

# Empowering minority group research

The experiences of Americans with disabilities from racial and ethnic minority groups, and what research methods, practices and strategies are needed to advance the field in culturally competent research, is the subject of Project Empowerment, a grant at the Virginia Commonwealth University (VCU), Department of Rehabilitation Counseling in the School of Allied Health Professions

**VCU'S DEPARTMENT OF** Rehabilitation Counseling in the School of Allied Health Professions was established in 1955 as one of the first rehabilitation counselling programs in the United States. VCU now ranks among the top 20 rehabilitation counselling training programs in the nation, according to U.S. News & World Report.

The Project Empowerment grant project is being funded by a five-year National Institute of Disability and Rehabilitation Research grant of \$1.78 million and will be used to identify and evaluate current practice and

methods in the conduct of minority disability research and to begin to increase capacity in this area. The National Institute on Disability and Rehabilitation Research is one of three components of the Office of Special Education and Rehabilitative Services at the U.S. Department of Education.

"The goal of the grant is to advance the state of the science in the conduct of minority disability research and to develop more persons who are passionate and interested in devoting careers to this line of research," said Dr Allen Lewis, the head of the project, its principal investigator

and associate professor and chair of the Department of Rehabilitation Counseling. Dr Lewis first became interested and involved in this work in 1998 when he began teaching on the subject matter, and more formally, in 2001 when he submitted his first version of this idea in an early unfunded grant proposal.

The Department of Rehabilitation Counseling is partnering with co-principal investigators Dr. Juan Carlos Arango, of the Department of Physical Medicine and Rehabilitation and Dr. Paul Wehman, of the Rehabilitation Research and Training Center in the School of Education. The



team also will collaborate with the Department of Biostatistics in the School of Medicine.

### Project Empowerment is conducting three primary studies:

**Study 1** is a national survey examining the experiences of Americans with disabilities from racial and ethnic minority groups to illuminate their current experiences receiving services and the capacity of the rehabilitation and disability system, as well as to learn what research methods and dissemination practices are needed to advance the field in culturally competent research. A very rough initial draft of the national survey has been disseminated for the first round of feedback from targeted members of the National Council on Rehabilitation Education and Project Empowerment stakeholders. This study is slated to start this year.

## Project Empowerment will deploy 13 strategies for training and dissemination. Each one is designed to promote minority disability knowledge translation system-wide

**Study 2** is a longitudinal study examining post-injury unemployment for racial and ethnic minority persons with traumatic brain and spinal cord injuries. This study is completed.

**Study 3** will examine prevalence and trends in employment discrimination due to disability for different racial and/or ethnic minority groups. This study is anticipated to start this year.

"Hopefully, the broadest impact of this research will be a clearer picture of the current nature of disability disparities related to one's cultural status, i.e. race and ethnicity," said Dr Lewis. "Specifically, we want to know more about the incidence, access patterns, participation levels, and outcomes of these groups in the public disability system in the US.

"Additionally, we would like to be able to improve the current state of the science in the conduct of research on the disability experiences of these groups by elevating the quality and relevance of the research that is conducted. Ultimately, we would like to improve the ability of research and dissemination methods to be more culturally competent. That is, we would like to be able to generate research findings that are salient within the specific cultural milieus that these groups are a part of."

The capacity building component of Project Empowerment is very important as well. It represents a way to engage in succession planning by identifying individuals who can be developed to be ready, passionate and interested in devoting careers to the study of racial and

ethnic minorities with disabilities. The project's capacity building efforts are based primarily on collaboration with the minority partner institutions in the US as well as interested minority students identified at any university. So far, Project Empowerment has done the following related to capacity building:

Engaged in initial recruitment efforts to attract students at state-wide minority serving institutions and has started to identify a small cadre of interested persons.

Additional recruitment strategies for ethnic and racial minority students are currently being developed.

Further contact with minority institutional partners has recently been made to schedule presentations to potential student participants and faculty members.

The project has identified several minority doctoral students outside of VCU, and its current minority institution partners who are currently working directly under the guidance of Project Empowerment mentors (PI and post doctoral fellows) on manuscripts as a way of increasing research capacity within more advanced, up and coming minority researchers.

Project Empowerment will deploy 13 strategies for training and dissemination. Each one is designed to promote minority disability knowledge translation system-wide. Together, they constitute a multi-pronged approach to ensure broad reach and maximum system penetration of knowledge generated by Project Empowerment. One such strategy is 'Research to Action Notes' (RANs), a primary tool that Project Empowerment will utilise to attempt to move research to practice in an ongoing manner. RANs will be a one-page summary of the bottom-line "lessons learned" from Project Empowerment research that will apply to rehabilitation and disability practice. The language of RANs will be distilled down from "researcher ease" to include only language that is easily understood by frontline rehabilitation and disability practitioners and programme staff. The goal is to eventually have a RAN that corresponds to each research article published under the auspices of Project Empowerment. Once each RAN is disseminated, a designated Project Empowerment researcher will be available for follow up consultation via telephone and email as needed.

## INTELLIGENCE

### CONTACT

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**American Association of People with Disabilities (Andrew Imparato, JD).**

Contribution: *cross disability advocacy.*  
Gain: *more culturally competent system*

**Reginald Alston, PhD**

expert *research and cultural competency*

**Keith Wilson, PhD**

expert *research and cultural competency*

**Phil Rumrill, PhD**

expert *research and general rehabilitation*

Three minority universities in Virginia (students and faculty mentees – improved research)

**Advisory Board contribution:**

expert *culture/disability and services*

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**DR. LEWIS** is Associate Professor and Chair of the VCU Department of Rehabilitation Counseling, School of Allied Health Professions. He has conducted or co-conducted more than 60 refereed and invited presentations locally, regionally, nationally, and internationally over the past five years. His research focuses on the influence of culture on the disability experience and evaluating the effectiveness of disability services. He has authored or co-authored 35 publications (refereed articles, book chapters, abstracts and reports). He is currently Principal Investigator on more than \$2.5 million in grant funding. Dr. Lewis has worked in the health and disability arena for over 25 years.



# Improving disabilities research

Dr Allen Lewis, of Virginia Commonwealth University, explains the evolution of a project to track the experiences of people with disabilities from ethnic and racial minority groups

## Can you explain a little about the background of the project, its aim and where the concept came from?

This project has been on my mind for a long time. My initial teaching experience in the rehabilitation field was back in 1998 when I developed an early iteration of a multicultural counselling course in my academic department (Department of Rehabilitation Counselling in the School of Allied Health Professions at Virginia Commonwealth University in Richmond, Virginia, USA). After teaching that course for several years, two things became apparent to me from my exposure to the literature, that persons who are members of culturally diverse groups (members of racial and ethnic minority groups and other groups that are underserved in the public system) have a different, i.e., disproportionately negative, experience in the public disability system in the US. Also, the experiences of persons from culturally diverse groups are typically not researched often and with maximum methodological rigor.

The aim of the project is to provide documentation of the current experiences of culturally diverse populations in the public disability system in the US AND evaluate the current status of research on these groups to offer recommendations on how the research conduct process can be more culturally competent. In addition, the project aims to build more capacity (interest and know how) in the conduct of this type of research, including mentoring young, up and coming researchers and developing a community of practice.

## What are the expectations and objectives of the project?

### GOALS:

Improve knowledge of ethnic/racial minority experiences in the public disability system AND enhance knowledge of minority disability research methods and dissemination.

Engage in capacity building through training and mentoring the next generation of minority disability researchers.

### OBJECTIVES:

1. Conduct three primary research studies, using the participatory action research model with persons with disabilities and racial/ethnic minorities.
2. Establish a cadre of the next generation of minority disability researchers and begin formation of a community of practice for minority disability research.

## Why is it the case that disabled people from ethnic minority groups have reduced long-term functional outcomes after rehabilitation when compared with their white counterparts, and how does the project aim to address this?

What you are referring to is a concept called disability disparities. The definition of disability disparities that I propose is when an ethnic minority cultural group's aim is to receive services in the formal disability system, 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. The existence of differential outcomes at the conclusion of rehabilitation services is documented by Section 21 of the Rehabilitation Act Amendments passed by the United States Congress in 1992. There are several hypothesized reasons for these differences or disparities in the experiences and outcomes of formal disability system services such as: (1) cultural, biological, and genetic traditions that influence a cultural group's intergenerational response to things such as oppression, poverty, and social stress; (2) the ethnocentric worldview that many systems operate from OR the inability of the system and services to embrace pluralistic values and view points; and (3) practitioner and service system bias (conscious and unconscious) that contraindicates the provision of effective services to culturally diverse groups.

This project will not necessarily solve the disability disparities challenge because it is

too enormous. The project does attempt, however, to validate the current status of whether these disparities are still in existence in the 21st century and to what extent AND it will make recommendations on how to improve the state of minority disability research to make it more culturally competent going forward, as well as train more up and coming minority disability researchers who will do much more of this type of research in the coming years.

## Can you tell us if you faced any major challenges during the project? How did you overcome them?

The major challenge has been gaining and sustaining enough participation from students and faculty mentees at minority academic institutions. The reason for this is that most such institutions have a much smaller research expectation in comparison to their teaching mission and little time to expand research functioning. Therefore, as a practical matter, engaging students and faculty mentees from such institutions is a challenging proposition at best.

We have been as persistent and creative as possible in devising strategies. We have thought a lot about how to target the key motivators for these institutions and have some new strategies such as taking more "show and tell" productions to the institutions. We also are targeting a broader pool of faculty and students.

## What is the expected output of the project?

- 1 The findings from three major studies
- 2 Published papers and conference presentations
- 3 Several new spin-off grant proposals
- 4 A cadre of young, up and coming, culturally diverse researchers to carry forward the torch and do more of this type of research
- 5 A more formalised and growing community of practice of researchers interested in this type of research
- 6 A state of the science conference
- 7 A textbook