item sample for these children; (3) appropriateness of the measurement dimensions; (4) ability to provide a meaningful description of function; (5) ability to detect changes in function; (6) feasibility of the Spanish translation of the PEDI to be used as parent report; and (7) the feasibility of this test to be used by therapist/educators in Puerto Rico (Feldman et al. (1990); Gannotti & Cruz, 2001) Principal components analysis revealed a single cultural agreement, that these experts believed the items on the PEDI were appropriate and meaningful for use in Puerto Rico (*ratio of the first factor eigenvalue to the second was 5.14, explaining 92% of the variance; average level of agreement 0.80 (SD 0.22); reliability=0.96; validity=0.96; multiple regression test for intracultural variation stemming from informant variation in age, education, gender, and rural or urban residence yielded an F-ratio of 0.559, P=0.673*).

Childcare customs

In informal interviews and observations, Puerto Rican parents, caregivers, teachers, and therapists, expected that children should be dependent on their parents for many of the skills on the PEDI until much later than seven and a half years of age—the ceiling age of the

PEDI—especially for certain activities. A sample of 391 people from different parts of the island were asked to report the ages they expected children to be able to perform these activities. Principal components analysis revealed a single cultural agreement among these people which identified *later* expectations for use of a fork, performance of chores, and independence in car transfers and *similar* expectations as compared to the normative data of the PEDI for (1) stop drinking from a bottle, (2) drink from a glass, (3) require spoon-feeding, (4) wash their body, (5) dry their body, (6) perform toileting hygiene, (7) climb stairs, (8) wait for help, and (9) stop using diapers (*first factor eigenvalue 4.5 times larger than factor two, explaining 65% of the variance, average loading 0.80 (SD 0.10); reliability= 0.95, validity=0.97; multiple regression test for intracultural variation stemming from informant variation in age, education, gender, time spent in the US mainland, and rural or urban residence yielded an F-ratio of 1.529, P=0.187*).

Customary practices included the use of a bottle for children between three and five years of age when out of the house to prevent spills on clothing or for children five, seven, or eight years of age or older to have a bottle at night to make them feel special. Parents reported that they were sure that their child could perform bathing and grooming skills independently, but they rarely gave the child an opportunity, because they wanted their children to look their best when they went out in public. Parents reported limiting children to playing inside the house, on locked, enclosed porches, or under close supervision in parks because of dangers such as strangers or illnesses from rain, sweat, falling down hills, or microbes in the dirt. Small children were rarely placed on the floor where they could harm themselves by hitting their head or teeth or become ill from germs. Instead, they were routinely kept in a car seat, their parent's arms, a high chair, or a playpen. Parents reported avoiding disciplining their children and taking measures to prevent their child from crying (e.g., giving them what they want, doing difficult tasks for them), to make sure their children felt loved. The consistency of these practices were confirmed with a principal components analysis of a sample of 391 people throughout the island (*first factor eigenvalue=81 [5.3 times larger than factor 2, explained 76.3% of informant variance]; average factor loading=0.77 [SD=0.22]; reliability=0.97; validity=0.95*).

Explanations for these practices and expectations revealed the following themes: interdependence of children and parents, *añoñar* (pampering or nurturing behaviors), *sobre protectiva* or *sobreprotección* (over-protectiveness), and the importance of the social demeanor and appearance of children. The emphasis on the interdependency of children and adults with prolonged assistance with activities of daily living, the

promotion of smooth, pleasant interactions, and the importance of the appearance of children are rooted in the values of *familialism* and *allocentrism*, which emphasize family and group relationships and ties. Caregivers explained, “You want your children to be able to do things for themselves, but you want them to be dependent on you.”

Psychology of the parents

Informal interviews and observations with the children, parents, teachers, and therapists included in our primary sample included questions like: (1) what are the types of activities that children do on a daily basis, who helps them, and how much? (2) who are the children that are considered disabled? (3) what are the types of things that make them different from other children, what types of activities do they do, who helps them and how much? Caregivers were asked to list the activities children perform and, for each, how it is performed, if it is performed independently or with assistance of what kind, and in what circumstances the activity might be performed differently. Observations were compared to the reports given by the caregivers. These observations and interviews also elicited information on the key social actors in children’s lives and the relationships through which Puerto Rican children and adults forge their understanding of disability or its absence. The distinguishing attribute of children with disabilities was the inability to perform usual activities. Usually, but not always, adults linked this inability to a medical condition like spinal bifida or Down’s Syndrome.

We asked 67 parents of children with disabilities to evaluate whether or 32 daily activities generated from the sub-categories of the PEDI were important childhood activities for performance in a regular classroom, playing with children their own age, or for not creating more work than expected for their parents. Informants were recruited at a pediatric disability clinic at Centro Medico, San Juan, Puerto Rico. Principal components analysis revealed a single cultural agreement, that all of the skills used by the PEDI to evaluate function and disability were **important** to respondents (*ratio of the first factor eigenvalue to the second was 73.7, 97.5% explained variance; average level of agreement 0.93 (SD 0.098); reliability coefficient 0.96; validity coefficient 0.98; multiple regression test for intra-cultural variation stemming from informant variation in age, education, gender, and rural or urban residence yielded an F-ratio of 0.397, P=0.810*).

Reoccurring sentiments present in the unstructured interviews of families, teachers, and therapists regarding children with disabilities included *delicado* (delicate or fragile), *apegado* (close), *ay bendito* (sympathy) and *aguantar* (endure). The perception that children with disabilities are fragile and can die easily reinforced the

belief that they must be kept very clean, be protected from illness or emotional upsets, and be granted special privileges. For example, some people felt that spending the entire day in school was too difficult for children with disabilities, that they would become too tired or exposed to illnesses, would not be cared for properly, or that they would be hurt by others. Many respondents stated, “Puerto Ricans have too much *ay bendito* for children with disabilities. We feel so much sympathy for them, we don’t want them to have to do difficult tasks.” This was evident in the fact that although many parents of children with disabilities desired that their children learned functional skills in rehabilitation sessions, at home they felt too much sympathy to have the child try things independently.

To confirm the consistency of these themes in the larger population, a group of parents, teachers, and members of the general community (Total $N = 218$) were asked a series of structured questions regarding perceptions of childhood disability. Respondents in the general community ($N = 79$) believed that children with disabilities are a gift from God, who have a greater risk for more frequent, severe, and complicated illnesses, a greater likelihood of dying, need care their entire life, have more difficulty attending school because of lack of mobility, understanding, speech, and resistance to illness, can grow up to be productive adults with jobs and families, and need protection from illness and prejudice, besides disabilities that run in the family (*first factor eigenvalue 7.7 times larger than factor two, 82% explained variance; average factor loading 0.74 (SD 0.14); 0.90 reliability; 0.98 validity; multiple regression test for intracultural variation stemming from informant variation in age, education, gender, time spent in the US mainland, and rural or urban residence yielded an F-ratio of 0.865, P = 0.509*). Teachers ($N = 79$) believed that children with disabilities get more tired than other children and it is difficult for them to spend the entire day in school, that they get hurt more easily and require special attention, they have difficulty attending school because of lack of mobility, understanding, speech, and resistance to illness, and that these children end up staying in the house with their parents and do not have jobs after graduation from high school (*first factor eigenvalue 12.4 times greater than factor two, 87% explained variance; average factor loading 0.79 (SD 0.14); 0.90 reliability, 0.95 validity; multiple regression test for intracultural variation stemming from informant variation in age, education, gender, time as a teacher, and public or private school yielded an F-ratio of 1.374, P=.248*). Parents of children with disabilities ($N = 60$) agreed it was important for their children to use their braces and do their exercises, to be independent in activities of daily living, to be very attached to them, to have special opportunities and privileges, and that it was important for them as caregivers to look for treatments

to make their children as independent as possible (*first factor eigenvalue 15.5 times larger than factor two; 90%, explained variance; average factor loading 0.88 (SD 0.10); 0.92 reliability; 0.96 validity; multiple regression test for intracultural variation stemming from informant variation in age, education, gender, time spent in the US mainland, and whether they worked outside of the home yielded an F-ratio of 1.011, $P=0.410$*).

A conventional analysis of the psychometric properties of the Puerto Rican Spanish version of the PEDI confirmed its content and construct validity and reliability, and is described in detail elsewhere (see Gannotti & Cruz, 2001). The 44 children in our primary sample (22 with disabilities and 22 without, matched on age, gender, socio-economic status and region) were evaluated with the Spanish translation of the PEDI. Principal components analysis confirmed the items on the test measured valid constructs and paired *t*-tests confirmed that the test distinguished between children with disabilities and those without.

Our findings concerning Puerto Rican children's developmental niche, however, suggests culturally specific modifications to the PEDI, provides contextual information for informed interpretation of test scores, and points to the need to re-standardize normative values. For example, on the Functional Skills Scale, the ability of a child to state their address should be modified to reflect the limited use of addresses in some areas of the island (e.g., accept the knowledge of telephone number as equivalent). Similarly, the ability to perform a transfer in and out of the bathtub should be modified to reflect the limited use of bathtubs in some areas of the island (e.g., accept the ability to step over the 4-in threshold of the "ducha" as a tub transfer).

Moreover, for a child dependent on a wheelchair for mobility, evaluation of the ability to independently propel themselves inside or outside of the home must consider the fact that the home may not be wheelchair-accessible nor may the outside because of the steep mountainous terrain, lack of sidewalks, and traffic. Although children may never propel themselves in their homes and in their yards, test administrators should consider if that they can propel themselves in a school room, mall, or at a park.

Likewise, many children may have the capability to play unsupervised in their neighborhoods and community or cross the street, but did not, or were not allowed to, because the island's high crime rate, the dense traffic, and the high rates of drug abuse/trafficking made it unsafe. Test administrators should consider the capability of these children given a less hostile environment. Another real consideration is the unavailability of adaptive equipment to enhance and promote function and architectural barriers to independence. A child may be unable to perform toilet transfers because the

wheelchair does not fit into the bathroom and/or the toilet has no rails.

The capabilities and performance of children with disabilities need to be evaluated by reference to their peers. Our findings show that in Puerto Rican children's developmental niche, parental expectations and child care customs may lead to the mastery of some skills at later ages in comparison to the mainland US normative values used to standardize the PEDI. In our sample of children without disabilities, none of the children matched the normal model of item mastery, and many were more than two SD below the mean (Gannotti & Cruz, 2001). Application of these normative values to the PEDI test scores of Puerto Rican children will make a child appear more disabled than he/she actually is, will suggest a functional deficit that does not exist. The value Puerto Rican parents and other caregivers place on the interdependence of children and parents, *añoñar* (pampering or nurturing behaviors), and *sobre protectora* (overprotectiveness) means that families may not expect that their disabled child will or can or should perform certain functional activities or may have never given him/her the chance. The PEDI scores of Puerto Rican children with disabilities may be lower than expected, given the severity of their impairments.

Certainly, one should expect differences in the meaning of PEDI test scores for each individual child and family, and in which skills are important to focus on and which are not. However, by understanding the Puerto Rican children's developmental niche, clinicians gain a critical understanding of the culture that shapes children's capabilities. This understanding makes possible an informed interpretation of clinical observations and test scores bearing on behavioral function. Informed interpretation can help clinicians to design treatment programs that can have the greatest impact on reducing functional limitations and improving disability status. Given that the goal of intervention is to make children more capable, we need to be particularly aware of the constraints on their capabilities, whether these constraints are the attributes of the physical and social environment, the psychology of the parents, or the physical impairments of the children.

Discussion and conclusion

Like the PEDI, many if not all standardized measures of child health measure important dimensions of human universals. We see evidence of this in psychometric evaluations of these instruments that confirm their construct validity and reliability in different cultural environments. Discordance between the culture for which the PEDI was created and normed and Puerto Rican children's developmental niche, however, reveals that conventional evaluation of the psychometric

properties of a standardized measure of child health fails to provide information that would allow optimal assessment for designing or evaluating effective interventions. Cultural validation of the PEDI thus provides critical information.

Since Puerto Rican children evaluated with the Spanish translation of the PEDI may appear to be more disabled than they are or appear not to be gaining independence when, in fact, they are, specific interventions may not be provided because of a child's skill level. Why should a child who usually only walks short distances in the home with supervision receive surgery to improve walking (walking outside and at school is too dangerous, but she could walk if she was brought to the mall and closely supervised)? Moreover, the impact of therapeutic interventions may be misinterpreted. For example, after six months of therapy the child still usually receives maximal assistance for dressing (she can now put on her shirt, but the grandmother still does everything for her because she does not want the child to struggle with this or other difficult tasks). After surgery, intensive therapy, and bracing, a child with congenital lower extremity deformities still is unable to walk for more than a few feet. His parents are afraid that he will fall and "undo" the surgery, so they do not encourage walking.

More generally, these findings raise the possibility that psychometric validation of standardized measures of health without concomitant cultural validation constitutes a form of selection bias. Without cultural validation, standardized measures of health cannot realize their promise. Unless we make it our business to start by determining core cultural constructs, in fact, standardized measures may severely distort the reality we seek to understand. As Pachter & Harwood note (1996, p. 197):

"self-esteem is currently an extremely popular notion in American psychology. We can take measures of self-esteem that are normed in this country, do our best to make them "sensitive" to another population; we can attempt to insure linguistic and conceptual equivalence, as well as to control for differences in response styles, but these movements toward methodological equivalence fail to address the larger cultural issue: Is the phenomenon we purport to study one that is culturally central in the group being examined? In a highly sociocentric culture, in which one's sense of self-fulfillment is tied to one's sense of group membership, the very construct of "self-esteem" becomes less useful in defining social competence or in understanding how a child becomes a socially competent adult."

Even if we make less fundamental errors of interpretation, the absence of cultural validation means that

comparative studies will suffer irretrievable instrumentation problems. Instrumentation internal validity confounds will muddy evaluations of the efficacy of interventions, the impact of public health programs, and public health policy. Policies and interventions that do work may appear not to. Policies and interventions that adversely affect health may not receive appropriate critical attention and continue to waste scarce public resources.

Future studies that seek to establish the cultural validation of a standardized instrument need to practise caution, however. As Keesing (1994) pointed out, global movement and communication not only have placed individuals who embodied different cultures face-to-face, they have often placed us face-to-face with people we might *think* embody different cultures, but who do not. One must identify and measure the cultures before one can culturally validate the instrument.

Historically, social scientists used assumptions, not evidence, to equate cultural boundaries with social identities like Puerto Rican, Yankee, and African American. We dismissed, overlooked, or downplayed both cultural variation among people who use the same social identity and cultural equivalence among people who use different social identities. To make sense of cultural diversity in the contemporary world, rather than look at cultural variability between reified and essentialized ethnic groups, we need to pay attention to cultural variability between individuals. This means that we must ask questions bearing on the details of the social distribution of cognition, emotion, and behavior, and about the patterns, networks, and character of social interaction through which cultures evolve locally, regionally, and globally. When we ask these questions, we make the reality regarding social groups, the existence of cultures, and the location of cultural boundaries, empirical issues that require explicit tests for construct validity. Once we define cultures by reference to shared cognitive models and recurrent patterns of behavior, we make it possible to explicitly measure cultures and their effects on health.

In planning this study, we anticipated that we might find more than one developmental niche culture in Puerto Rico. We also anticipated that we might find significant intracultural variation. Either intercultural or intracultural variation might reflect, for example, the training clinicians receive that non-clinicians do not, or the experience of being or not being a parent of a child with a disability. Explicit analysis revealed a single developmental niche culture in Puerto Rico and no significant intracultural variation. We found systematic differences between a Puerto Rican developmental niche and the culture on which the PEDI was constructed and normed. However, we cannot characterize the latter culture except by contrast with our findings from Puerto Rico. Within the continental US, there may exist

significant intracultural and intercultural variation in children's developmental niches. Neither intracultural nor intercultural variation may correspond with ethnic identities. Finally, because our research design incorporated only the single comparison of the culture on which the PEDI was constructed and normed, we cannot say that the developmental niche culture we found on Puerto Rico is distinctively "Puerto Rico." It may be shared widely beyond people of Puerto Rican ethnicity.

The methods we describe here provide tools designed to probe the nature and limits of cultural diversity generally. However, see Handwerker (2002), for the theory underlying these procedures, and Handwerker (2001) for the procedural details. They make it possible to see cultures that exhibit specific forms of historical and regional variation (e.g., Dressler & Bindon, 2000). They make it possible to see clinical variation over space, rather than sharp boundaries (e.g., Caulkins, 2001). They also make it possible to see sharp boundaries between neighbors, to probe their origins, and to identify the clinical implications of cultural differences.

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