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Measuring Participation for All

Ensuring access and equity in participation instruments

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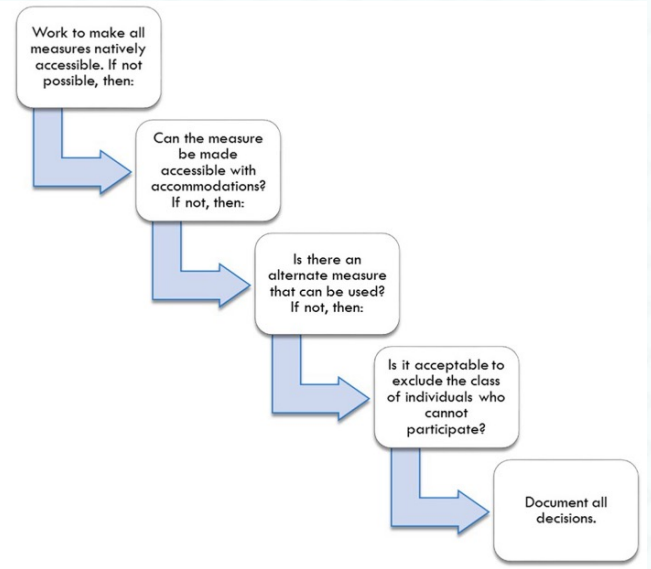
Introduction

Capturing outcomes in participation, activity, and participation-related constructs

Frameworks and approaches for accessible measurement



Content
The meaning conveyed in each item.

Layout
The arrangement of words, images, and response options.

Administration Procedures
The processes followed by respondent and professional to complete the PROM.

Cognitive Accessibility

Equity in Measurement

Foundational principles

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Nothing about us, without us

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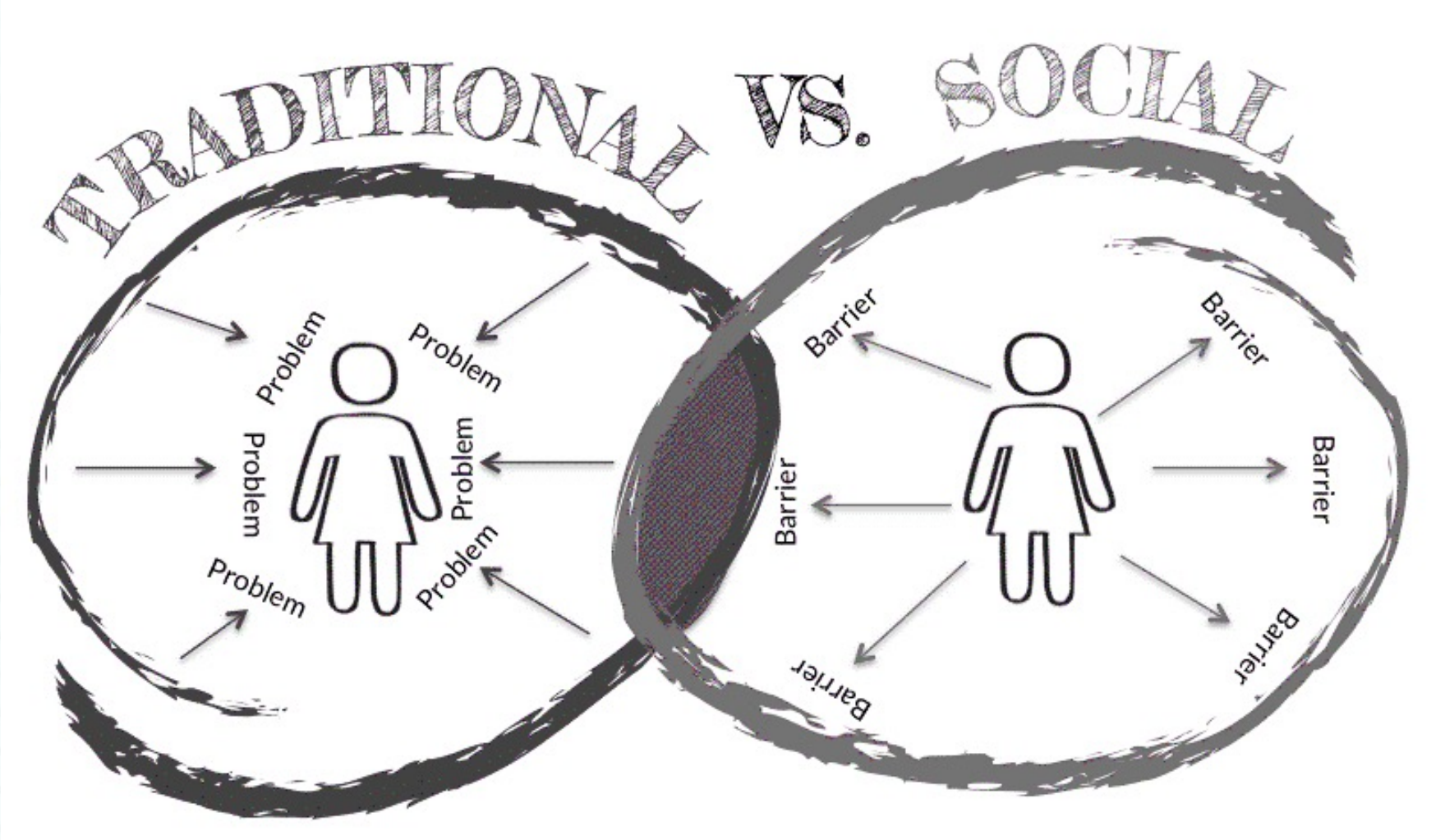
- Children have the right to give their opinions freely on issues that affect them. Adults should listen and take children seriously.
- Children have the right to share freely with others what they learn, think and feel,

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Respect for the evolving capacities of children with disabilities
- Accessibility;

Social Model of Disability & Impairment



(Goodley, 2001; Oliver, 2013)

https://www.advocations.org/working-definition-disability/

Critical questions about rehabilitation measures

- What assumptions are reflected in this measure?
- What social forces have affected the design and use of this assessment?
- What is really being measured?
- Whose voice is represented?
- How do we know if information from our measures is trustworthy?

(Coster, 2006)

https://hrprofessionalsmagazine.com/2020/12/31/measure-implicit-bias-in-your-organization-and-eliminate-it-now/

Developing Accessible Measures

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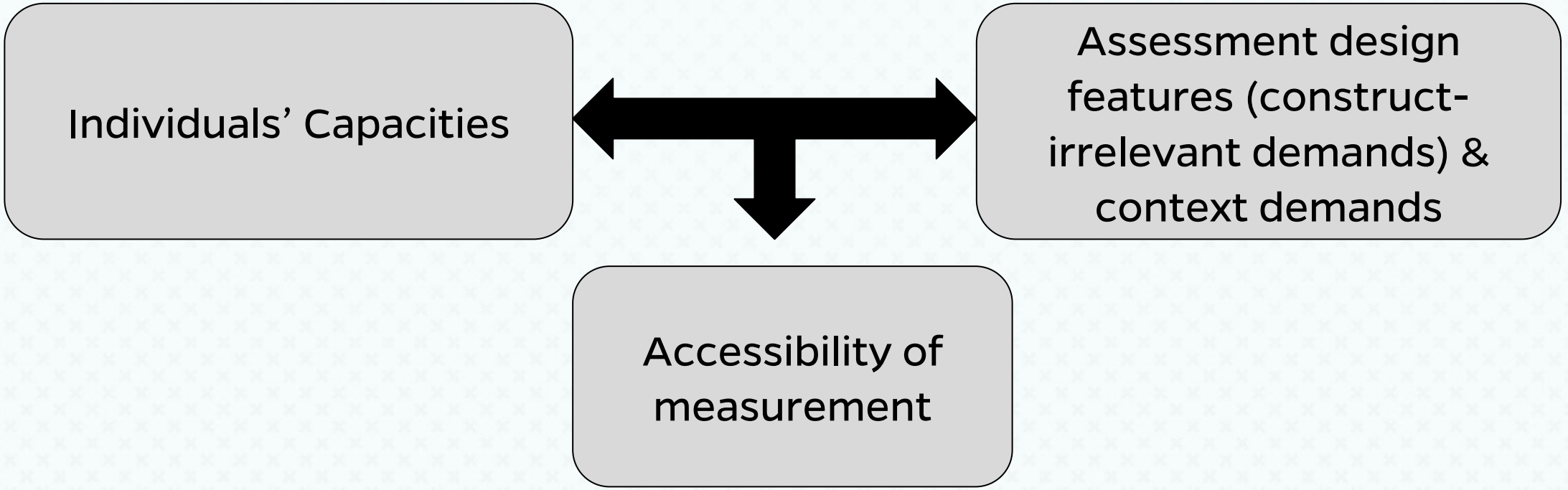
Defining accessibility

- **Accessibility:** Within a measurement context, accessibility is defined as the unobstructed opportunity for the test taker to demonstrate their standing on the construct the test is designed to measure (Magasi et al., 2018)
- **Cognitive accessibility** is present when assessment design anticipates respondent variability in cognitive abilities and, to the greatest extent possible, reduces cognitive demands and/or supports cognitive processes to enable respondents with a range of cognitive abilities to interpret and respond to assessment items as intended. (Kramer & Schwartz, 2017)

Interaction between capacities and demands



(Kramer & Schwartz, 2017; Magasi et al, 2018)

Interdisciplinary approach to the development of accessible computer-administered measurement instruments

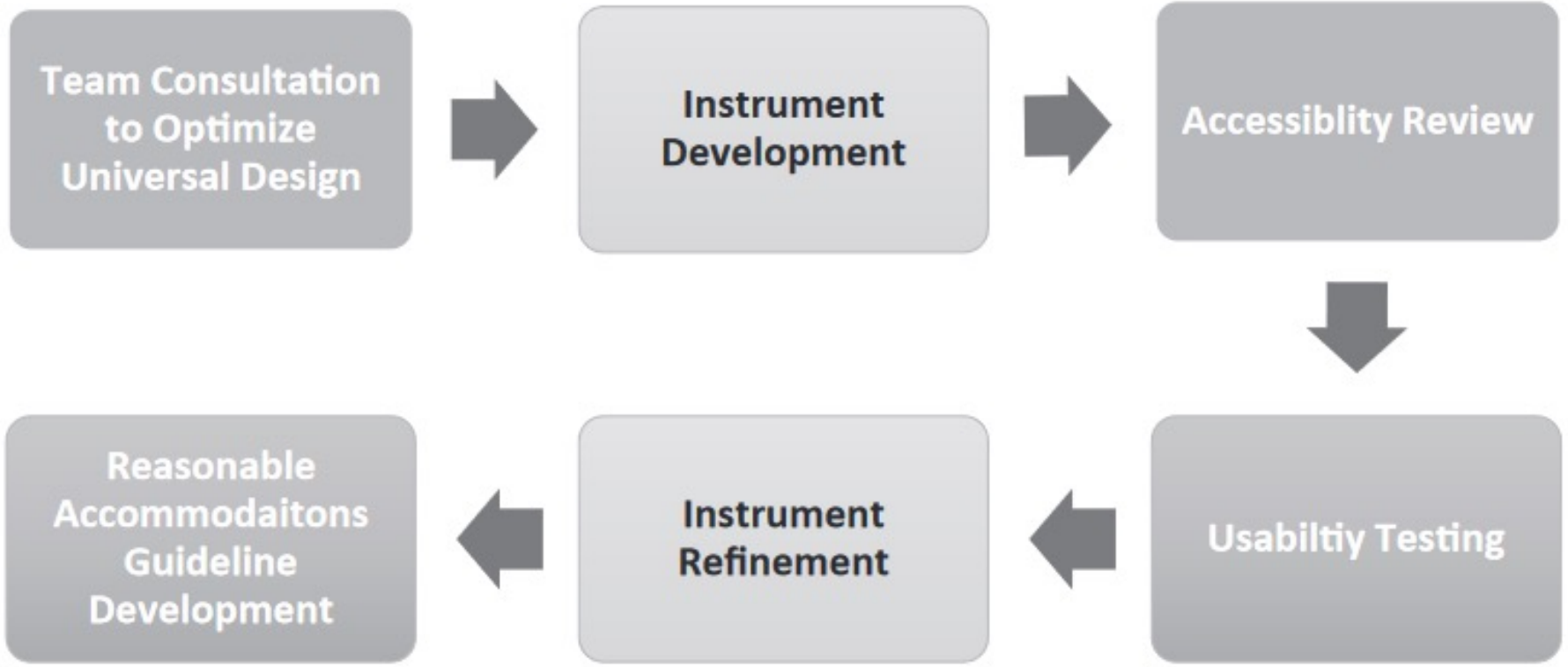


Fig 1 Schematic of the instrument review and refinement process.

(Magasi et al, 2018, pg 206)

Accessibility Summary

Table 3 Sample accessibility summary

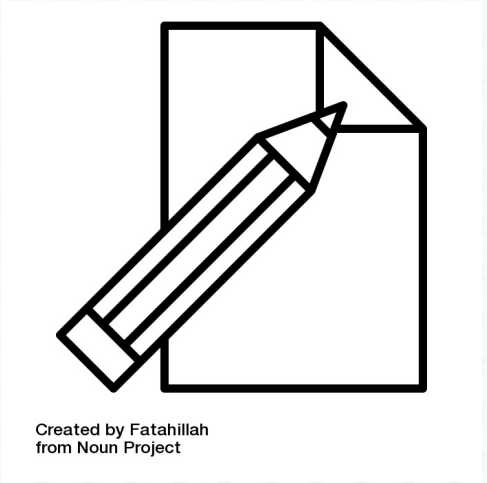
	Vision		Physical and Motor Skills		Hearing		Language and Learning	
Measure	Blind	Low Vision	Decreased Hand Function	Mobility Impairment	Deaf	Hard of Hearing	Speech Impairment	Reading Impairment
NIH Toolbox Picture Vocabulary Test	N	P	P	A	U	P	A	A

Abbreviations: A, currently accessible; N, not accessible and not feasible to make accessible; P, not accessible but can be made accessible with reasonable accommodations; U, not accessible but can be made usable with modifications.

(Magasi et al, 2018, pg 207)

Background

- The cognitive demands required for self-reporting outcomes pose a challenge for youth with intellectual/developmental disabilities.
- Paper based PROMs* can be cumbersome or impossible to modify to reduce the visual-perceptual, motor, and cognitive demands required for completion.



Created by Fatahillah
from Noun Project

*PROMs: Patient Reported Outcome Measures

Design Features to Optimize Cognitive Accessibility for Patient Reported Outcome Measures

Content
The meaning conveyed in each item.

Layout
The arrangement of words, images, and response options.

Administration Procedures
The processes followed by respondent and professional to complete the PROM.

Cognitive Accessibility

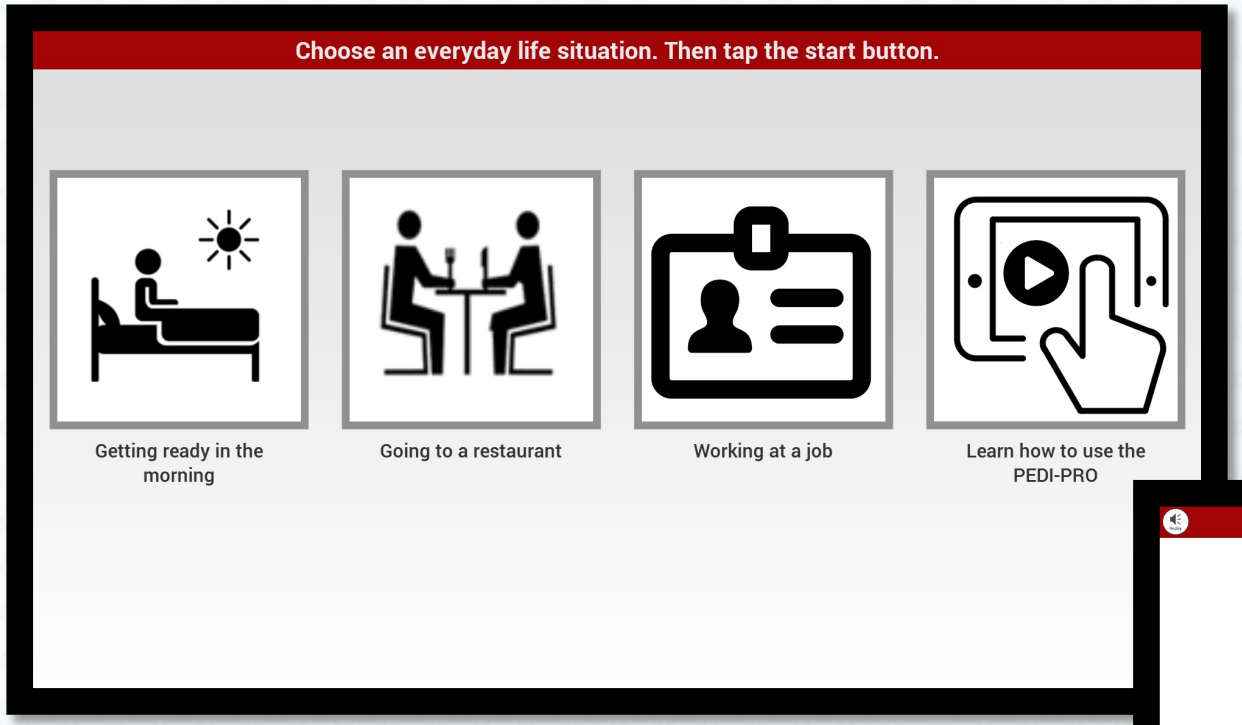
(Kramer & Schwartz, 2017, pg 1708)

Content

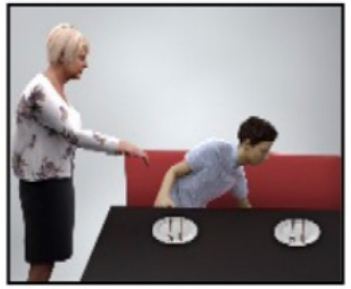
- Address semantics and pragmatics, or the meaning conveyed in each item.

Content Features
Grammatical complexity
Simple wording
Define unfamiliar words
Positively worded items
Reference specific contexts (e.g., locations, activities)
Current recall period
Self-perception & personal reference language

Content Example: PEDI-PRO



Content: Conceptually congruent visuals

Image Feature	Specification	Example Images
People	• Reflect the diversity of PEDI–PRO users by featuring people with a range of skin tones, hair lengths and textures, mobility devices (e.g., wheelchair), and facial features. • Design clothing that is age appropriate, has realistic textures, and fasteners.	Wait for my turn to talk to the waiter or waitress. Type on a computer keyboard.
Body positioning	• Depict functional trunk, limb, hand, foot, and head and neck postures while sitting, standing, walking, and manipulating and carrying objects.	Open a taped box with scissors. Walk up stairs to the next floor.
Background and props	• Generate realistic props used to complete tasks described in each item (e.g., fork, keyboard). • Image background includes key conceptual features of the environment to support comprehension (e.g., toilet, table and chairs). • Reduce extraneous background features to enhance attention to salient item information.	 Slide into a booth. Put books, videos, papers, or files in alphabetical order.

Layout

Layout: The arrangement of words, images, and response options.

Layout
Font style and size
Left justification
Length of text
Simple punctuation
White Space
Visual Contrast

Layout

Layout: The arrangement of words, images, and response options.

Layout
Consistent layout and color throughout
Text adjacent to images
Visual integration of items & response scale
Visual integration of response scale choices & words
Integration of item stem & item

Layout Example: Visual integration

Visual integration

Lack of integration

In the last 7 days….

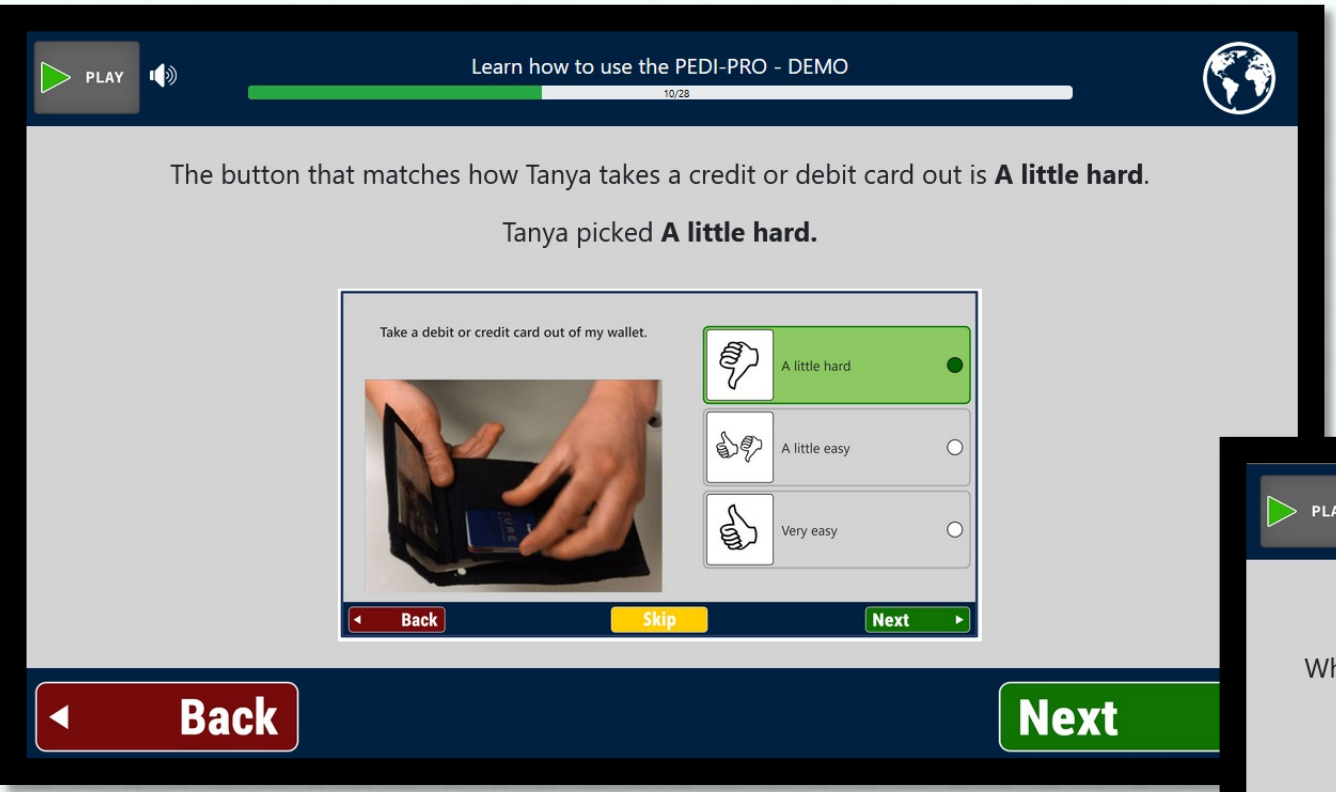
	Hard	Easy
1. “Item 1”	_____	_____
2. “Item 2”	_____	_____
3. “Item 3”	_____	_____

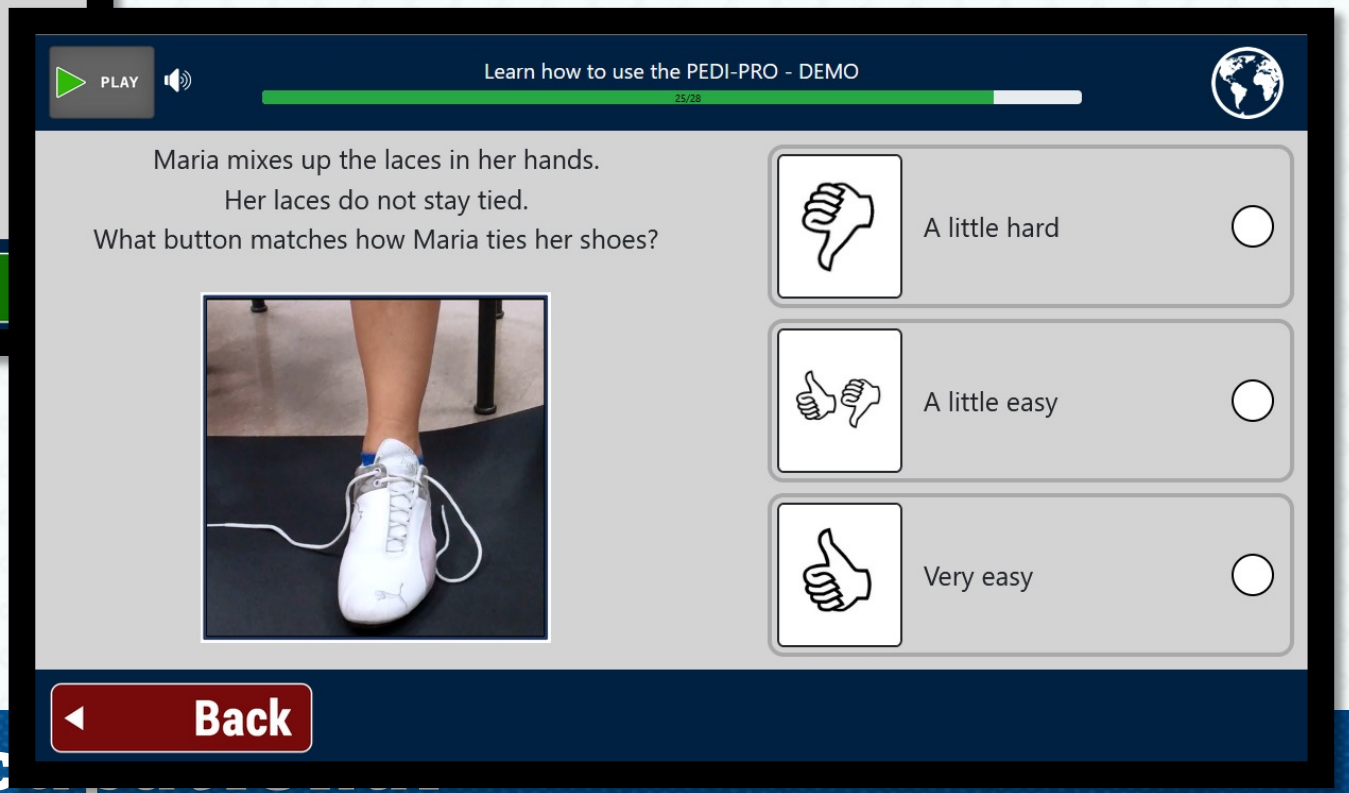
Administration Procedures

Administration procedures: The processes followed by respondent and professional to complete the PRO.

Layout
Reading
Responding
Self paced
Individualized content
Validate & encourage
Teaching

Administration Example: Teaching



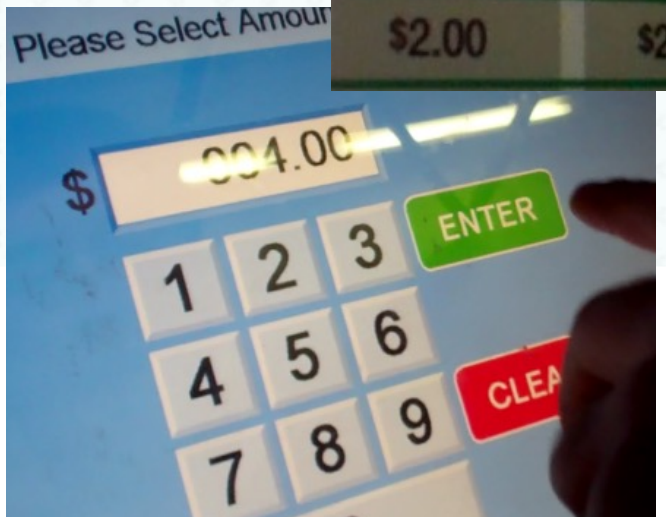


PEDI-PRO: Inclusive Development

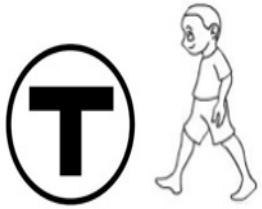
The Design Team “Inclusive Cool Cats” has contributed 393 hours to the design of the PEDI-PRO:

- Boston: 330 hours
- UF: 63 hours

Developing items embedded in everyday experiences



How did you get there?



Think about how much the T would cost

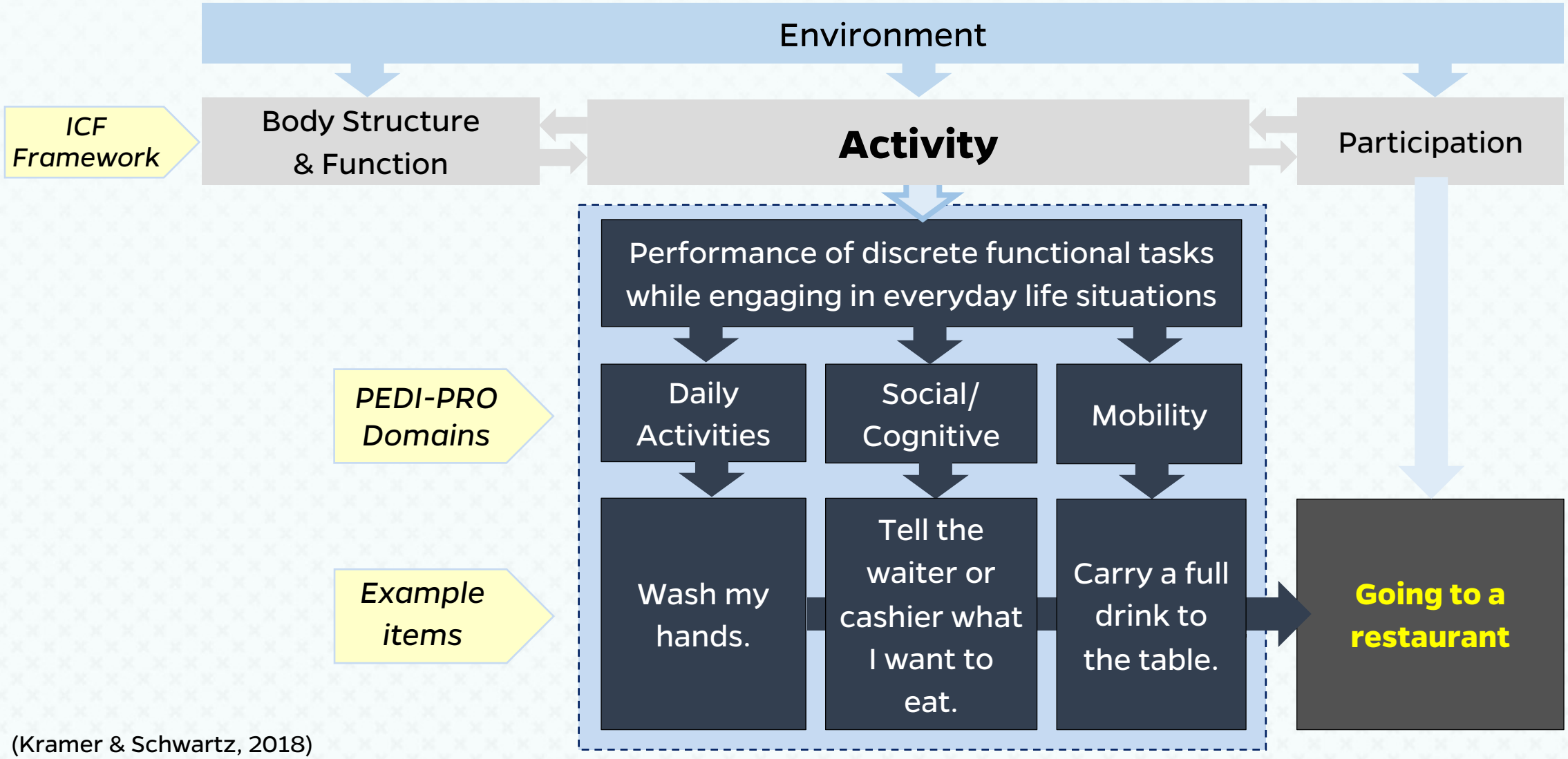
Think about how long the T ride would be

What did you have to figure out to do your activity?

Figure out how hungry I am before I order

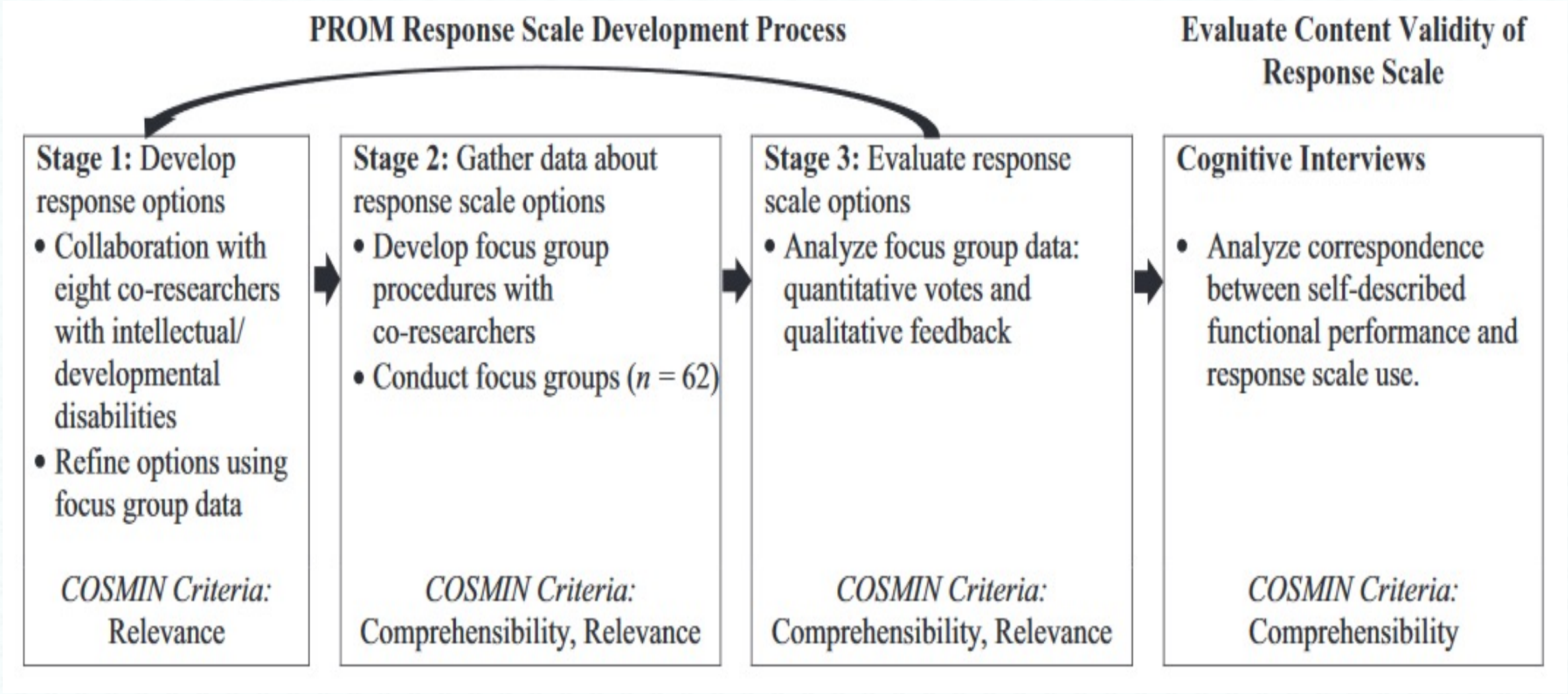
Find an empty seat at the restaurant

The PEDI-PRO Conceptual Measurement Framework



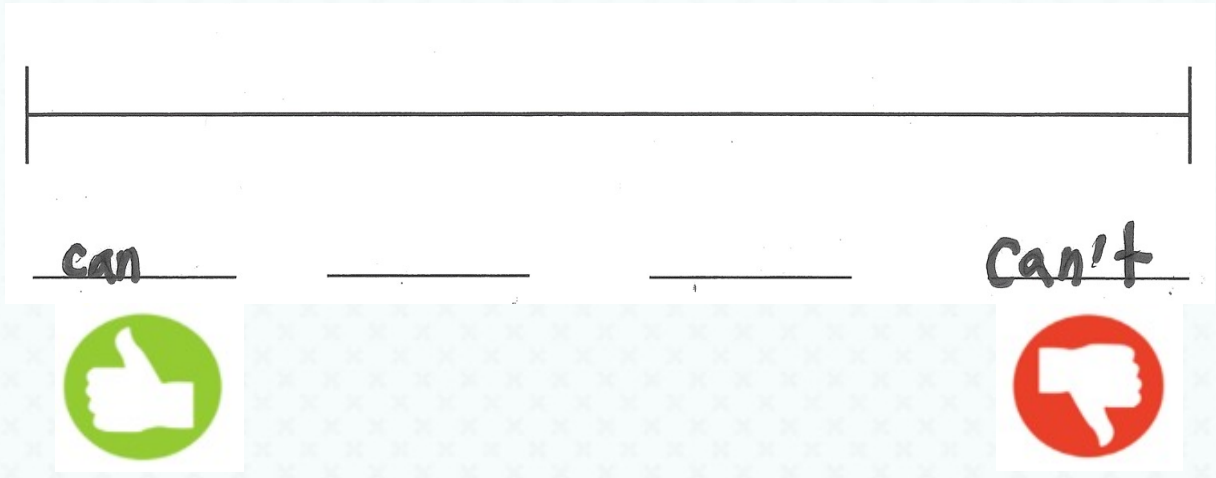
(Kramer & Schwartz, 2018)

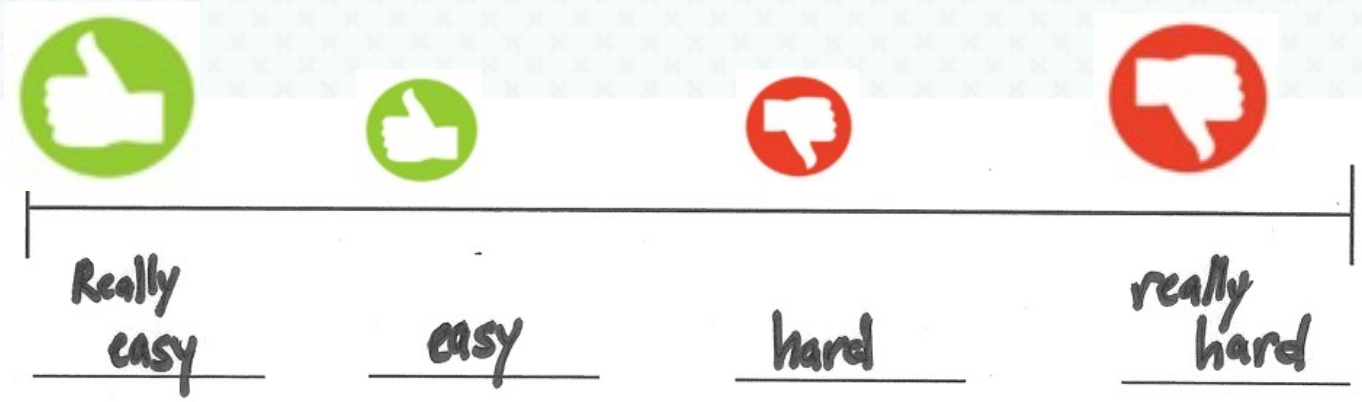
Response Scale Development



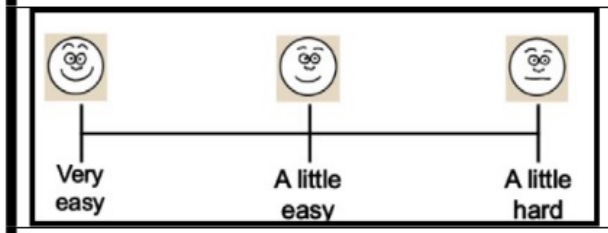
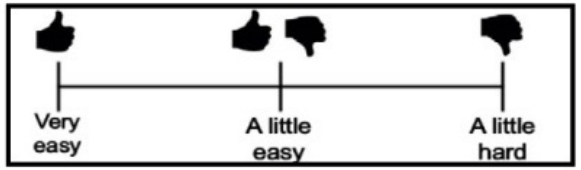
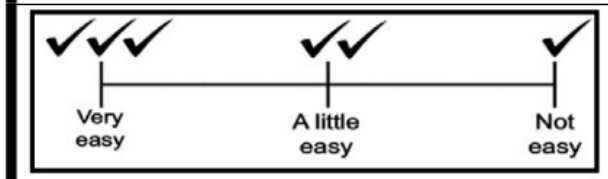
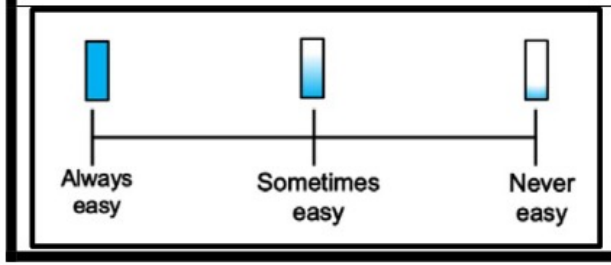
(Schwartz et al., 2021, pg. 102)

Response Scale Development





Response Scale Development

Rating Scale	Votes for	Votes against	Summary of the main ideas
	18	9	18 people liked everything and 9 people didn't like things.
	12	15	People like the pictures, but 2 don't.
	9	18	A lot of people didn't like the word "not."
	8	19	19 people didn't like it and we don't know why.

(Schwartz et al., 2021, , pg. 106

Opportunities in Research & Practice

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Accessibility categorization

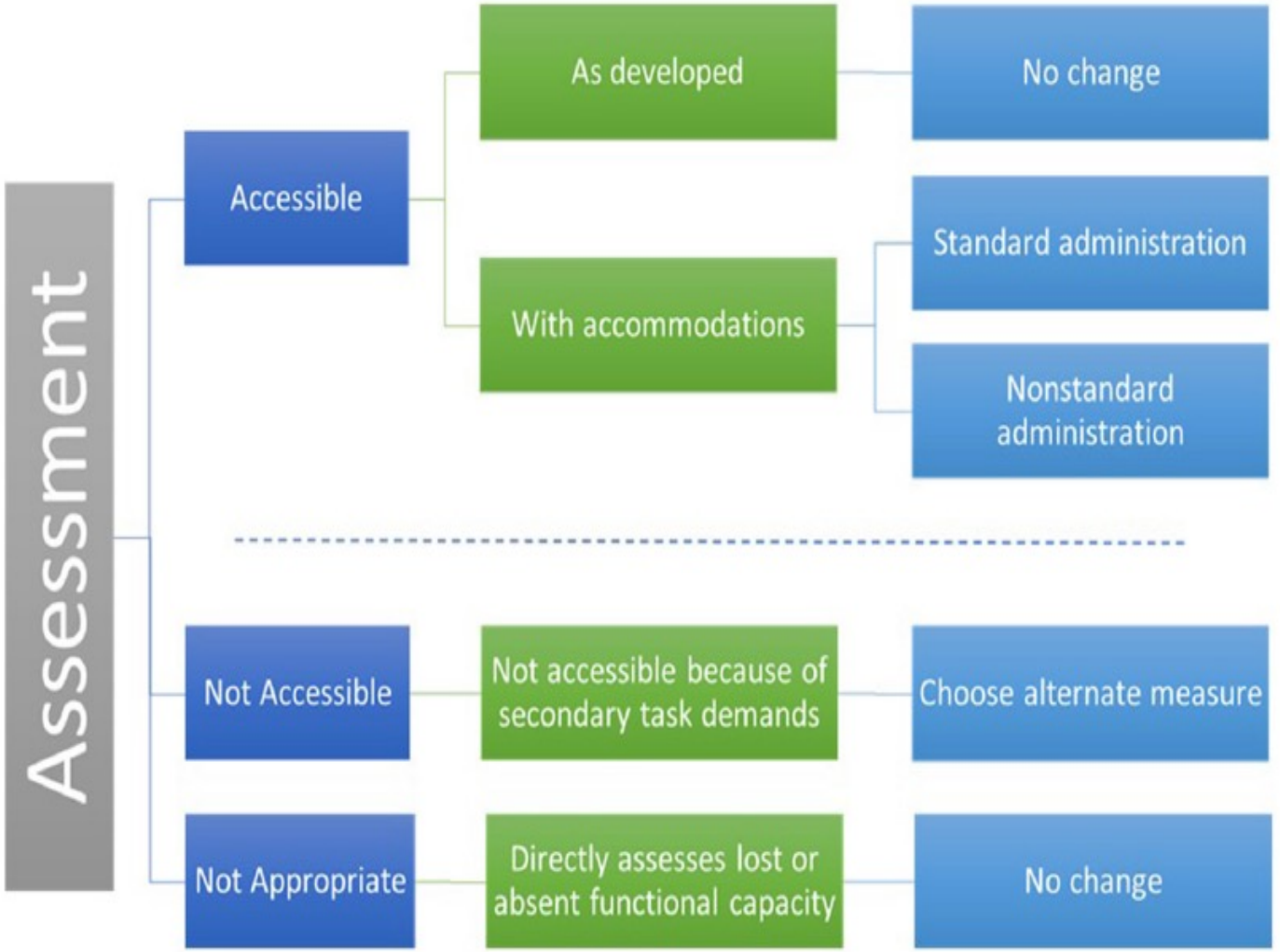

FIGURE 1 | Accessibility categorization of measures.

(Harniss et al ., 2021, pg. 3)

Application of frameworks to existing assessments

- Critically review measures using accessible framework

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY REVIEW

Patient-reported outcome measures for young people with developmental disabilities: incorporation of design features to reduce cognitive demands

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ABBREVIATIONS

ICF-CY	International Classification of Functioning – Children and Youth
PROMIS	Patient-Reported Outcomes Measurement Information System
PROM	Patient-reported outcome measure

Use of patient-reported outcome measures (PROMs) may increase the involvement of young people with developmental disabilities in their healthcare decisions and healthcare-related research. Young people with developmental disabilities may have difficulty completing PROMs because of extraneous assessment demands that require additional cognitive processes. However, PROM design features may mitigate the impact of these demands. We identified and evaluated six pediatric PROMs of self-care and domestic life tasks for the incorporation of suggested design features that can reduce cognitive demands. PROMs incorporated an average of 6 out of 11 content, 7 out of 14 layout, and 2 out of 9 administration features. This critical review identified two primary gaps in PROM design: (1) examples and visuals were not optimized to reduce cognitive demands; and (2) administration features that support young people's motivation and self-efficacy and reduce frustration were underutilized. Because assessment demands impact the validity of PROMs, clinicians should prospectively consider the impact of these demands when selecting PROMs and interpreting scores.

Funding agencies, advocacy groups, and expert panels have called for increased involvement of all patients, including young people with developmental disabilities,* in healthcare decision-making and healthcare-related research.[2,3] This emphasis on patient involvement has coincided with calls for increased 'accessibility' and equity in rehabilitation measurement and research.[3] Use of patient-reported outcome measures (PROMs) is one way rehabilitation professionals can increase the involvement of young people with developmental disabilities in their healthcare and healthcare-related research.[2] A PROM is an evaluation of 'the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else'.[4] Young people with developmental disabilities often have cognitive impairments that can make it difficult to read, interpret, and respond to a PROM.[5–7] Rather than discounting the ability of young people to use PROMs because of such impairments, clinicians and researchers should carefully consider how a PROM's design may impact a young person's ability to access PROMs, and subsequently, their involvement in healthcare decision-making and research.

Selecting an appropriate PROM for young people with developmental disabilities and related cognitive impairments requires an understanding of assessment demands, which are the specific skills and processes respondents must execute to complete a PROM. Young people with cognitive impairments may have difficulty meeting PROM assessment demands that require attention, working memory, long-term memory, and judgment, such as interpreting the meaning of an item and selecting a response category.[8–10] When PROMs pose extraneous assessment demands, scores reflect respondents' abilities to meet these demands, rather than their healthcare experiences and outcomes. Therefore, assessment demands that exceed the abilities of respondents threaten PROM validity.

Although assessment developers have addressed ways to reduce motor and perceptual demands of PROMs,[3] there is no model for systematically evaluating demands related to cognitive processes (henceforth referred to as 'cognitive demands') and ensuring cognitive accessibility of PROMs. To fill this gap, we recently proposed a framework describing how specific PROM design features may be used to reduce cognitive demands.[7] Based on extensive multidisciplinary evidence (Table SI), the framework suggests three features that can reduce cognitive demands in PROMs. (1) Content features (11 features) address how linguistic

*Terminology varies over time and across contexts. Here, we use the term 'developmental disability' to describe individuals who have a disability attributable to a mental and/or physical impairment with onset before 22 years of age that is expected to continue throughout the life course and who need support in at least three areas of 'major life activities', as defined by the United States Developmental Disabilities Assistance and Bill of Rights Act.[1]

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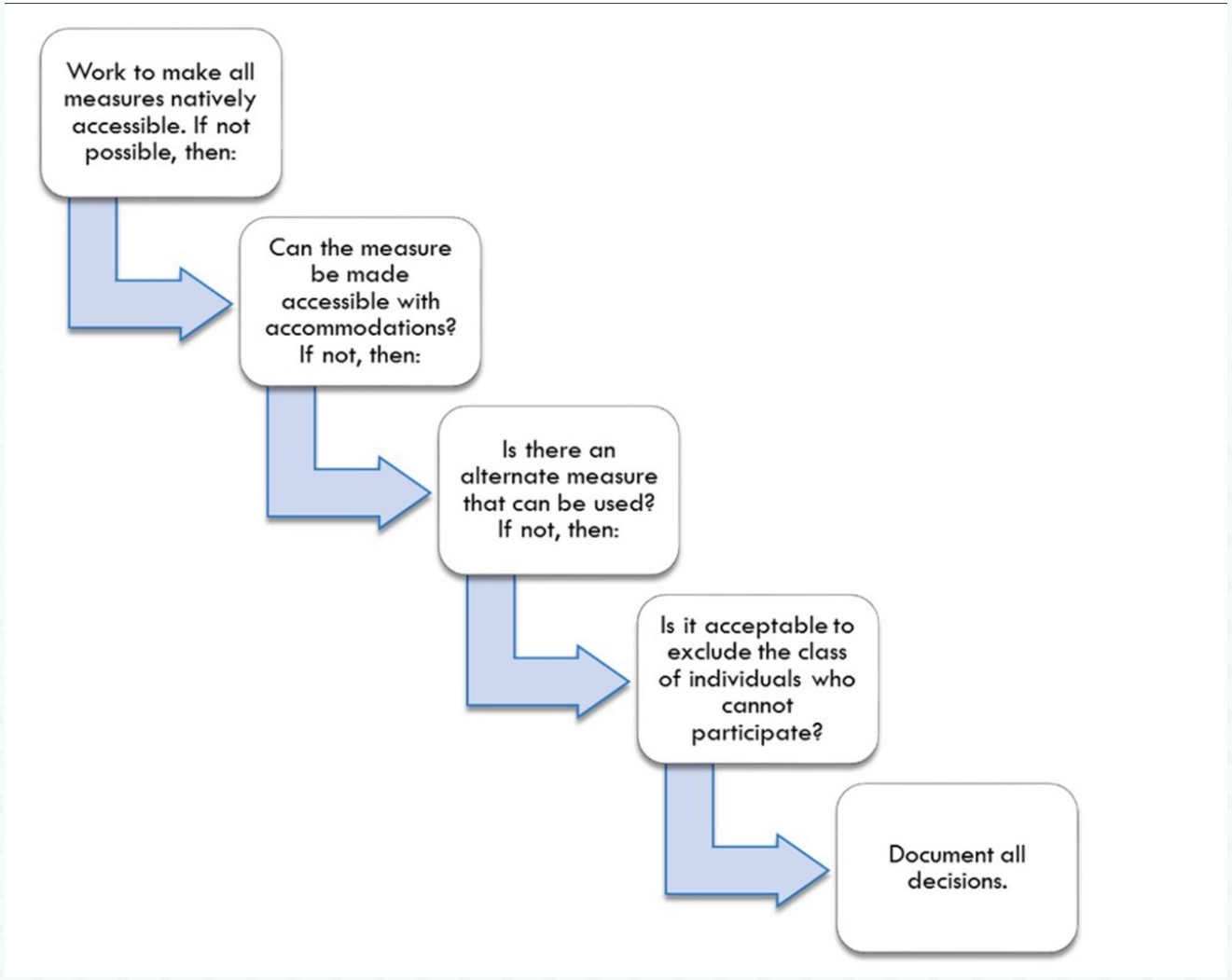
(Schwartz et al., 2018)

Incorporating Accessible Measures into Research Design



(Harniss et al ., 2021, pg. 4)

Concluding Critical Questions

- What could we do differently to provide more equitable participation in assessment?
- What social forces about the structure and purpose of assessment limit our enactment of equitable participation in assessment, and how can we change those social forces?
- What technologies could be used to enhance the accessibility of measures
- What methodologies could be used to demonstrate that children, teens, and young adults can engage in the measurement process when our instruments are accessible?

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