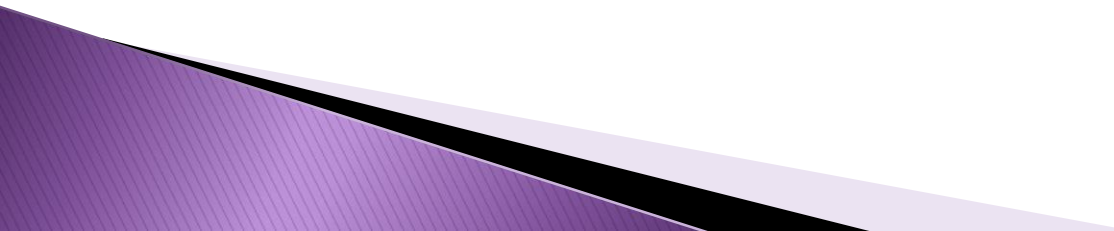# The Alzheimer's Disease Caregiver Support Initiative Evaluation

What We've Learned, Why It Matters, and Where We're Going

ALZHEIMER'S DISEASE PROGRAM ANNUALCONTRACTORS MEETING
May 23 – 24, 2018

Mary Gallant, Statewide Evaluation Lead
Meghan Fadel, Evaluation Coordinator, DOH
Mary Riley-Jacome, Project Coordinator
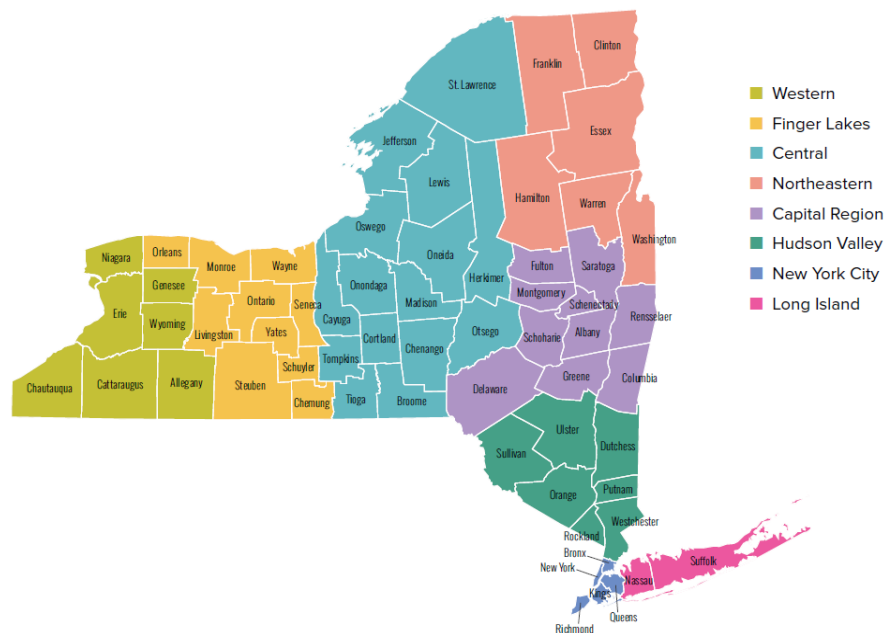Emily Gudewicz, Graduate Student Assistant

Workshop Objectives

1. Describe the goals of the Alzheimer's Disease Caregiver Support Initiative Evaluation

2. Identify 2 service delivery successes and challenges relevant to your region

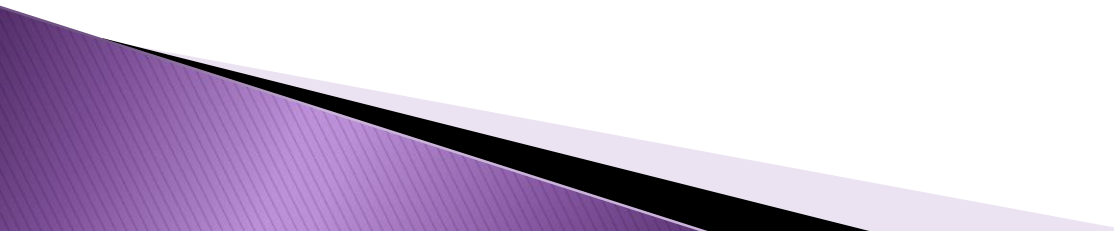3. List 3 possible strategies to help address identified barriers

Statewide Evaluation Objective

◦ People with dementia and caregivers

◦ Organizations providing support

◦ New York State

New York State Department of Health Alzheimer's Disease Program

Legend:
- Western
- Finger Lakes
- Central
- Northeastern
- Capital Region
- Hudson Valley
- New York City
- Long Island

Primary Evaluation Questions

1. Who is reached by this initiative?

2. What is the impact of this initiative on people with dementia and their caregivers, and on providers and organizations?

3. Are recommended practices being adopted?

4. What are the lessons learned with respect to implementation of programs and services?

5. Does this initiative result in sustainable enhanced capacity at organizations and in the state?

Who Are You Reaching?

- Focus to date has been on understanding numbers and characteristics of caregivers reached and on initial implementation barriers and successes

- THANK YOU for all your efforts in collecting and submitting information about the clients you serve, and for your responses to the survey of contractors

- Instrumental for understanding whether the target audience is being reached and for making the case for future funding

Where Are We Going?

- Annual contractor survey
  - Summer 2018
  - Focus on implementation of core services, staffing
  - Will allow us to document the type of evidence-based services being delivered, fidelity of implementation, understand lessons learned in terms of core service delivery

- Survey of caregivers
  - Implemented by evaluation team
  - Examine outcomes for caregivers and care recipients
    - E.g. burden, positive caregiving outcomes, care recipient health care utilization
  - Will allow us to document impact your work is having on caregivers and care recipients

- Analysis of NYS DOH data
  - E.g. Medicaid data
  - Will allow us to examine impact of initiative on health care utilization and costs for state

Community Support and Education To Date*

55,932 care consultations

39,389 helpline calls serving 21,521 individuals

6,791 support group sessions
180,279 hours of respite

25,157 participants in 3348 education sessions

* From Progress reports CG1 Y1-Y2, Alzcap Y2 & Y3 (Q1-Q3) & CG2, Y1& Y2,Q1-Q3

Diagnostic and Professional Training*

11,965 diagnostic assessments

43,878 referrals to community providers

34,455 (duplicated) medical and healthcare professionals trained by CEADS. Another 10,722 healthcare professionals and professional caregivers received training from other contractors

ADCSI Initiative Year 1 Evaluation Highlights

Implementation Experience – Year 1

	% of Providers Experiencing
New informal partnerships	92
New formal partnerships	59
Staffing/Hiring Challenges	
Lack of applicants with experience in dementia	39
Staff turnover	37
Lack of applicants with desired qualifications	34
Service Delivery Challenges	
Participant recruitment	46
Reaching target audience	43

Community Support Goals – Year 1

Services	# of Services	Goal	% of Goal	People Reached	Goal	% of Goal	Avg # per person
Consultation Services	20,389	29,219	70%	6,234	6,959	82%	3.27
Support Group Sessions	3,217	4,327	74.4%	5,174	2,939	176%	4.33
Educational sessions	1,770	3,181	55.6%	12,803	9,082	141%	1.50
Respite (hours)	49,897	233,547	21.4%	1,188	2,580	44.4%	42 hours
Helpline calls	23,505	22,650	104%	12,596	11,129	88.2%	1.86

Respite

| Barriers	Strategies
• Lack of respite partners, especially in rural areas • Lack of trained home health aides • Time constraints (to recruit/train respite volunteers and to match care recipients with appropriate volunteers) • Agency volunteer requirements • Lack of understanding about respite • Some caregivers appeared intimidated by the scholarship process • Medicaid/MLTC restrictions limited caregivers' ability to access respite for stress reducing rather than employment or health-care related activities	• Meet with respite providers to brainstorm solutions to barriers • Expand recruitment of volunteers and respite providers • Modify hours/schedules for respite care and training • Reorganize staff workloads to prioritize respite coordination • Increase outreach and education to families about respite, respite scholarships and Medicaid reimbursement options • NYSDOH grant management policy changes to allow consumer directed model of respite care in response to respite provider shortages

Center of Excellence Goals – Year 1

Diagnostic and Patient Care Services Provided and Individuals Reached	#	Goal	% of Goal
Diagnostic Process			
• New Diagnostic Assessments	5,076	4,885	103.9%
• Referrals Received from providers	5,058	3,785	133.6%
• Consultations to review assessments	6,737	4,885	137.9%
• Primary care provider consultations	5,621	4,465	125.9%
Patient Management and Care			
• Care Plans Developed	5,880	4,400	133.6%
• Care Consultations	4,044	4,365	92.6%
• Total referrals to community services	18,359	14,850	123.6%
• Clinical Trial information	1,949	724	269.2%
Technical Assistance to PCPs	967	1,267	76.3%

Center of Excellence Goals – Year 1

Health Professional Trainings	#	Goal	% of Goal
Education programs to physicians	309	173	178.6%
• Primary Care Physicians (PCPs) trained	1,487	2,560	58.1%
• Specialty Care Physicians trained	2,036	1,594	127.7%
Education programs to non-physician health care providers (HCPs)	221	116	190.5%
• Non-physician HCPs trained	3,178	2,550	124.6%
Education programs to students	193	109	177.1%
• Medical students trained	3,770	2,119	177.9%
• Health Professions students trained	1,697	1,725	98.4%

Underserved populations:
Successes and Challenges
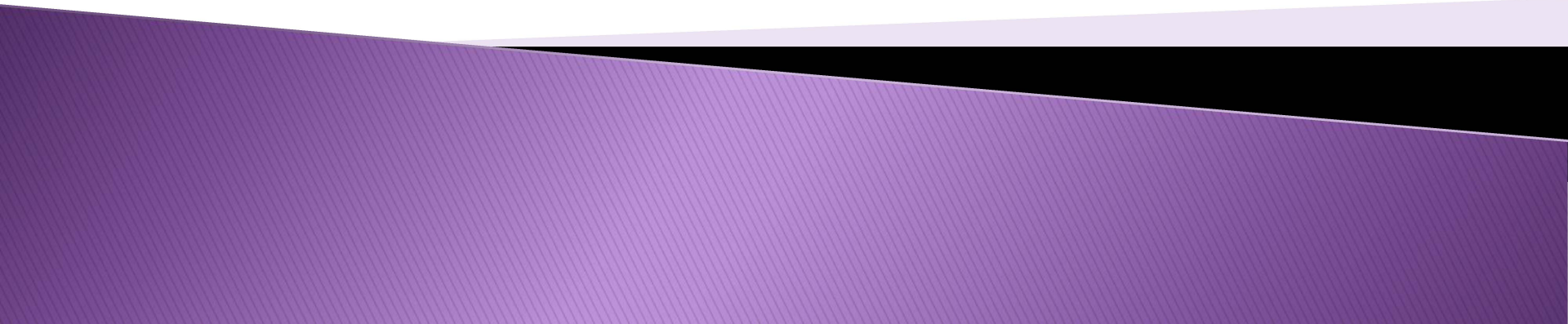
Data and analysis

Key points:

- Snapshot from 1st year of demographic data

- Preliminary findings
  ◦ Successes
  ◦ Areas of improvement
  ◦ "Best practice" strategies

- Limitations:
  ◦ Incomplete data set – most demographic data collection began July 1st or after
  ◦ Missing data
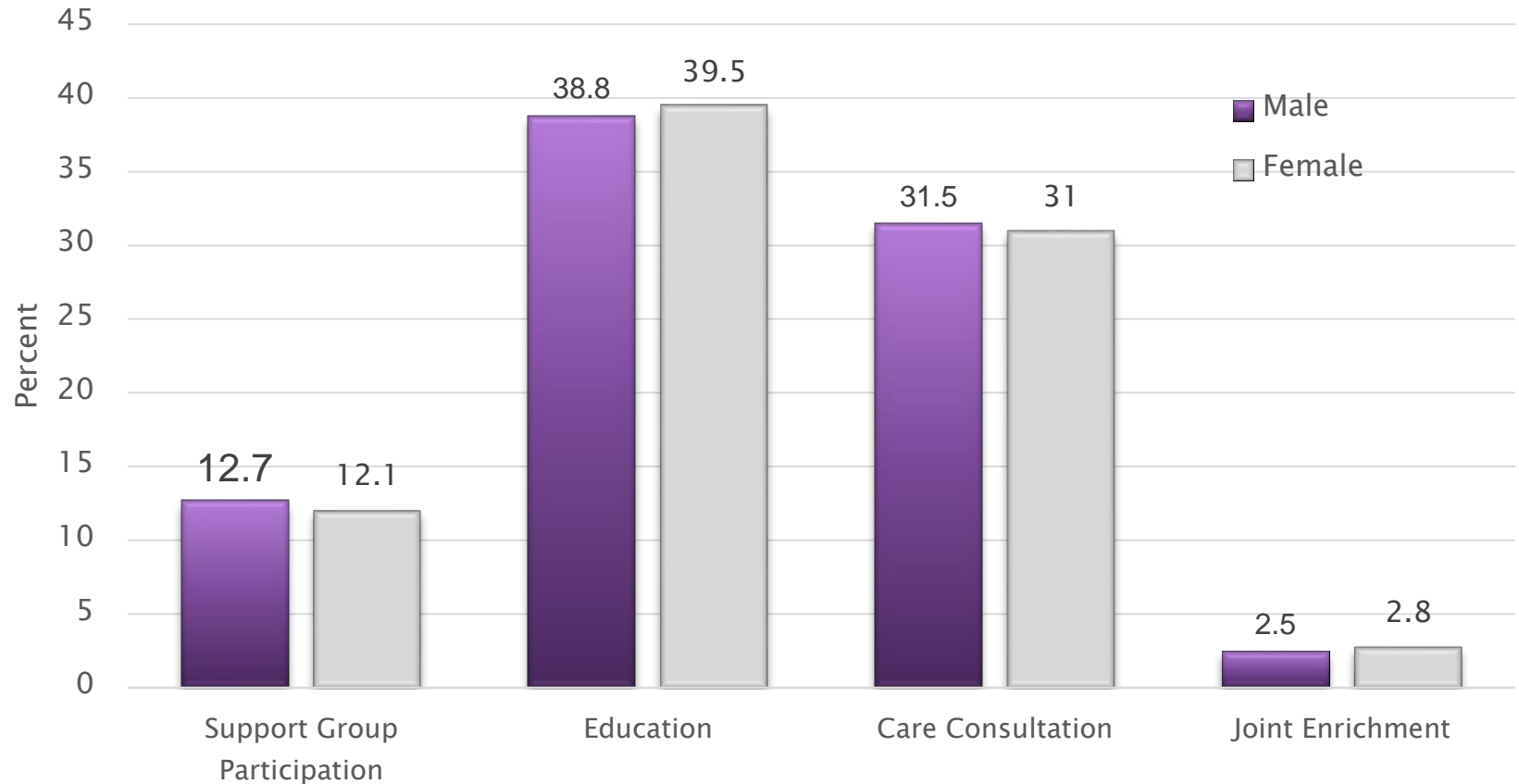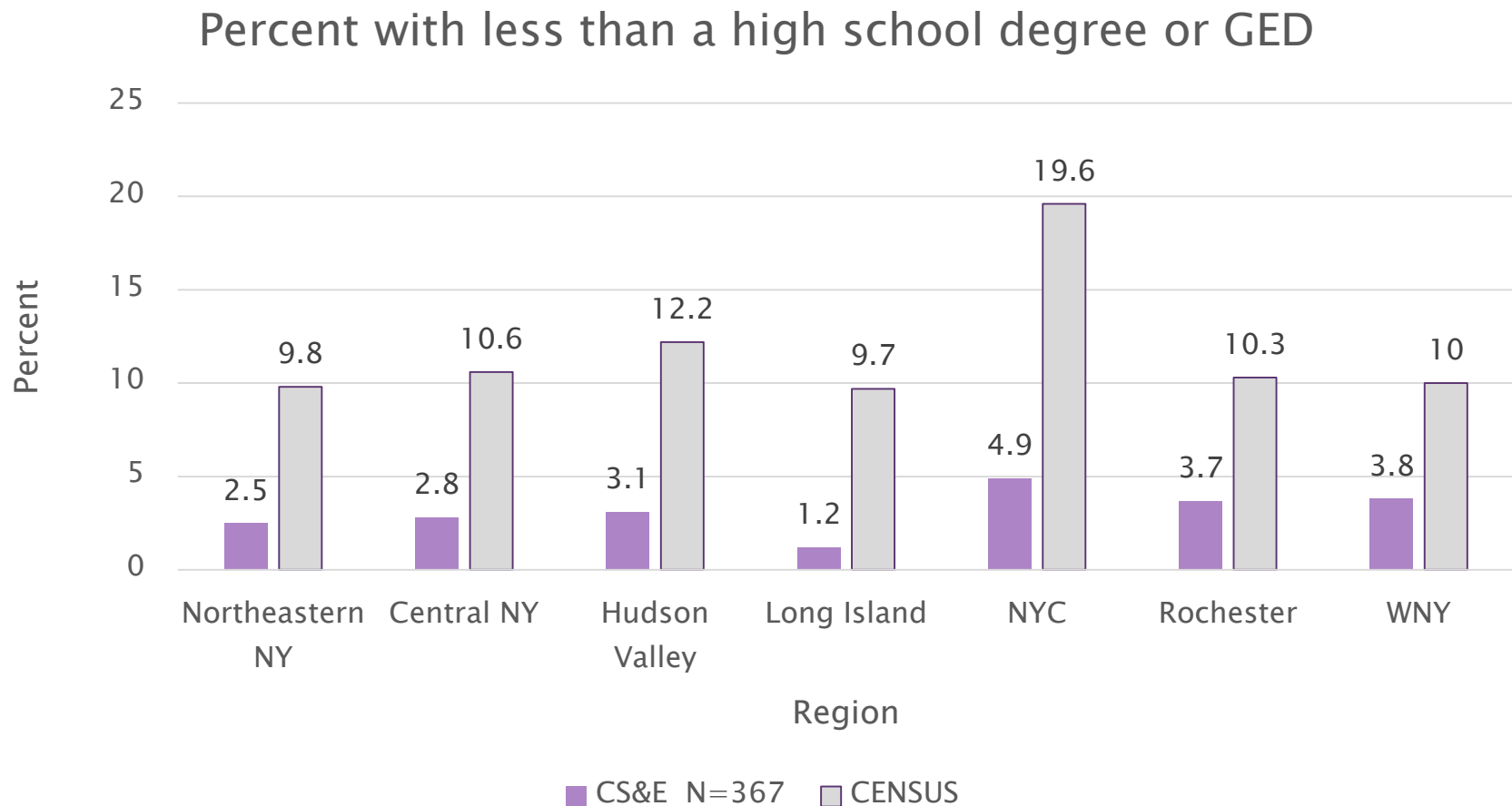 ◦ No data on non-responders
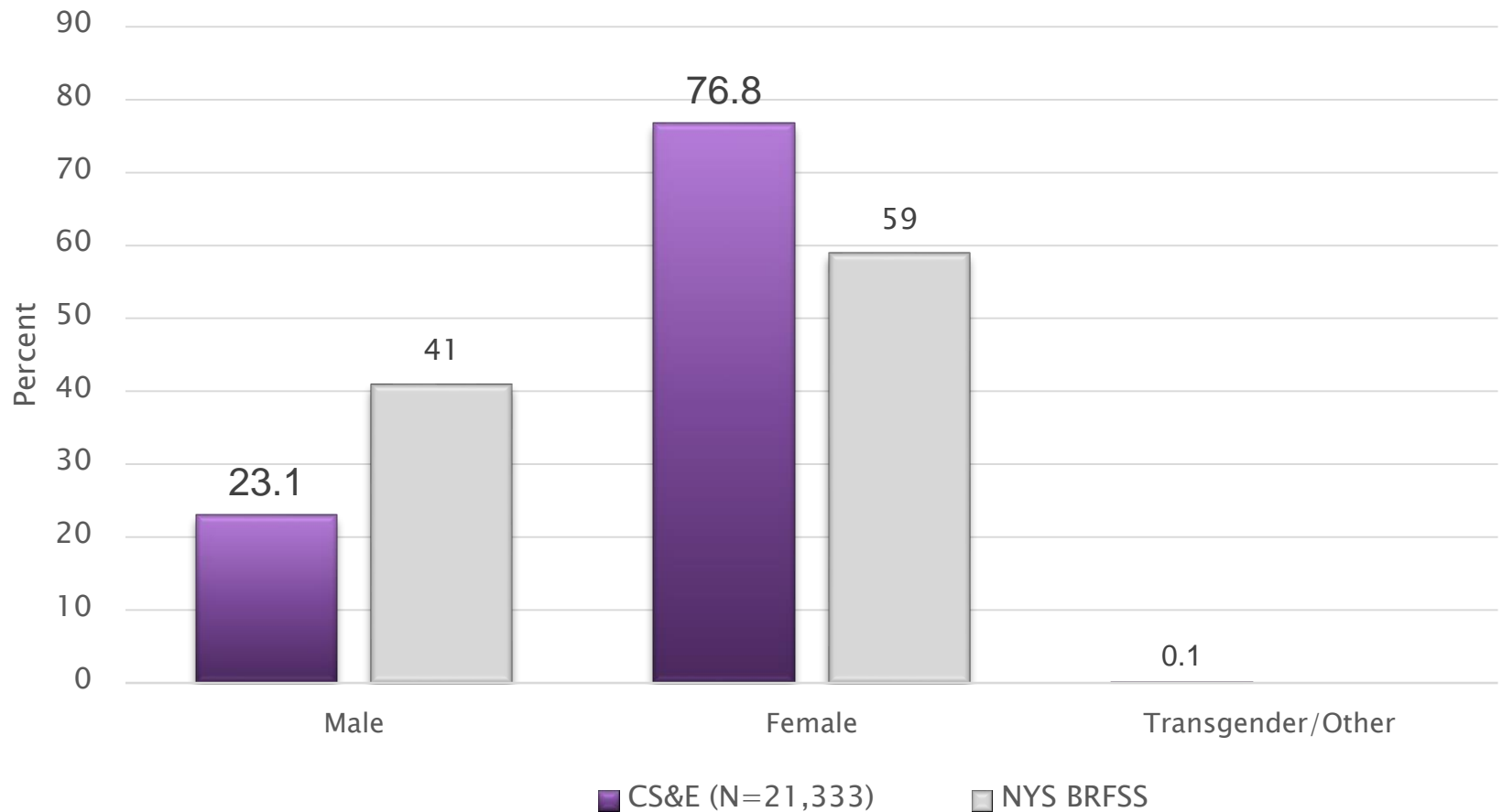
Participation in Services by Gender

N=16,389
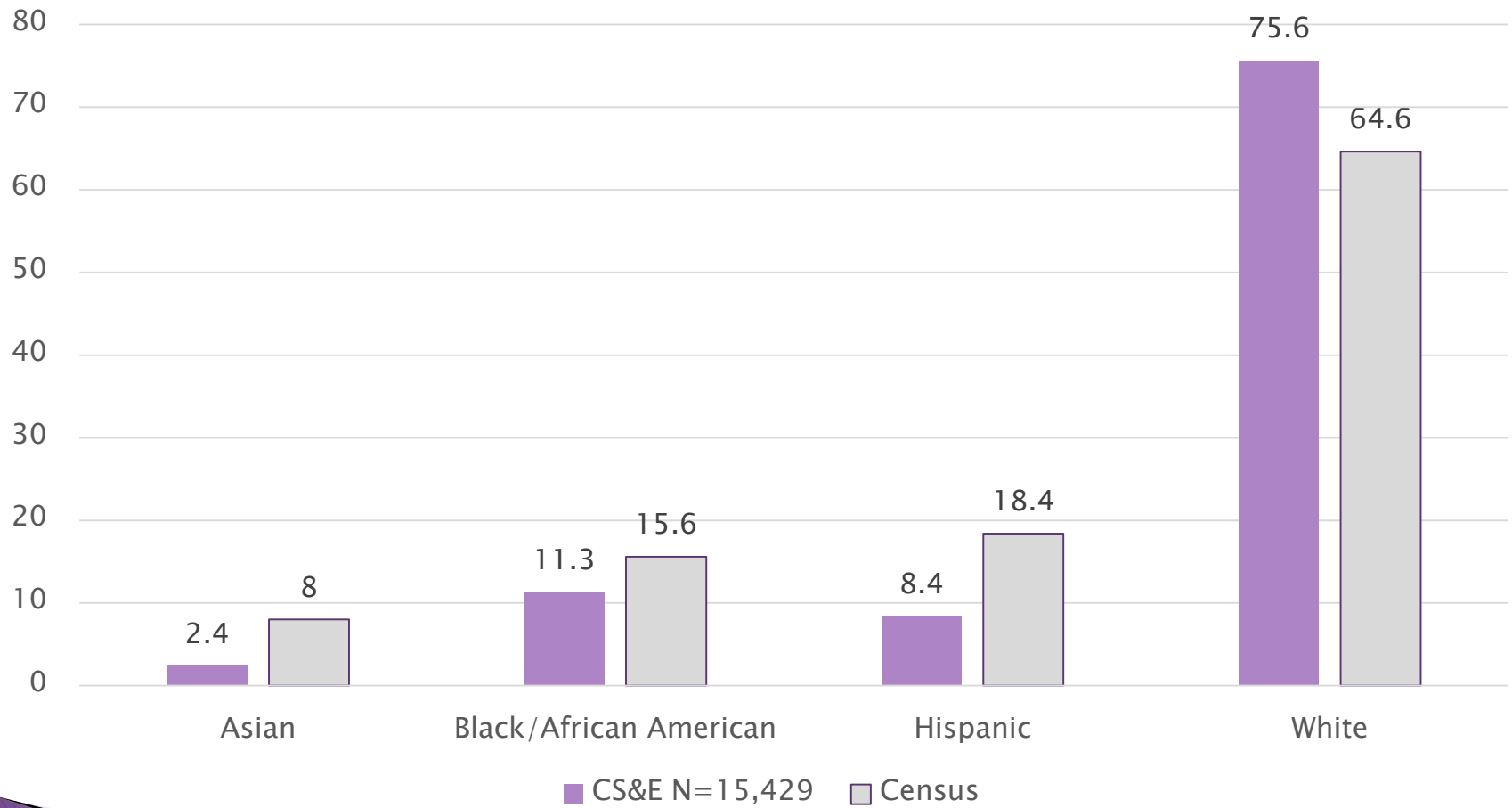

Source: CS&E contractor demographic data April 1 2016–March 2017

Educational Attainment of Caregivers by Region Compared to Census Estimates

Percent with less than a high school degree or GED

Region	CS&E N=367	CENSUS
Northeastern NY	2.5	9.8
Central NY	2.8	10.6
Hudson Valley	3.1	12.2
Long Island	1.2	9.7
NYC	4.9	19.6
Rochester	3.7	10.3
WNY	3.8	10

Data source: U.S. Census Bureau, American Community Survey 2011–2015; CS&E contractor demographic data April 1 2016–March 2017

Race and Ethnicity Compared to U.S. Census Estimates for New York
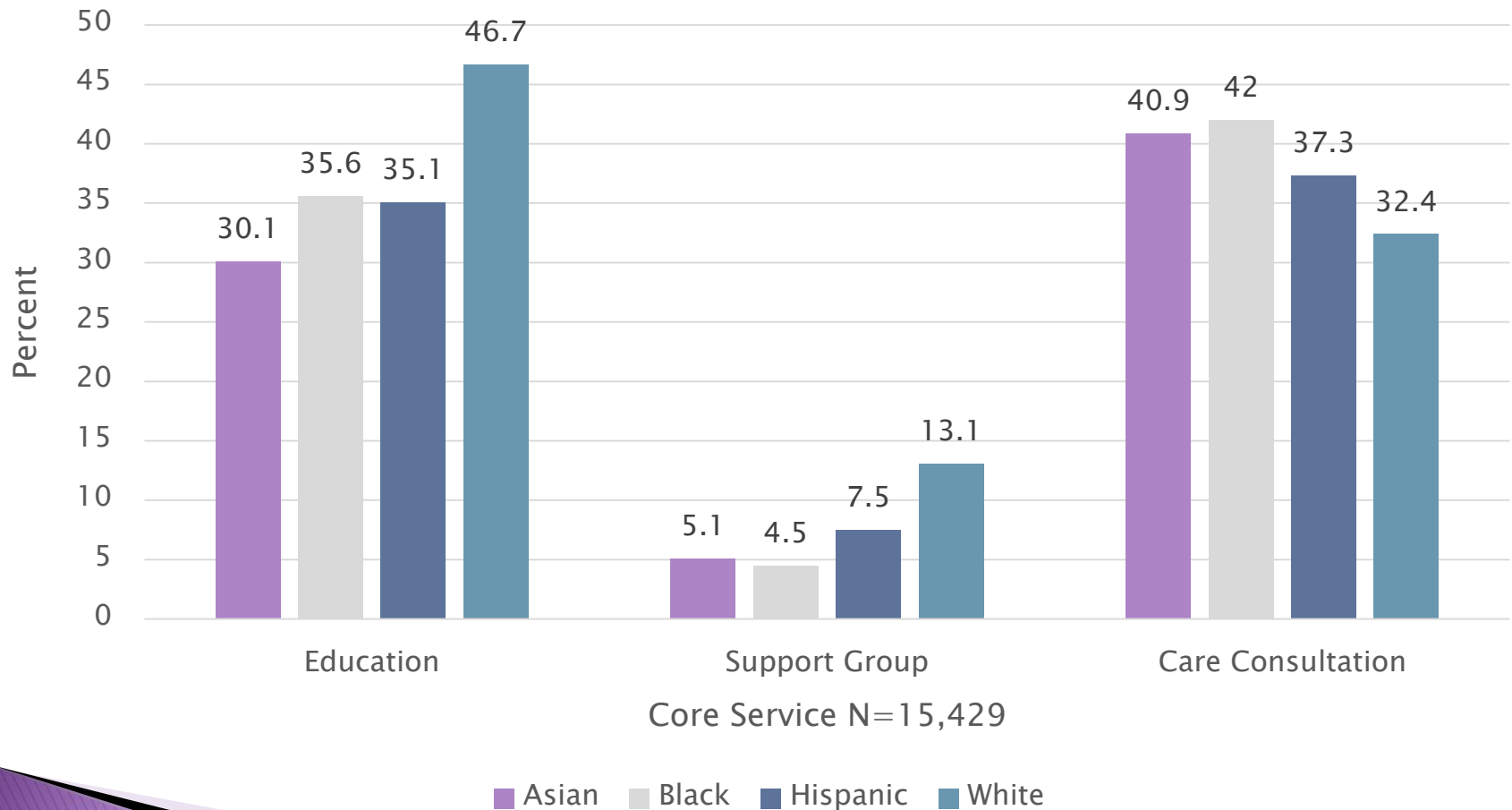

Data source: U.S. Census Bureau, American Community Survey 2011–2015; CS&E contractor demographic data April 1 2016–March 2017
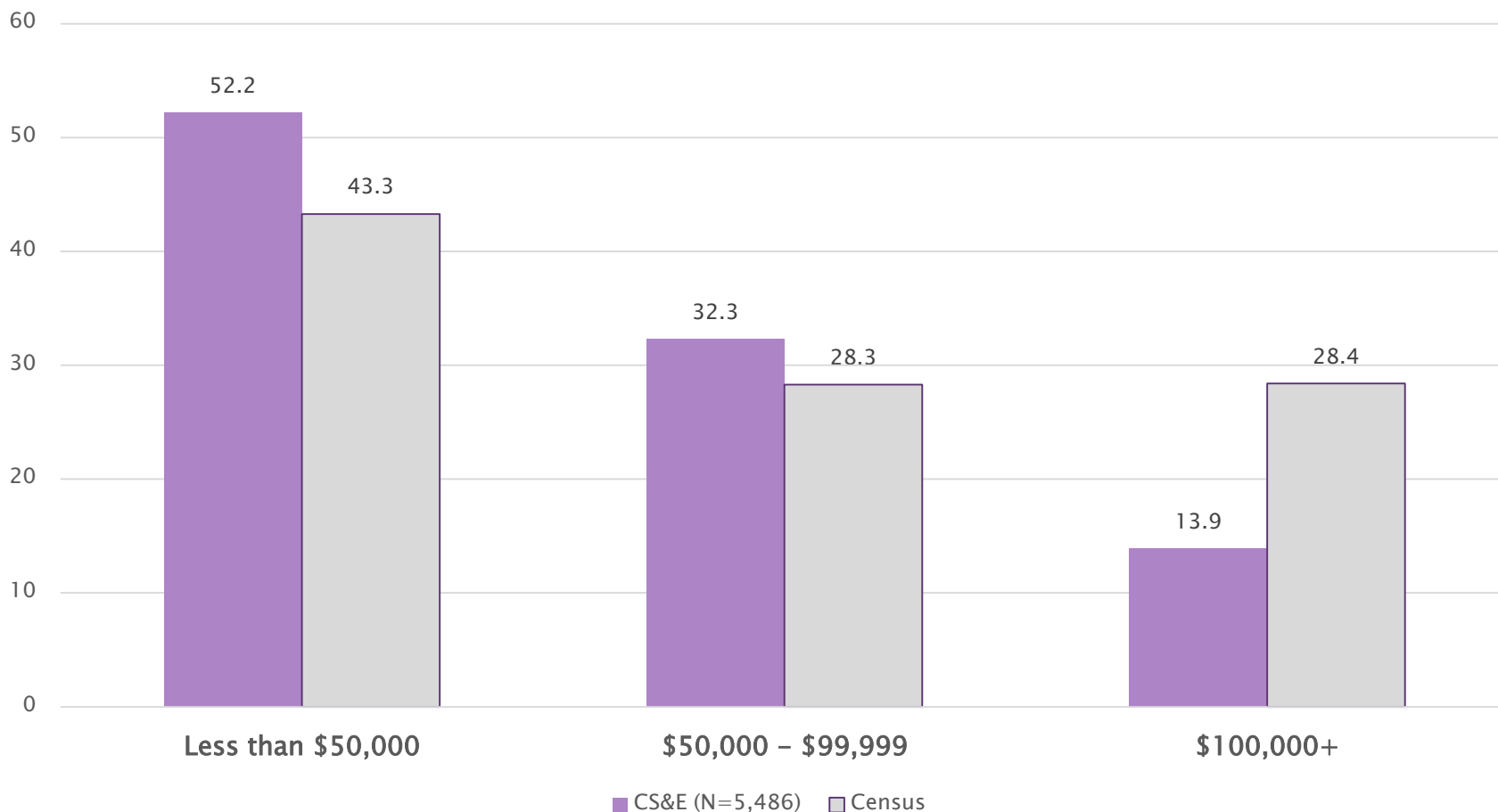
Reaching Racial/Ethnic Minority Populations

‣ Reach to minority populations is less than expected when compared to Census data

◦ Asian and Hispanic caregivers underrepresented in population served by ADCSI in all regions

◦ Black/African American caregivers underrepresented in ADCSI population in most regions

‣ When compared to Census data, White/ Caucasian caregivers overrepresented in the ADCSI service population in all regions except NYC and Hudson Valley

Participation in Core Services by Race/Ethnicity

Core Service N=15,429

Legend: Asian, Black, Hispanic, White

Education: Asian 30.1, Black 35.6, Hispanic 35.1, White 46.7
Support Group: Asian 5.1, Black 4.5, Hispanic 7.5, White 13.1
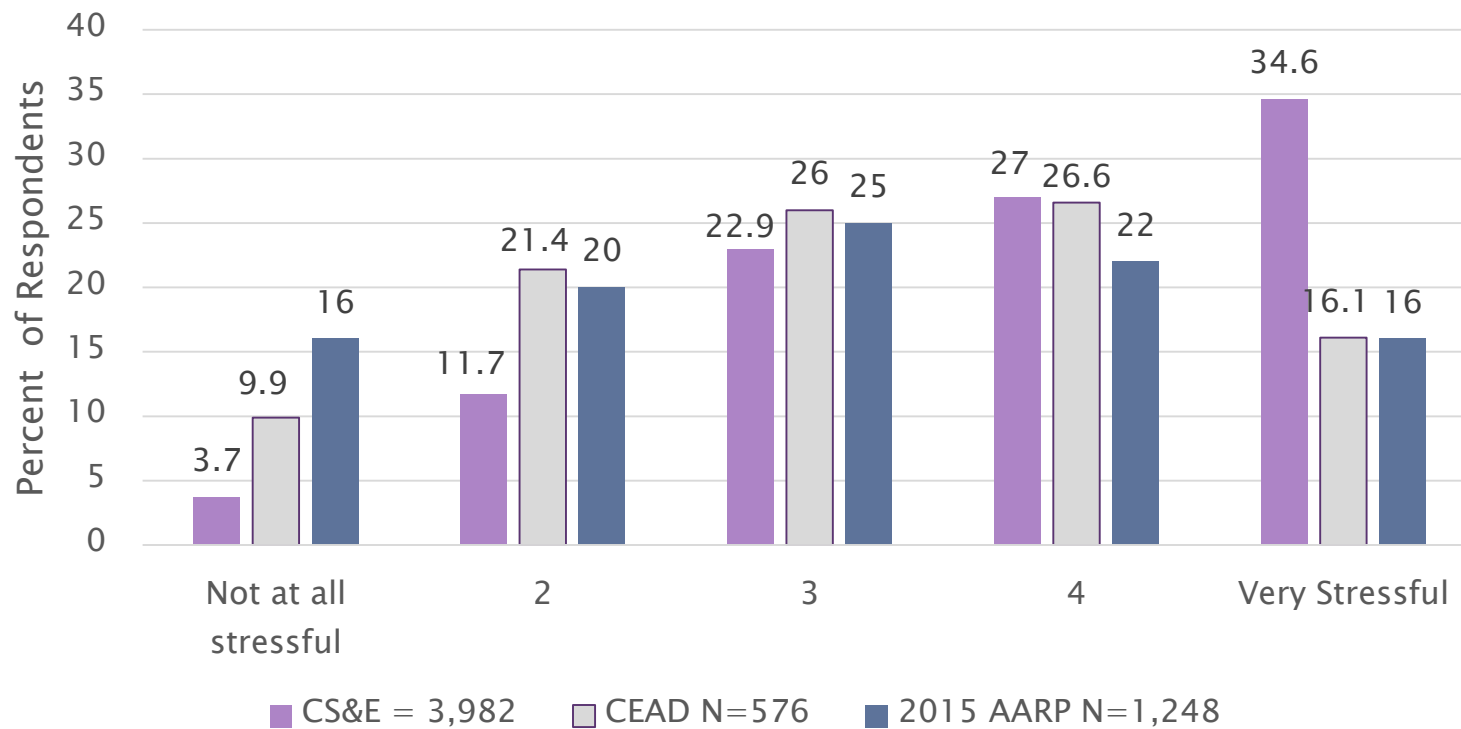Care Consultation: Asian 40.9, Black 42, Hispanic 37.3, White 32.4

Caregiver Annual Household Income Compared to Census Data

Data source: U.S. Census Bureau, American Community Survey 2011–2015; CS&E contractor demographic data April 1 2016–March 2017

Emotional stress of caregiving compared to a national sample

Data sources: National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S; and ADCSI data.
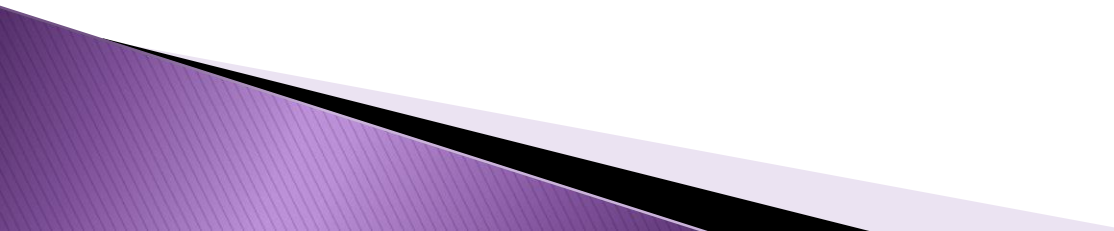
Discussion Questions

- Share experiences and learn strategies to effectively engage target populations
- Form small groups to discuss - please include other contractors in your group!
- Each group should have:
  ◦ Someone to take notes
  ◦ A speaker to report out
- Approximately 5 minutes to discuss each topic
- After 20 minutes, we will reconvene for a brief report out
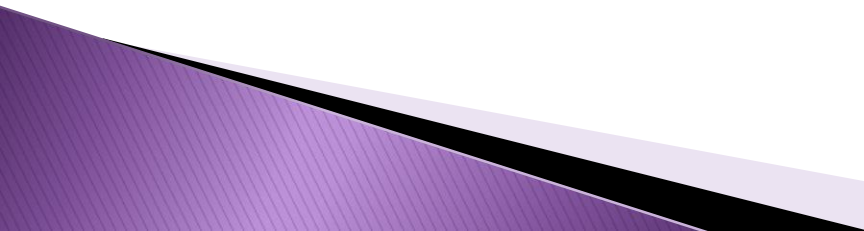- Notes will be collected, compiled and then e-mailed out to participants

Discussion Topic 1

Finding: 3/4 of the caregivers served by this initiative are women

- In your experience, what strategies are effective in reaching and engaging caregivers of different genders?
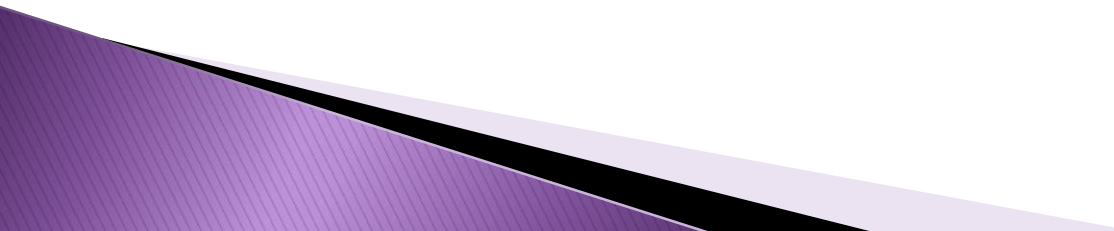
- What strategies have proven ineffective?

Discussion Topic 2

Finding: Caregivers with lower levels of education seem to be underrepresented in the population served

▸ Is it a challenge to reach populations with lower levels of education? Or is it a challenge to engage them in data collection efforts?

▸ What strategies are effective for overcoming these barriers?

Discussion Topic 3

Finding: Racial/ethnic minority caregivers seem to be underrepresented in the population served

- In your experience, what are the barriers to engaging diverse populations in core services?

- What strategies have worked to engage diverse populations?

Discussion Topic 4

Finding: This initiative seems to be reaching caregivers who have spent a longer time caregiving, spend a high number of hours per week caregiving, and report relatively high levels of strain

▸ How would you use this information to help you plan your services?

OR

Finding: Fewer primary care providers received training in year 1 compared to other types of providers

▸ What strategies have worked to engage primary care providers in training?

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