Disability Disparities

Allen Lewis, PhD; Andrew Imparato, JD;
Keith Wilson, PhD; & Philip Rumrill, PhD

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Welcome and Overview

- Talk about a concept called "disability disparities"

Will Provide:
(1) some key background - introduction,

(2) disability disparities model,

(3) and a beginning discussion on how to address disability disparities.

Welcome and Overview

- Panel experts:
Andy Imparato, CEO of the American Association of People with Disabilities, the largest cross-disciplinary voice of individuals with disabilities in the nation;

Keith Wilson, Professor at Penn State and one of the seminal researchers and writers in the realm of disability and culture; and

Phil Rumrill, Professor at Kent State & one of the most prolific researchers in the field of rehab.

Introduction

- Concept of health disparities is documented in field of health care
- IOM arguably offers the predominant definition of health disparities today.

Introduction

- IOM says a health disparity is a differential outcome attributed primarily to one's race or ethnicity (Smedley, Stith, & Nelson, 2003).
- This difference is apparent even when factors such as social economic status & access to care are eliminated as possible contributors to uneven outcomes (Smedley, et al., 2003).

Introduction

- Health disparities - personal interest , curious about the link between disability and culture.
- Searched the literature for an explicit disability disparities model, but to no avail

Introduction

- Sec 21 of Rehab Act Amendments of 1992, though not a model, comes closest to specifying the disability disparities concept.
- Sec 21 provides much of legislative impetus for the public rehab and disability system to strive to do a better job in serving culturally diverse populations.

Introduction

- Section 21 posits that ethnically diverse persons in state-fed system typically have higher incidence of disability, lower levels of participation when they access the formal system, and fewer successful outcomes at the end of the rehab process.
- Given the lack of an explicit model in the rehab literature that addresses "disability disparities," goal was to begin to draft a definition & a beginning model to help specify the phenomenon conceptually.

Cultural Competency & Disability Disparities

- Cultural competency and disability disparities are linked
- Disability disparities are the problem that cultural competency attempts to eliminate

Cultural Competency & Disability Disparities

- In the absence of disability disparities, one of cultural competency's primary 'reasons for being' is eliminated.
- Cultural competency includes 3 aspects: (1) an awareness of own assumptions, biases and limitations when working cross-culturally, (2) understanding the worldview of persons who are different without imposing negative judgments, and (3) the ability to practice appropriately with culturally different clients

(Sue, Arredondo, & McDavis, 1992).

Keith Wilson, PhD, CRC, LPC, NC, ABDA
Professor of Education at The Pennsylvania State University

Business Argument for Disability Disparities

- There is also a business argument that underscores the value of working to eliminate disability disparities through enhanced cultural competency of the disability system.

Business Argument

- Argument offers that publicly funded disability & rehab programs face high pressure & accountability that takes on the four primary forms of:
  (a) limited and uncertain funding,
  (b) increasing demands for services,
  (c) consumers that insist upon public services meeting their needs, and
  (d) expectation imposed by taxpayers that govt bodies expend public resources responsibly to maximize the reach of such funds

Andrew J. Imparato
President and CEO of the American Association of People with Disabilities (AAPD)

DEFINITION AND THE MODEL

Definition and Model

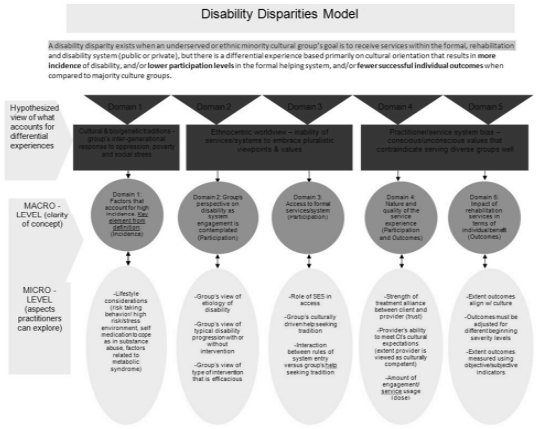
- A disability disparity exists when an underserved, ethnic or racial minority cultural group's goal is to receive services within the formal, rehabilitation and disability system (public or private), but there is a differential experience based primarily on cultural orientation that results in higher incidence of disability, and/or lower participation levels in the formal helping system, and/or fewer successful individual outcomes when compared to majority culture groups.

Definition and Model

- Note that the working definition builds on Section 21 of Rehab Act Amendments of 1992 by including the factors of higher incidence of disability, lower participation in services, and fewer successful outcomes of services.

Phillip D. Rumrill, Jr., Ph.D., CRC
Professor of Rehabilitation Counseling and Director of the Center for Disabilities Studies at KSU

- Full visual representation of the disability disparities model
- The model is a beginning model (i.e., starting point in the discussion), it is broad, conceptual, and hopefully explanatory.
- Can look complex, but I intend to orient you to the model's depiction and walk you through it to see all that is there.



Model

- Five domains that appear horizontally across the top
- Each domain represents a point on a five-part continuum.

- Represents the total disability experience from having a disabling condition and understanding its incidence within one's cultural group all the way to the point of achieving an outcome (i.e., some individualized benefit) at the conclusion of rehabilitation services.

- 5 point continuum conveys a disability disparity can occur at any one or several points throughout the disability experience.
- Next row is "hypothesized view of what accounts for differential experiences"

- Along this row, there is a reason or set of reasons that I hypothesize is plausible and to some extent accounts for why there is a differential experience among groups based on cultural orientation at each point along the continuum.

- 3rd row represents "macro-level"
- This level attempts to offer clarity of the concept of disability disparities at each point along the continuum from a 'big picture' vantage point, particularly for researchers who desire to be conceptually clear about the disability disparity phenomenon at each point along the five-domain continuum.

- 4th row or level represents the micro-level vantage point
- A much more "up close and personal" perspective on factors potentially related to a disability disparity across each of the five-domains of the continuum represented in the model

- Point of the micro-level viewpoint is to drill down considerably from the previous level's macro attribute to a more specific level of abstraction

- This more micro-level orientation is designed to offer a set of factors aligned with each of the five domains for practitioners or clinicians to explore to determine if a specific client with a disability is challenged with a disability disparity at any of the five points along the continuum.

Five domains

- Along the continuum from the 3 levels of:

  (a) hypothesized view of what accounts for the differential experiences (disability disparities),
  (b) macro-level to clarify the disability disparity concept for researchers, and
  (c) micro-level to afford a set of factors for practitioners to explore in working with clients.

Domain 1

- Hypothesized reason for a differential experience based on cultural orientation (i.e., ethnic orientation) would be those cultural, biological, and genetic traditions that influence a cultural group's intergenerational response to things such as oppression, poverty, and social stress.

Domain 1

- Macro-level – those factors that account for a higher incidence of disability among culturally diverse groups.

Domain 1

- Such factors may derive directly from the cultural, biological & genetic traditions in response to societal pressures that manifest directly into lifestyle patterns OR could be related to other anomalies such as data collection idiosyncrasies when measuring incidence

Domain 1

- There are the micro-level aspects that practitioners can explore in providing services to specific clients.
- Those lifestyle considerations that could arguably be endemic to the experience of being a member of a group that is ethnically different.

Domain 1

- Such considerations might be, e.g. residing in a high risk, high stress environment and participating in behavior that might be considered coping such as self medication in the case of substance overuse, misuse and abuse, and overeating that can be linked to metabolic syndrome

Domain 2

- Hypothesized reason for a differential experience based on cultural orientation (i.e., ethnic orientation) would be the ethnocentric worldview that many systems operate from OR the inability of the system and services to embrace pluralistic values and view points.

Domain 2

- Macro-level - main concern is culturally diverse group's perspective on disability at the point that there is contemplation about whether to engage with the formal system or not.
- Potential client contemplates participation in the formal services system.

Domain 2

- Micro-level - aspects that clinicians can explore in providing services to specific clients.
- Some aspects might be the cultural group's: (a) view of the origin of disability, (b) view of the typical progression of disability with or without intervention, and (c) view of the type of intervention that is believed to be effective.

Domain 3

- Hypothesized reason for the differential experience is the same as for domain 2, the ethnocentric worldview and inability of service delivery systems to embody a pluralistic set of values and view points.

Domain 3

- Macro-level concern is access to the formal services system.
- At this point, the potential client has made a decision to access the formal services system.

Domain 3

- Micro-level - aspects that clinicians can explore in providing services to specific clients:

  (a) role of SES in access decisions,
  (b) group's culturally embedded help seeking tradition, and
  (c) interaction between the rules that govern services system entry and the client's culturally driven help seeking inclination.

Domain 4

- Hypothesized reason for the differential experience is both practitioner and service system bias (conscious and unconscious) that contraindicates the provision of effective services to culturally diverse groups.

Domain 4

- Macro-level concern is the nature and quality of the service experience for the client in the formal services system.
- At this point, the potential client has accessed the formal services system and is engaged in receiving services.

Domain 4

- Micro-level - aspects clinicians can explore in providing services:

  (a) strength of the treatment alliance between client and provider (measure of trust), (b) provider's ability to meet the client's cultural expectations (measures extent provider viewed as culturally competent), and (c) extent of engagement in services (measure of service usage/dose for client).

Domain 5

- Hypothesized reason for the differential experience is the same as for domain 4, both practitioner and service system biases (conscious and unconscious) that contraindicate the provision of effective services to culturally diverse groups.

Domain 5

- Macro-level - primary concern is the bottom-line impact of rehab services.
- Idea is to be clear that we are talking to what extent has an individualized benefit from services been realized by the client (i.e., positive outcomes).

Domain 5

- Micro-level - offers components clinicians can explore in providing services, e.g.
  (a) degree outcomes align with client's culture, (b) degree outcomes have been adjusted for different severity levels at start of services, and (c) extent outcomes are measured using objective indicators (to minimize bias in the picture) AND subjective indicators (accepting client bias to gain client input).

Disability Disparities Model

- Conveys that a disability disparity can occur at any one or several points along the five-domain continuum that represents the disability experience.
- It is a broad and conceptual model that hopefully offers some explanatory power.

Disability Disparities Model

- A beginning point in clarifying the concept of disability disparities at the macro-level and offering prompts for clinicians to explore in working with specific clients.

General Discussion

- At this point, the model as presented here has not been validated, realizing that such efforts are underway.
- However, esteemed panelists, what are your initial impressions about the model at this point?

General Discussion & Wrap-Up

- Strategies to eliminate disability disparities has not been the focus of our webcast

General Discussion & Wrap-Up

- Some key observations from our esteemed panelists, Dr. Wilson, Dr. Rumrill, and Attorney Imparato, about strategies to address & work toward elimination of disability disparities beyond the general comment made at the outset about the link between cultural competency and disability disparities.

General Discussion & Wrap-Up

- If we can do a good job of previewing strategies to address disability disparities, then we will have offered a nice segway to a subsequent webcast with a focus on the strategies.