

Specialized Supportive Services for Adults with Intellectual and Developmental Disabilities (IDD) and Alzheimer's Disease and Related Disorders (ADRD)

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Project Director

Seven Hills RI

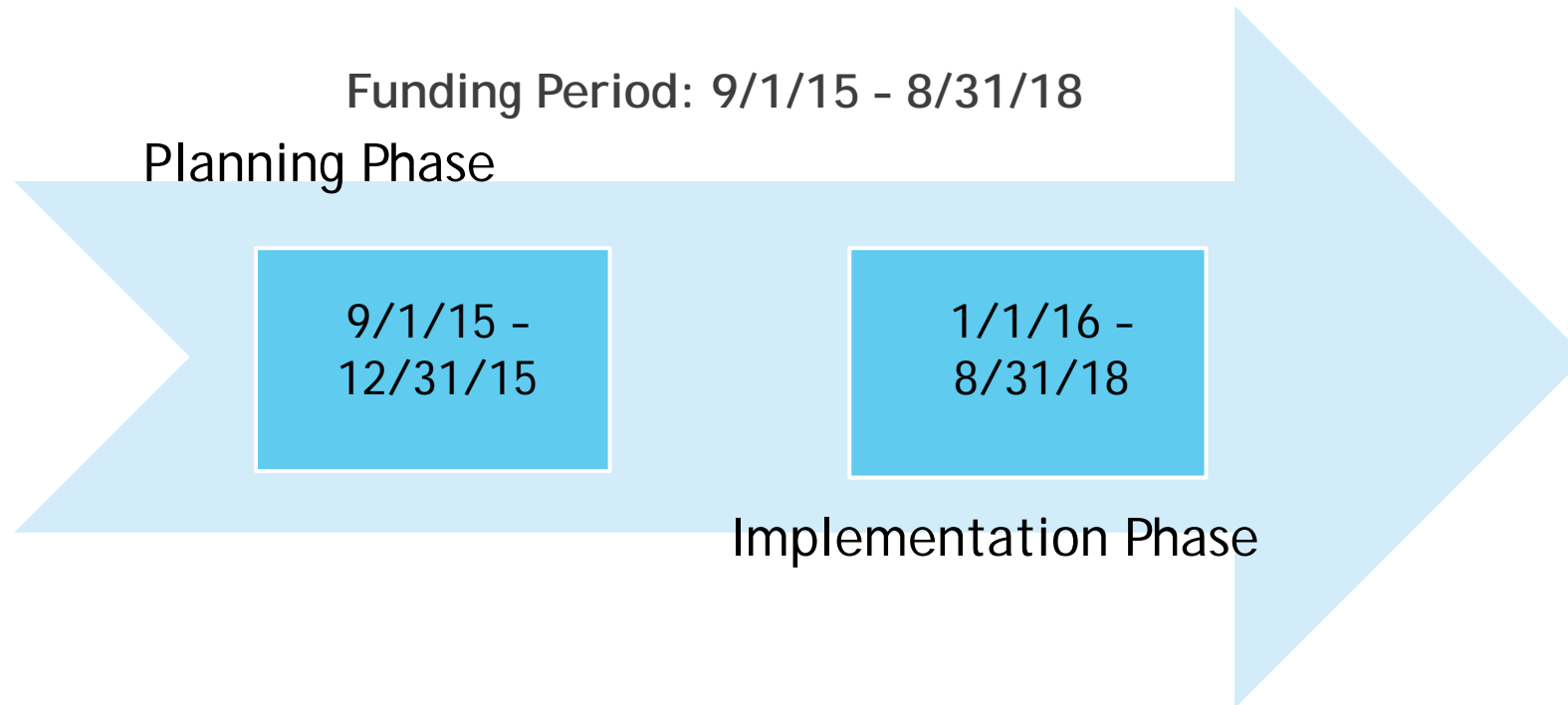
- ▶ Grant number 90AL0014-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services



Overarching Project Goal

- ▶ Engage key community stakeholders including Alzheimer's and Developmental Disability (DD) provider organizations, self-advocates, and others throughout Rhode Island in order to strengthen and expand the current dementia-capable system of care for older adults with IDD and ADRD, and their caregivers.

Timeline



Partners

- ▶ National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
 - ▶ Collaborate with SHRI to provide a statewide two-day workshop and a third day train-the-trainer workshop using its national curriculum, will provide technical assistance to SHRI on the project, and will sit on the Project's Advisory Board.
- ▶ Alzheimer's Association of Rhode Island (AARI)
 - ▶ Collaborate with SHRI to provide ADRD related trainings for staff and caregivers, will provide technical assistance to SHRI on the project, and will sit on the Project's Advisory Board.
- ▶ Healthcentric Advisors
 - ▶ Collaborate with SHRI to serve as the evaluator, informing the development and implementation of the program evaluation, quality assurance program, and "Lessons Learned" document. They will also work closely with the Project Director to adhere to all semi-annual grant reporting and will sit on the Project's Advisory Board. Efforts also include marketing of events.

Additional Stakeholders

- ▶ Advocates in Action
- ▶ American Nurses Association of Rhode Island
- ▶ Charter Care
- ▶ Community Provider Network
- ▶ RI Developmental Disabilities Nurses Association
- ▶ RI Department of Health
- ▶ John Stoukides, MD
- ▶ LeadingAge Rhode Island
- ▶ Senior Agenda Coalition
- ▶ RI Department of Behavioral Healthcare, Developmental Disabilities and Hospitals
- ▶ RI Disability Law Center
- ▶ RI Governor's Council on Disability
- ▶ RI Governor's Long-Term Care Coordinating Council
- ▶ PACE
- ▶ University Centers on Excellence in Developmental Disabilities - Paul V. Sherlock Center on Disabilities at Rhode Island College
- ▶ Visiting Rehab Services



Target Population

- ▶ Over 4000 adults supported by RI DD Provider organizations annually and their paid and family caregivers
- ▶ Adults with I/DD living in the community who have not previously accessed DD supports



Purpose and Goals

Purpose:

Details how we identify, collect, and analyze the defined metrics that assess each proposed intervention's impact and determine whether or not the program achieved its anticipated outcomes

QA program - to track adherence to program deliverables and anticipated outcomes

Objectives and activities:

1) Promote and provide person- and family-centered care and training to improve care for and prepare individuals living with moderate to severe impairment and their caregivers for the future

- Resource Guide
- Legal and Financial Planning workshop
- Support groups

2) Improve the quality and effectiveness of programs and services dedicated to individuals aging with IDD and ADRD, or those at high risk of developing ADRD

- Expansion of SHRI's Adult Day Health (ADH) program to include Alzheimer's Certification
- NTG Educational and "Train-the-Trainer" workshops
- Support adults with IDD, with evidence-informed interventions, MUSIC & MEMORYSM and Geri-CareTM

3) Deliver Behavioral Symptom Management Training and expert consultation to family caregivers

- Access to a full-time Clinical Specialist at SHRI
- Educational workshops on Behavioral Symptom Management

Methods

Methods

Process Measures

- Collected to track reach/impact for all trainings and workshops

Demographic Data

- Collected from training and workshop participants and individuals with IDD and ADRD who received interventions through the grant

Proximal/Outcome Measures

- Collected to assess impact of grant interventions on participant satisfaction, knowledge, caregiver stress/burden and the dementia attitude scale for providers/clinicians

Developed/adapted surveys to:

- elicit both qualitative and quantitative data from program participants
- evaluate the efficacy of intervention strategies
- collect information on barriers or successes throughout the project

Evidence-based surveys were included where available:

- Caregiver Stress
- Caregiver Burden
- Dementia Attitude Scale (DAS)

Demographic Information: for grant activity participants and individuals with IDD/ADRD

Integrated Care and Support

- ▶ To sustain our efforts we sought to educate:
 - ▶ Current caregivers (paid and unpaid) and professionals in the DD field
 - ▶ Professionals not specializing in the DD field
 - ▶ Those who provide education
 - ▶ Funding source
 - ▶ Managed care organization and 3rd party payers

Results

Results

Total Project Reach

Selected Outcomes

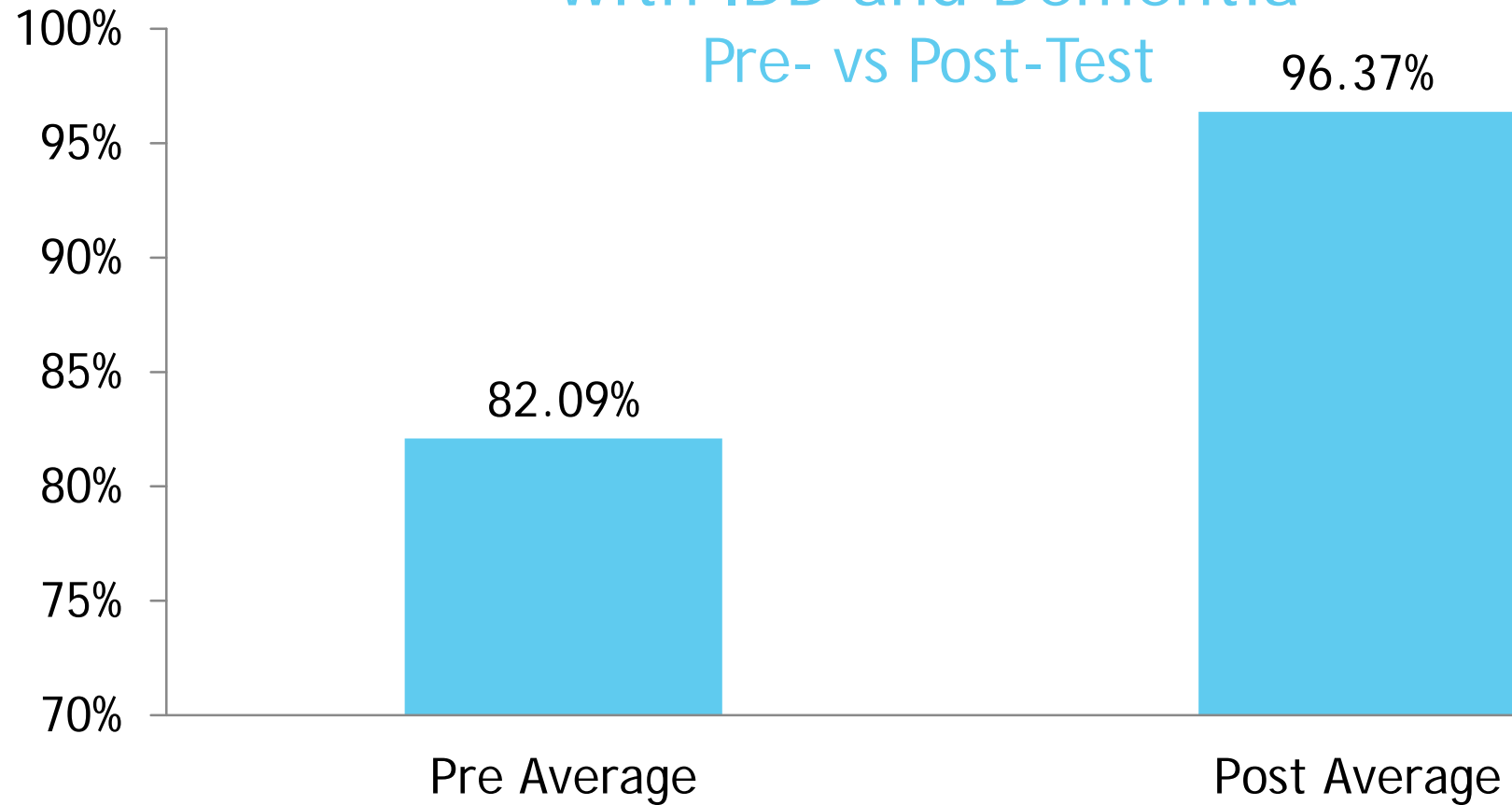
- National Task Group Training: Knowledge Gained
- National Task Group Training: Dementia Attitude Scale
- Support Group: Caregiver Strain Index (Post)
- Music and Memory Intervention
- Qualitative Data

Project Reach: September 2015 - May 2018

Grant Activity	Caregivers & Professionals
National Task Group (NTG) Training	754
Support Groups	59
Behavioral Self-Management Educational Series (includes Legal and Financial Planning workshops)	127
Behavioral Symptom Management Training Geri-care Trained Music and Memory Training	47 individuals 14 sites/facilities
Miscellaneous Trainings (powerful tools for caregivers)	177

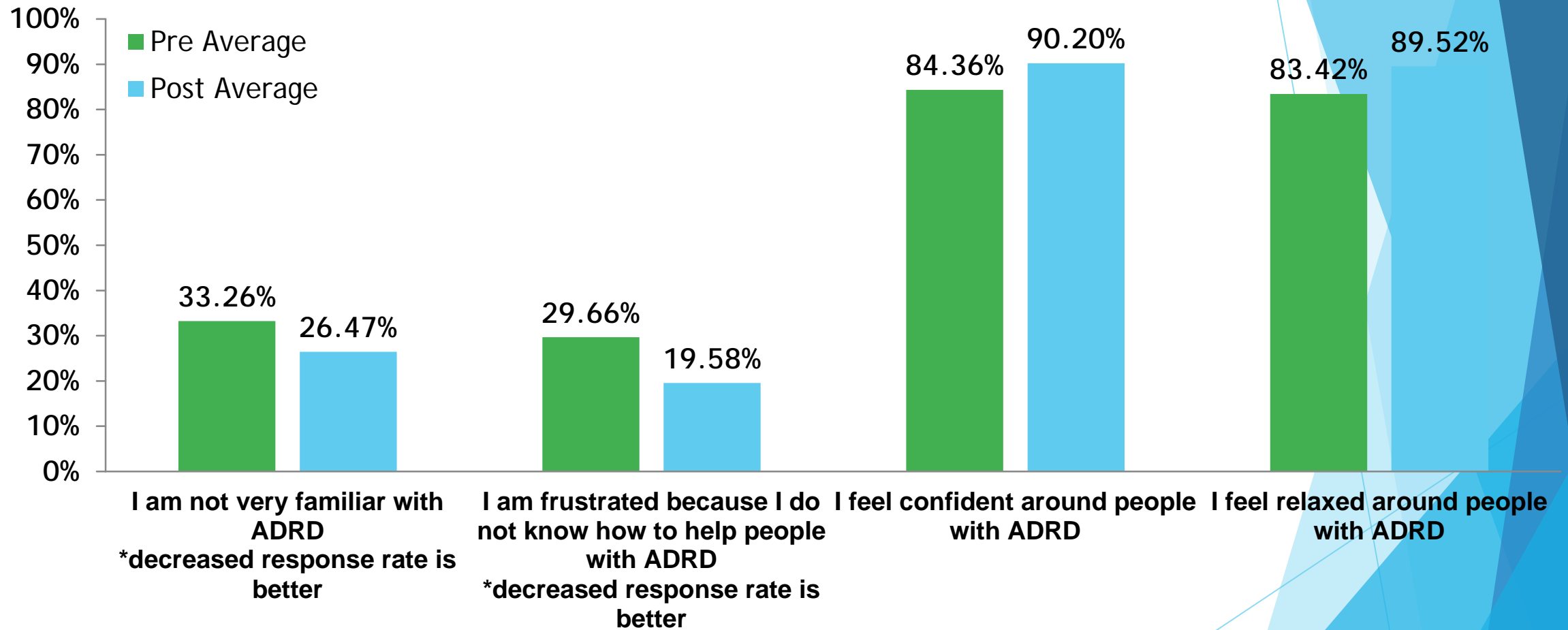
Grant Activity	Individuals with IDD & ADRD
Music and Memory Participants & Occupational Therapy Assessments	142

NTG Training: Overall Knowledge Increase in Caring for Adults with IDD and Dementia



NTG Training - Changes in Dementia Attitude Scale

Pre- vs Post-Test



NTG Training- Qualitative Data

"I will be more knowledgeable to teach caregivers about the population we serve surrounding Alzheimer's"

"[allow me to] asses individuals more adequately"

"I will take this knowledge to better understand and educate my CNA to better understand the resident with dementia"

"[allow me to] make environmental changes to meet the individual needs"

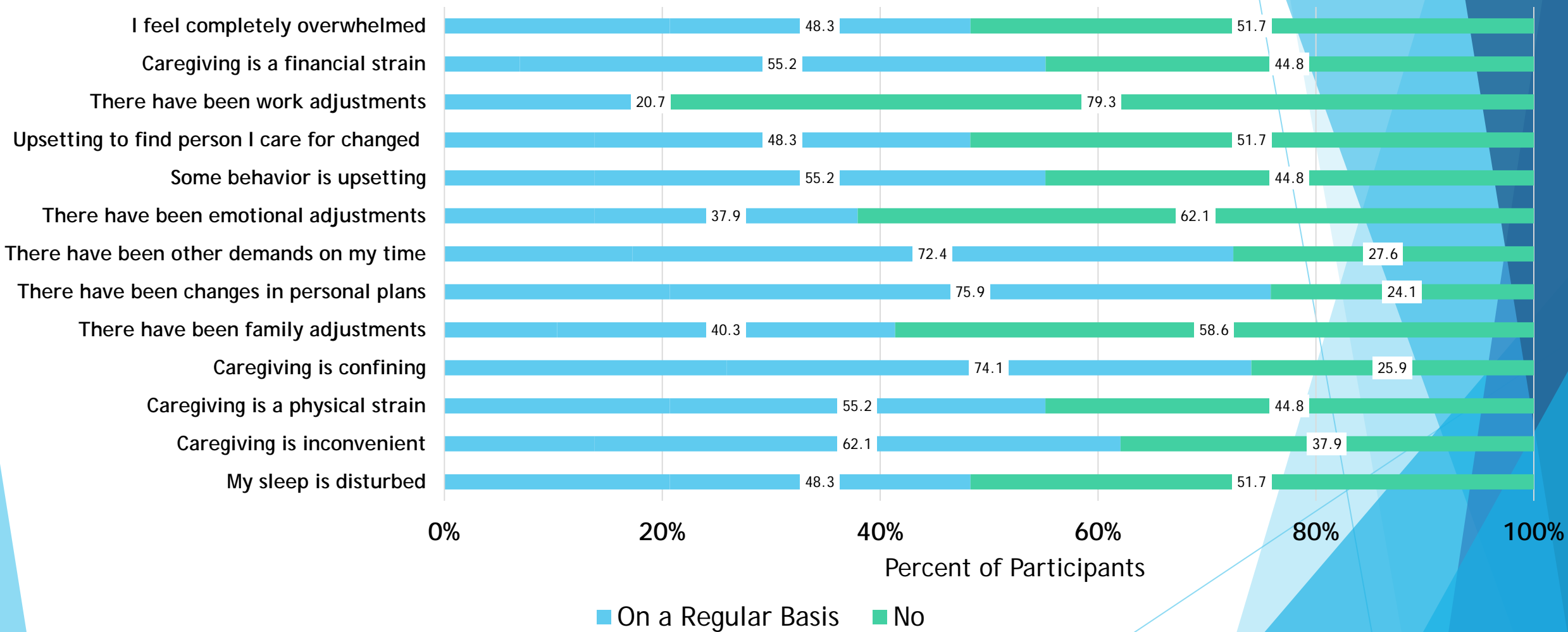
"Supporting them with health advocacy; importance of through assessment, differential diagnosis modifying environments"

"Highly recommend this training to other healthcare professionals"

"Excellent training; great awareness if only we could be make more medical providers to create more awareness and understanding of ID and dementia"

"This training/seminar is very useful and informative"

Post-Support Group-Caregiver Strain Index (N=29), through Feb 2018



Project Impact - Qualitative Data

Support Groups

"The speaker was amazing and friendly, connected to the staff and was supported very informative and responsive to every question asked"

"It was a positive meeting we were able to bring our concerns to the table with honesty"

"Need more and more"

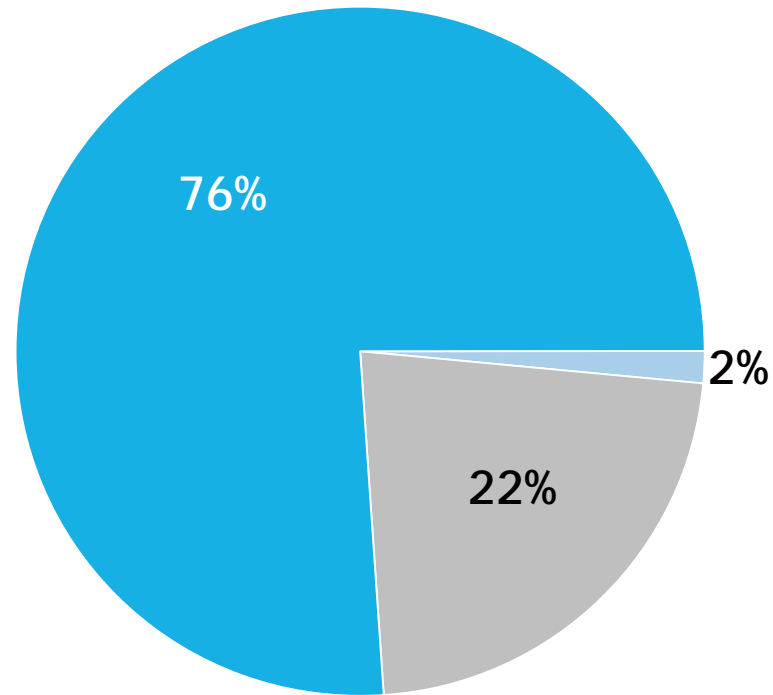
"Very informative"

Music and Memory Demographics

Demographics	
Number of unique patients	59 patients
Gender	56% Female 44% Male
Average Age Age Range	65 years old 23 -97 years old
Average number of sessions per patient	7 sessions
Number of facilities involved (Group homes, assisted living centers, personal homes)	14 facilities

Change Reported Post Music And Memory Intervention

■ Negative Change ■ No effect/Stayed the same ■ Positive Change



Dementia Capable Quality Assurance Assessment Tool

Nearly 51% of respondents said that if a person has possible cognitive impairment, there is a standard protocol in their organization for supplying the information to service providers, case managers, and eligibility determination staff.

46% of respondents reported that if a person is identified with possible dementia or cognitive impairment, there is a standard protocol in their organization for a referral to a physician or clinic for a diagnostic evaluation.

67% of respondents said staff in their organization receive formal training on dementia and cognitive impairment.

Key Takeaways

- ▶ Far reach in the Rhode Island developmental disability and healthcare communities
- ▶ Positive event and training feedback
- ▶ Innovative patient-centered approaches to treatment
- ▶ Where do we go from here?
 - ▶ Use more focused interventions with goals that are not that easy to reach
 - ▶ Healthcare workforce- how we can we help foster practice change in these settings?
 - ▶ How can we continue to care for a changing population

NTG 3-Day Training

Please describe at least one way that you intend to change your clinical approach/practice

Observant of communication provided by individual, evaluations of medical concerns, completing screening at baseline to be preventative

Ruling out all medical possibilities so there is no misdiagnosis

Consider how we can implement the screening tool on a more wide-scale approach especially with some of our older clients with challenging behaviors

I will perform a better diagnostic workup. I will also utilize the screening tool

All behaviors are communication--- Investigate!

Reintroduce hospice and their role

Start with history, medical and medication check

Share info and resources with caregivers and families

Barriers

- ▶ Difficult to get the buy in from other agencies
 - ▶ Seemingly distrusted “free”
 - ▶ Difficult for the agency to arrange to have staff out of circulation for 2-3 days for training
 - ▶ Once they are on board, be sure to have more than 1 contact person---turnover is frequent and sometimes involved out main contact
- ▶ Difficult to maintain trainers r/t busy schedules, budget cuts, LIFE!
 - ▶ Returned to contracting with NTG to do their full curriculum; by the end of the 3 years, only 3 of the nurse trainers could remain committed to continued training
- ▶ Delays in publication of Resource Guide, Supplements and Webinars
 - ▶ Too much review; too many reviewers

Barriers

- ▶ Among survey respondents, the majority were Clinical or Professionals (41%) and Paid Direct Care workers (25%).
- ▶ Remaining participants were managers/administrators (11%), Case managers/care coordinators (11%), health educators (7%), and family members (7%).
- ▶ The majority of participants were female (77%) and 45 was the average age.

Sustainable Efforts

- ▶ Free Resource Guides and Supplements online and via USB flash drive
 - ▶ Model being replicated by several projects in other states
- ▶ Free online learning activities (also linked on USB flash drive and promoted on Project Partner websites)
 - ▶ Proposed to BHDDH as “suggested training” for all new staff
- ▶ RIGEC funding shortened NTG material for BHDDH
- ▶ 54 new Regional Trainers
 - ▶ 49 fully funded by grant; 5 partially funded by grant
- ▶ Increased awareness among DD providers and professionals

Questions?

