

Summary of “Strengthening Alzheimer’s Research in Diverse Populations”

Nina Silverberg
Presented in Salt Lake City
Education Core meeting
September 19, 2008

NIA's Health Disparities Toolbox

Health Disparities Toolbox - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites RSS Feeds Print Mail

Address <http://www.nia.nih.gov/ResearchInformation/outreach.htm> Go Links

Google Go Bookmarks 45 blocked ABC Check AutoLink AutoFill Send to Settings

U.S. NATIONAL INSTITUTES OF HEALTH

National Institute on Aging

LEADING THE FEDERAL EFFORT ON AGING RESEARCH

Health Research Grants & Training News & Events About NIA

Enter Search SEARCH

Research

Research Programs (Extramural)

Research at NIA (Intramural)

Conferences, Workshops & Meetings

Scientific Resources

Health Disparities Toolbox

Study Investigator's Toolbox

[NIA Home](#) > [Research](#)

[Print this page](#) [E-mail this page](#)

Health Disparities Toolbox

[Outreach, Recruitment and Retention of Health Disparity Populations in Aging Research](#) Adobe PDF (1.4M)




This document assists investigators to understand and comply with the NIH's inclusion policies for women and minorities when planning clinical research studies and submitting an application for NIH/NIA funding. The notebook presents advice on inclusion criteria, provides an overview of key elements in recruitment and retention processes, and includes suggestions on a number of practical applications, including ethical considerations.

[The Science of Inclusion](#)

A Gerontological Society of America publication, *The Science of Inclusion*, edited by Leslie Curry, PhD and James Jackson, PhD, offers guidance and lessons learned about recruitment and retention of diverse ethnic and racial groups in aging research from NIA-supported Resources Centers on Minority Aging Research.

Page last updated Aug 21, 2008

[Disclaimer](#) | [Accessibility](#) | [Policies](#) | [Contact Us](#) | [FOIA](#) | [Site Map](#)

Strengthening Alzheimer's Research in Diverse Populations

In conjunction with ICAD 2008
Saturday, July 26, 2008

1 – 1:15pm **Welcome and Overview**

Peggye Dilworth-Anderson, PhD
University of North Carolina, Chapel Hill

1:15 – 2:15pm **Recruitment and Retention**

*Recruitment & Retention of Diverse Groups in AD Research:
Approaches Used in Three Studies*

Peggye Dilworth-Anderson, PhD
University of North Carolina, Chapel Hill

Recruitment for Genetic Studies on AD

Goldie Byrd, PhD
North Carolina A&T University

2:15 - 3pm **Community Engagement & Recruitment**

The Links: Role of Community Organizations in AD Recruitment

Roslyn Fitch, MBA
University of Texas Southwestern Medical Center

*Recruitment for AD Studies: An Alzheimer's Association Chapter
Perspective*

Edie Yau
Alzheimer's Association, Northern California and Northern Nevada
Chapter

3:15-4:15pm **Cognitive Assessment**

Education and Literacy

Jennifer Manly, PhD
Columbia University

Bilingualism: Effects on Assessment and Cognitive Status

Ellen Bialystok, PhD, FRSC
York University

4:15-4:45pm **Post Mortem**

Brain Autopsy

John Morris, MD
Washington University

4:45 – 5:00 pm **Summary, Closing and Next Steps**

Cornelia Beck, PhD, RN
University of Arkansas

*Recruitment & Retention of
Diverse Groups in AD Research:
Approaches Used in Three Studies*

Peggye Dilworth-Anderson

- Community Based Participatory Research
- CDC Health Marketing
- Community outreach
- Advertising (print, word of mouth, radio)
- Paid recruiters/trainers
- Personal sales

The Marketing Mix: the Four Ps



- ***Product:*** the goods, services, or ideas provided
- ***Price:*** the cost incurred to participate in a study, including any barriers that must be overcome
- ***Place:*** the locations where the recruitment and the study take place
- ***Promotion:*** the media used to recruit participants

Recruitment for Genetic Studies on AD

Goldie Byrd

- Consent – surrogate
- Intergenerational survey
 - Knowledge of Tuskegee did NOT play a role
 - Older people participate more often
 - >50% in all groups WILLING to participate
- Look at average income/edu for area – tailor message
- Bring finance people to health fair

What African Americans want to know

- What's happening in their brain?
- Am I going to get it?
- How do I get help?
- Where is mom's DNA going?
- Can you test me?
- Will this (AD) break the family? (financially)

The Links: Role of Community Organizations in AD Recruitment

Roslyn Fitch

www.linksinc.org



The screenshot displays the homepage of The Links, Incorporated. At the top left is the organization's logo, and at the top right is a "MEMBERS ONLY" link. A green navigation bar contains the following menu items: Home, Welcome, About Us, In the News, The Links Foundation, Programs, 36th National Assembly, and Contact Us. The main banner features a photograph of a smiling woman in a professional suit, with the text "Seizing the Opportunity to Provide *World Class Leadership, Friendship and Service.*" overlaid. Below the banner, a green box contains text about the organization's history and a link to "LEARN MORE ABOUT THE LINKS". To the right of this box is a "The Links in Action" section with a "Select Links Area" dropdown menu currently set to "Eastern Area". The bottom of the page is divided into three columns: "In the Spotlight" with a group photo, "Links in the Community" with a photo of women at a whiteboard, and "Info & Resources" with a link to the "36th National Assembly Highlights" and a city skyline graphic.

MEMBERS ONLY

Service Through Friendship

Home Welcome About Us In the News The Links Foundation Programs 36th National Assembly Contact Us

Seizing the Opportunity to Provide
*World Class Leadership,
Friendship and Service.*

The Links, Incorporated founded in 1946, is one of the oldest and largest volunteer service organizations of women who are committed to enriching, sustaining and ensuring the culture and economic survival of African Americans and other persons of African ancestry. [LEARN MORE ABOUT THE LINKS](#) »

The Links in Action
Select Links Area >
Eastern Area ▾

In the Spotlight

Links in the Community

Info & Resources
36th National Assembly Highlights

Recruitment for AD Studies: An Alzheimer's Association Chapter Perspective

Edie Yau

- San Francisco, Chinese community
- Alz. Assoc recruitment initiative – dispel myths about clinical study participation
 - Physicians
 - Media
 - Grass roots
- Created task force
 - Clinicians, geriatricians, general medicine
 - AA experts, AD researchers

Edie Yau (cont)

- Pitfalls
 - Studies do not allow for limited English proficiency participants
 - FDA, pharma, NIH
 - Fulfillment, what can we offer?
 - Diversity of ads and brochures – marketing group created different brochures
- Community opinions
 - Cognitive decline is normal
 - Research could be harmful
 - Label has a negative connotation

Education and Literacy

Jennifer Manly

- Deconstructing race and education effects on cognitive performance
- Lifetime experience
 - Klineberg, 1935 – examined test data from World War I recruits that had previously been used as proof of intellectual inferiority of African Americans and immigrants (Brigham, 1923; Pintner, 1931), demonstrated that African American recruits educated in Northern states obtained higher scores on the Army Alpha and Beta tests than did White recruits born and raised in Southern states.
 - Todd & Wolpin (economists, U Penn) – cognitive achievement: home, school, racial test score gap
 - State schooling laws, compulsory attendance
- Literacy or local info on schools (such as student: teacher ratio) better proxy than yrs of education

Bilingualism: Effects on Assessment and Cognitive Status

Ellen Bialystok

1. What is bilingualism? (not categorical; prevalent)
2. Consequences of bilingualism
 - Verbal disadvantages (smaller vocab, more TOTs)
 - Cognitive advantages (executive fxn)
3. Protection against cognitive decline?
4. Assessing bilingualism



ELSEVIER

Neuropsychologia 45 (2007) 459–464

NEUROPSYCHOLOGIA

www.elsevier.com/locate/neuropsychologia

Note

Bilingualism as a protection against the onset of symptoms of dementia

Ellen Bialystok^{a,b,*}, Fergus I.M. Craik^{b,c}, Morris Freedman^{b,d,e}

^a Department of Psychology, York University, 4700 Keele Street, Toronto, Ontario, Canada M3J 1P3

^b Rotman Research Institute at Baycrest, Canada

^c Department of Psychology, University of Toronto, Canada

^d Division of Neurology, Baycrest, Canada

^e Department of Medicine, Division of Neurology, Mt. Sinai Hospital, University Health Network, and University of Toronto, Canada

Received 19 June 2006; received in revised form 23 October 2006; accepted 24 October 2006

Abstract

This study examined the effect of lifelong bilingualism on maintaining cognitive functioning and delaying the onset of symptoms of dementia in old age. The sample was selected from the records of 228 patients referred to a Memory Clinic with cognitive complaints. The final sample consisted of 184 patients diagnosed with dementia, 51% of whom were bilingual. The bilinguals showed symptoms of dementia 4 years later than monolinguals, all other measures being equivalent. Additionally, the rate of decline in Mini-Mental State Examination (MMSE) scores over the 4 years subsequent to the diagnosis was the same for a subset of patients in the two groups, suggesting a shift in onset age with no change in rate of progression.

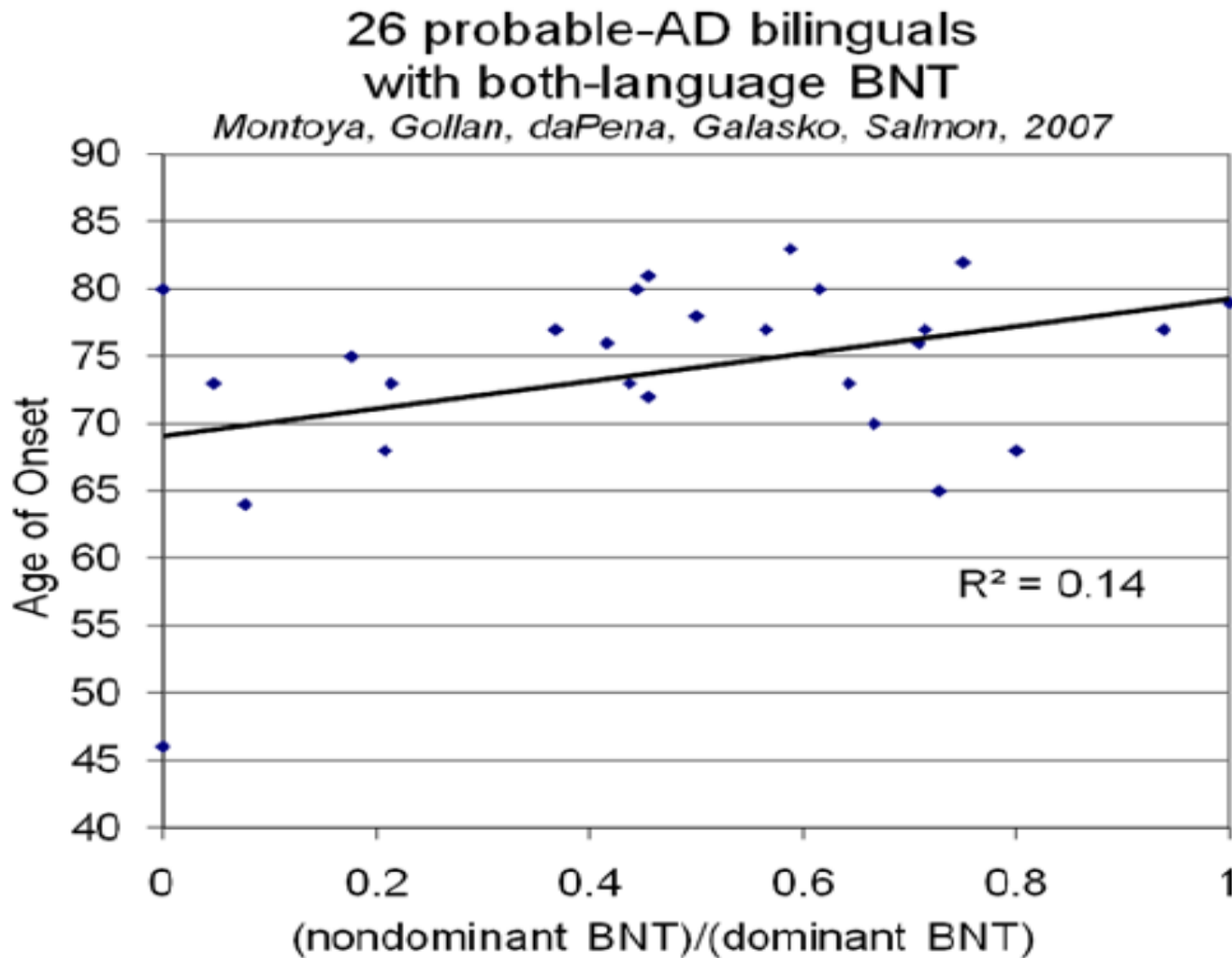
© 2006 Elsevier Ltd. All rights reserved.

Keywords: Bilingualism; Cognitive reserve; Dementia



Group	N	Years Duration	Years Education	MMSE	Onset Age
Monolingual	91	3.7 (3.2)	12.4 (3.8)	21.3 (6.4)	71.4 (9.6)
Bilingual	93	3.0 (3.1)	10.8 (4.1)	20.1 (7.1)	75.5 (8.5)

Onset of Symptoms and Degree of Bilingualism



New paper coming out

Neuropsychological, Cognitive, and Theoretical Considerations for Evaluation of Bilingual Individuals

Monica Rivera Mindt & Alyssa Arentoft &
Kaori Kubo Germano & Erica D'Aquila &
Diane Scheiner & Maria Pizzirusso &
Tiffany C. Sandoval & Tamar H. Gollan

Received: 29 July 2008 / Accepted: 31 July 2008

Brain Autopsy

John Morris

- Clinically relevant findings in up to 1/3 of autopsies
- 40% undecided
 - Y (43%) advance medical knowledge, establish correct cause
 - N (17%) “fear of disfigurement,” “suffered enough”
- Barriers
 - Physician discomfort
 - Attitudes of pts, families
- Value
 - Necessary for AD dx confirm (ex. ADNI autopsy case DLB)
 - Obtain tissue to ↑ understanding of disease mechanisms