
Data Collection in Adult Day Services: A Plan for Action

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Standardized Data Collection in ADS

- Researchers and industry have renewed calls for standardized data collection in ADS (Anderson et al., 2018; Jarrott & Ogletree, 2019)
- Benefits of standardized data collection
 - Evaluating and enhancing programs and services
 - Leveraging additional funding
 - Influencing policy
 - Improving the well-being of ADS participants and their caregivers

To Date, A Lack of Standardized Data Collection in ADS

- Services provided by ADS have positive benefits (Gitlin et al., 2019)
- But outcomes data collection in ADS has been inconsistent and unreliable (Sadarangani et al., 2022)
- Several factors account for this issue:
 - Lack of state and federal guidelines regarding data collection
 - Lack of understanding as to the purpose of data collection
 - Lack of staff capacity to conduct regular data collection
 - Cost of, and discomfort with, software to facilitate data collection

Private-Nonprofit-Academic Partnership



Software engineers
and technical experts



ADS practitioners and
policy advocates



Data analysts

Process Evaluation

Developing a Set of Uniform Outcome Measures for Adult Day Services

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Abstract

Adult day services (ADS) provide care to adults with physical, functional, and/or cognitive limitations in nonresidential, congregate, community-based settings. ADS programs have emerged as a growing and affordable approach within the home and community-based services sector. Although promising, the growth of ADS has been hampered by a lack of uniform outcome measures and data collection protocols. In this article, the authors detail a recent effort by leading researchers and practitioners in ADS to develop a set of uniform outcome measures. Based upon three recent efforts to develop outcome measures, selection criteria were established and an iterative process was conducted to debate the merits of outcome measures across three domains—participant well-being, caregiver well-being, and health care utilization. The authors conclude by proposing a uniform set of outcome measures to (a) standardize data collection, (b) aid in the development of programming, and (c) facilitate the leveraging of additional funding for ADS.

Keywords

adult day services, health outcomes, home and community-based care and services

Developing the First Set of Uniform Outcome Measures in ADS

- Participant Well-being
- Caregiver Well-being
- Healthcare Utilization

National Survey of Data Collection Efforts in ADS

- Survey of data collection efforts in ADS in the U.S. (Sadarangani et al., 2021)
- N = 248
- Only 32% of ADCs collected patient-level data
- Validated assessment tools were used in less than 50% of the cases
- More than 70% shared a willingness to collect data
- Uniform data collection efforts are needed to demonstrate impact

Outcomes

- **Demographics** (e.g., gender, race, age, living situation, language)
- **Assessments** (Falls risk, depression, ADLs, IADLs, loneliness, nutrition, cognitive function, pain, etc.)
- **Healthcare utilization** (e.g., ER visit, hospital admission, hospice/palliative care use, etc.)

National Secure Data Entry Portal for ADS

- Data entry portal and repository for the collection of this data free to use (NADSA members) for adult day service providers across the country
 - **Early 2021:** Data entry portal is developed
 - **July 2021:** Launched for alpha testing
 - **October 2021 - 2022:** Beta testing
 - **January 2023:** Full release
 - **2025 (Present):** Enrolling and educating providers across the US; actively partnering with academic institutions for funding and partnership; expected to produce longitudinal data by end of 2025

Demographics (N=1,182)

- **Age:** 20.98% 64 and under; 19.4% 65-74; 32.83% 75-84, 24.62% 85+
- **Gender:** 52.62% female
- **Race** 56.4% White; 21.58% Black; 4.2% Hispanic
- **Veteran Status:** 15.75% veteran
- **Primary Language:** 88.15% English; 4.57% Spanish

Assessment Data

23% show signs of depression (GDS-15)	58% have high falls risk (Hendrich II)	77% have high nutritional risk (DETERMINE)
38% are in severe pain (NRS)	83% live with someone else	36% require ambulatory assistive device

As of September 2025

Overview

- The number of persons living with dementia (PLWD) is rapidly increasing
- Need for high-quality, person-centered LTC options
- Adult day services (ADS) offer structured programming, social engagement, and healthcare services in a community-based setting
- Research focuses on outcomes relevant to payors or caregivers
- The voices of PLWD remain underrepresented in the literature

Phase 1: Qualitative Study of Person-Centered Outcomes in Adult Day Services (ADS)

Background

- CMS prioritizes cost-containment, efficiency, and clinical outcomes
- Dementia Care Practice Recommendations focus on priorities of PLWD
- Perspectives of PLWD on ADS care are largely unknown

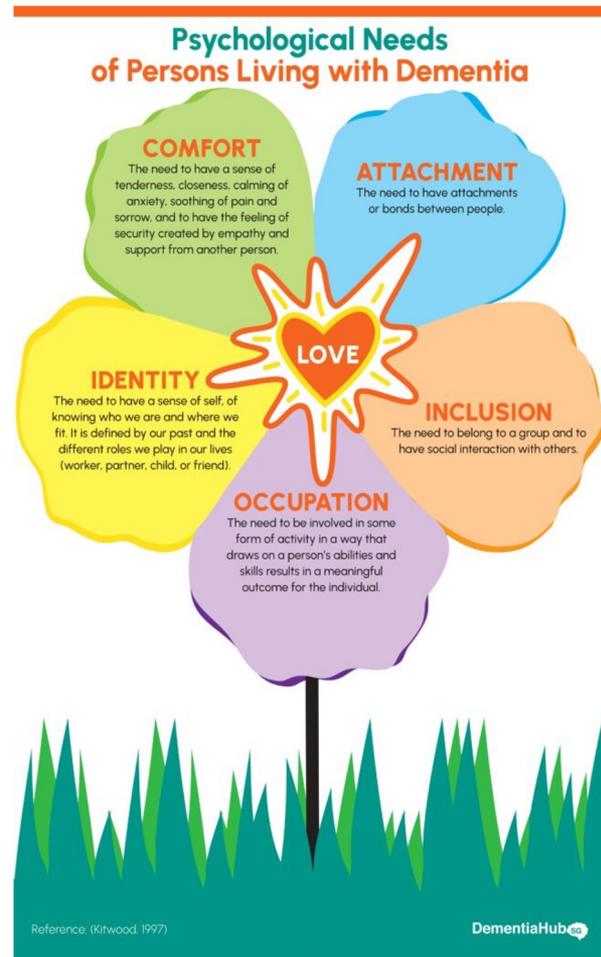
Research Gaps

- No firsthand perspectives of PLWD on the care they receive in ADS
- Lack of understanding of elements of ADS care that foster well-being, dignity and engagement

Conceptual Framework

Kitwood (1997)

- Inclusion
- Occupation
- Attachment
- Identity
- Comfort



Methods

- Exploratory, qualitative descriptive study
- Focus groups with PLWD (65+, ICD-10 diagnosis of ADRD) and caregivers
- Four ADS in the United States (2 in the South, 1 in the West, 1 in the East)
- Conducted in different languages (English, Spanish, Mandarin)
- Purposive sampling of ADS to create a representative sample
- Informed consent included capacity to consent during screening

Results

- June and September 2024
- Six focus groups with PLWD (n=51) and their care partners (n=6)
- Four ADS (Tennessee, New York, and California)
- Mean age of PLWD (75.61 years) and care partners (64.40 years)
- Diverse population of PLWD and care partners by racialized identity (Black, Hispanic and Asian) and socioeconomic status
- Largely male (n=40) and less than or some college education (n=47)

Results: Inclusion

Being involved in others' lives

- Described staff and center members as “family”
- The people and comradery are most important
- Expanded social network
- Reduced loneliness

*“My dad was social prior to COVID...but [because of the pandemic] he stopped going to McDonalds for coffee with his friends. This was the same time we saw a decline [in his memory]. We wanted to give him that [social] outlet again...so **we were able to come [to the ADC] to get that sort of socialization for him.** He gets to come here for his coffee in the mornings now...and make new friends.”*

Results: Attachment

Security and finding familiarity in unusual places

- Feeling safe and comfortable at the ADS
- “Second home”
- Staff members make participants feel safe

“It’s a safe place to come to...We all do stuff to help and keep each other safe...if something happens to you, you can get help, and it’s wonderful”

Results: Comfort

The feeling of trust that comes from others

- Trust in staff members
- Trust in ADS members

*“The staff know what medicine you gotta take and they document everything. And they know exactly what you need and what you don't need. **Let's say I want Tylenol, she'll say well, you don't need none right now, you [already took another medicine already]—and that's personal [care].** They know us better than we know ourselves.”*

Results: Meaningful Occupation

Being involved in the processes of normal life

- Getting out of the house
- Somewhere to go
- Increasing sense of purpose
- Motivation to engage in cognitively stimulating activities
- Reconnecting with old passions

*"[The ADS has] English classes, calligraphy classes, Peking opera classes, and music classes. **As you age, it's not just about staying physically healthy—you need to keep your mind healthy too.** [The classes] exercise your brain and helps delay aging. **We have many rich activities here, and I feel that we are healthy both physically and mentally.**"*

Results: Identity

What distinguishes a person from others and makes them unique

- Unique identities are valued
- Treated like a person (“not just a number”)
- Feeling accepted
- All identities (culture, class, race, etc.) are treated the same
- Sense of autonomy and independence

*“[The staff] treat us [all] the same. I am Puerto Rican. There are people from El Salvador, from Mexico—they treat us all good. **And we all still one same family.** Here, there is no distinction [between different] class[es] nor difference[s] in color. We’re good with them, and they are with us. **It’s not a divided family. It’s a united family.**”*

Discussion

- First step towards implementation of person-centered outcomes in ADS
- Findings validated the person-centered approach of ADS
- Relationships with ADS staff and members were described as familial
- Sense of community across differing cultures
- Small, mostly male sample; response bias; caregivers underrepresented
- **Next step is systematically identifying outcome measures that reflect key domains of person-centered dementia care**

Phase 2: Delphi Study of Person-Centered Outcome Measures

- Untapped potential of ADS for systematic outcomes data collection to improve dementia care (Anderson et al., 2020; Jarrott & Ogletree, 2019)
- National Adult Day Services Association (NADSA) adopted largely deficits-focused measures (e.g., function, health utilization, and cognition) (Anderson et al., 2020)
- These outcomes may not reflect the values of people with dementia and their caregivers (Sadarangani et al., 2022; Fazio et al., 2018)

Study Objective

- Our study sought to **identify person-centered outcome measures** that are practically **feasible to administer, relevant, and valuable** for assessing **quality-of-life domains** among **people living with dementia** utilizing **ADS**

Methods: Identify Person-centered Outcome Measures

- Using a scoping review of relevant measures (Mast et al., 2011)
- Conducting additional literature review and reaching out to experts
- 10 questionnaires from the following domains aligned with the themes of the qualitative study (Scher et al., 2025)
 - Meaning and Purpose in Life
 - Engagement
 - Social Networks/Friendships
 - Community, Belonging and Inclusion

Methods: E-Delphi Method

- Recruit panelists (ADS practitioners, researchers, and policy advocates)
- Round 1 (January - March 2025); 22/26 participated (84.6% response rate)
- Round 2 (June to July 2025); 21/22 participated (95.5% response rate)
- Reviewer consensus was defined at a supermajority (66.67%)
- Basic descriptive statistics for survey respondent and ADS characteristics

Results: Participant Characteristics

- **Job title:** CEO (45%), executive director (27%), other administrator (9.1%)
- **ADS location:** California (23%), Tennessee (14%), Connecticut (9.1%)
- **ADS type:** Private-for profit (50%), Private-nonprofit (50%)
- **Average number of attendees enrolled in ADS:** 108 (SD=90)
- **Average number of attendees living with dementia:** 51 (SD=28)

Results of the Delphi Panel

Domain	Questionnaire	Article	# of Items
Meaning and Purpose in Life	PROMIS Meaning in Life Questionnaire	Salsman et al., 2020	8
Engagement	Life Engagement Test	Scheier et al., 2006	6
Engagement	Engagement in Meaningful Activities Survey	Eakman, 2012	12
Social Networks/Friendships	Friendship Scale	Hawthorne, 2006	6
Community, Belonging and Inclusion	General Belongingness Scale	Malone et al., 2012	6

Discussion

- Panelists achieved consensus on person-centered outcome measures for use in ADS with people living with dementia
- The resulting toolkit can be used alongside more payor-focused measures
- Most instruments emphasize the present due to recall challenges
- Limitations: modest panel size with geographic skew (CA and TN)
- Next steps involve embedding measures into NADSA's data portal system to pilot across geographically and operationally diverse ADS

Conclusions and Call to Action

- We have now embedded the measures into NADSA's data portal system to pilot across geographically and operationally diverse ADS
- We have now begun piloting person-centered outcome measures within the national data entry portal
- We are actively recruiting ADS to become involved in this project!
- Fill out our registration form:
https://forms.office.com/Pages/ResponsePage.aspx?id=IcGIHWgOxkqKGLYc4ZxwwAP7_uRXG4pAgkLcMbXbka5UQIFZOTRQVE_MzQkVBMEE5VTM4WkhHRUdIU54u
- You can also email william.zagorski@centennialadultcare.com if interested!



JOIN A NATIONAL EFFORT TO ADVANCE DEMENTIA CARE THROUGH ADULT DAY SERVICES

Help Shape the Future of Person-Centered Care in ADS

Join ADS programs across the country who are participating in **groundbreaking national data collection effort** focused on the **quality of life of people living with dementia**.

With support from the Alzheimer's Association, the NADSA data set is being expanded to include **new, person-centered outcome measures** designed with and for people living with dementia. These measures were developed through focus groups conducted at adult day centers across the country, and through a national Delphi panel survey of ADS leaders.

What's New?

The NADSA database has been expanded to include the following **person-centered measures**:

- *PROMIS Short Form*
- *Life Engagement Test (LET)*
- *Engagement in Meaningful Activities Survey (EMAS)*
- *Friendship Scale (FS)*
- *General Belongingness Scale (GBS)*



Why Join?

- Be part of a **national research initiative** that strengthens the voice of people living with dementia.
- Get access to tools for **measuring and improving quality of life**
- Help build the **evidence** that shows the impact of ADS.

Already Collecting Data?

You can register to submit your existing or new person-centered data directly into the NADSA database.

To Learn More:

Attend our Zoom Office Hours:

Every Friday at 12:00 PM CT / 1:00 PM ET

Zoom Link: <https://nyu.zoom.us/j/93537124021>

If you have any questions and/or are interested in joining, you can email:

william.zagorski@centennialadultcare.com



How to Access and Use the CADCare Platform:

Here are your credentials:

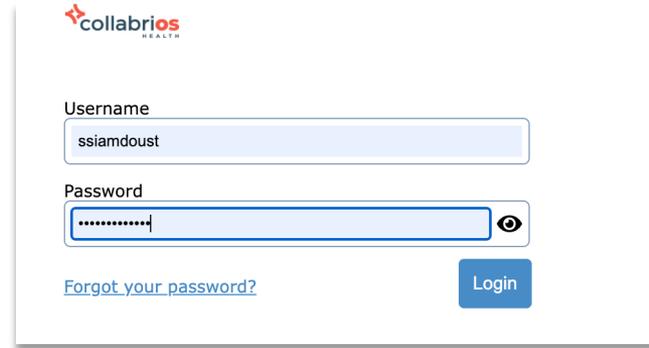
user name: Johndoe|

temporary password: 12345

Login:

<https://nadsa.cadcare.com/paceseam/login.seam>

1. We will create and send you your credentials. You can then click on the url to the CADCare website.



The screenshot shows the login interface for the CADCare platform. At the top left is the 'collabrios HEALTH' logo. Below it are two input fields: 'Username' with the text 'ssiamdoust' and 'Password' with masked characters '.....'. To the right of the password field is an eye icon for toggling visibility. Below the password field is a blue 'Login' button. At the bottom left, there is a blue link that says 'Forgot your password?'.

2. Login

3. Select Organization Information

collabrio HEALTH Client Information Attendance Recording **Organization Information** Reports User Preferences | Help | Logout

Number of Clients
4 (Inquiry 4)

Number of Assessments Done
11 (Inquiry 0)

Number of Progress Notes Recorded
0 (Inquiry 0)

Site: Include Disenrolled [+ Add Client](#)

Status	Client	Participant Site ID	System ID	DOB	Age	Site	Schedule	Progress Notes	Assessments
Inquiry	<u>Doe, John</u>		1425	01/01/1938	88		Setup	Open	Open
Inquiry	<u>Green, Sarah</u>		1426	04/23/1937	88		Setup	Open	01/29/2027
Inquiry	<u>Person, Test</u>		1385	01/01/1950	76		Setup	Open	11/05/2026
Inquiry	<u>Smith, Jack</u>		1412	07/14/1937	88		Setup	Open	Open

1 - 1 of 1 ← →

4. Select Add Site

collabrio HEALTH Client Information Attendance Recording **Organization Information** Reports User Preferences | Help | Logout

Organization Information [Home](#) / Organization Information

Program Address: /

Timezone: EST

Sites [+ Add Site](#)

Name	Address	Email	Phone Number	Contact Person	Timezone
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5. Fill out your site's information and click Save when you're Done

Add New Site

Name New York Adult Day Center **Abbreviation**

Address Park Ave New York NY 10170

Email name@newyorkadc.org **Phone Number** (212)999-9999

Contact Person Mary Smith

NPI#

Tax ID#

Licensed No Yes **Accredited** No Yes **Certified** No Yes

Business Identification Number **Model**

Specialized

Utilize Remote Technology to participant engagement

Entity Type Non Profit

Payer Medicaid VA Waiver LTC Insurance Other

Timezone

Cancel Save

6. When you're done, select Client Information

collabric HEALTH Client Information Attendance Recording Organization Information Reports User Preferences | Help | Logout

Organization Information / Organization Information

Program Address: EST

Timezone: EST

Sites + Add Site

Name	Address	Email	Phone Number	Contact Person	Timezone
New York Adult Day Center	Park Ave New York, NY 10170	name@newyorkadc.org	(212)999-9999	Mary Smith	Service Settings

Payers + Add Payer

Name	Validity
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collabrio HEALTH Client Information Attendance Recording Organization Information Reports User Preferences | Help | Logout



Number of Clients
4 (Inquiry 4)



Number of Assessments Done
11 (Inquiry 0)



Number of Progress Notes Recorded
0 (Inquiry 0)

Site: Include Disenrolled + Add Client

Status	Client	Participant Site ID	System ID	DOB	Age	Site	Schedule	Progress Notes	Assessments
Inquiry	<u>Doe, John</u>		1425	01/01/1938	88		Setup	Open	Open
Inquiry	<u>Green, Sarah</u>		1426	04/23/1937	88		Setup	Open	01/29/2027
Inquiry	<u>Person, Test</u>		1385	01/01/1950	76		Setup	Open	11/05/2026
Inquiry	<u>Smith, Jack</u>		1412	07/14/1937	88		Setup	Open	Open

1 - 1 of 1 ← →

7. Select + Add Client

Add Client

Identification:

Name: Add Client

Last Name	First Name	Middle Name	DOB
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8. Fill out your client's information and select Save

Name: Middle Name: Brown Nickname: DOB: Age: 86

Address:

Phone Number: This number can receive text messages:

Referral:
Marketing Method: Referral Source Types: Referral Source Contact:

Enrollment:
* - NADSA Data Project Element
System ID : 0 Participant Site ID: (optional) *Site: *Enrollment Date: Status:

Demographics:
* - NADSA Data Project Element
*Primary Language: *Race: *Ethnicity:
*Gender: *Sex at Birth: *Veterans Status:
*Living Situation: *Coverage for this client: Medicaid VA Waiver LTC Insurance Other Medicare
*Diagnoses : [+ Add a diagnosis](#)

Operations:
Emergency Contacts : Caregiver Contacts : DNR:
Mobility Status:
Transportation Status:

Allergies
Food Restriction:

[/nadsa.cadcare.com/paceseam/secured/responsive/nadsa/new_page/new_nadsa_clientinfo.seam?cid=257#](#)



9. Note: The 'Site' button under Enrollment is currently not working. However, this will not prevent you from creating an account. Coders are working on resolving this issue.

When you receive this warning, just select Save and Exit.



collabrio HEALTH Client Information Attendance Recording Organization Information Reports User Preferences | Help | Logout

Number of Clients 4 (Inquiry 4)

Number of Assessments Done 11 (Inquiry 0)

Number of Progress Notes Recorded 0 (Inquiry 0)

Site: Include Disenrolled [+ Add Client](#)

Status	Client	Participant Site ID	System ID	DOB	Age	Site	Schedule	Progress Notes	Assessments
Inquiry	Brown, Sam		1427	07/21/1939	86		Setup	Open	Open
Inquiry	Doe, John		1425	01/01/1938	88		Setup	Open	Open
Inquiry	Green, Sarah		1426	04/23/1937	88		Setup	Open	01/11/2022 027
Inquiry	Person, Test		1385	01/01/1950	76		Setup	Open	11/11/2021 026
Inquiry	Smith, Jack		1412	07/14/1937	88		Setup	Open	Open

1 - 1 of 1 < >

10. After you save your client's information, you'll be returned to the main client page. Under Assessments, click Open for the client you want to administer an assessment to.

collabrio HEALTH Client Information Attendance Recording Organization Information Reports User Preferences | Help | Logout

Basic Information Upload Photo

Number of Assessments Done 0

Number of Progress Notes Recorded 0

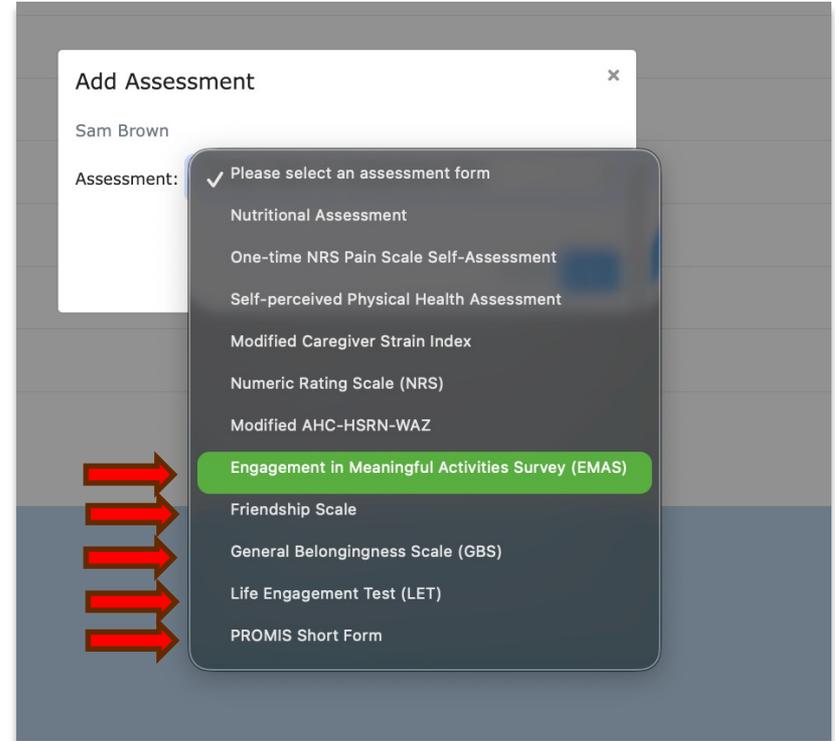
Assessment Name	Status	Total Score	Date Completed	Notes	Next Due Date	
DETERMINE Nutrition Assessment	Due					+ 🗑️ ✎️
Fall Risk/Hendrich II	Due					+ 🗑️ ✎️
Geriatric Depression Scale	Due					+ 🗑️ ✎️
Katz Index	Due					+ 🗑️ ✎️
Lawton Scale	Due					+ 🗑️ ✎️
Loneliness (UCLA Short Form)	Due					+ 🗑️ ✎️
SLUMS	Due					+ 🗑️ ✎️

+ Other Assessments

11. To access our selected questionnaires, select +Other Assessments at the bottom

12. Here you will see our selected measures at the bottom to add and complete:

- PROMIS Short Form
- Life Engagement Test (LET)
- Engagement in Meaningful Activities Survey (EMAS)
- Friendship Scale (FS)
- General Belongingness Scale (GBS)



Sam Brown

Assessment: Engagement in Meaningful Activities Survey (EMAS) Status: **Draft**

Assessment Date: 01/29/2026 Next Due Date: 01/29/2027

Assessment outside of system Total Score:

Note:

Engagement in Meaningful Activities Survey

1. The activities I do help me take care of myself. Rarely Sometimes Usually Always
2. The activities I do reflect the kind of person I am. Rarely Sometimes Usually Always
3. The activities I do express my creativity. Rarely Sometimes Usually Always
4. The activities I do help me achieve something which gives me a sense of accomplishment. Rarely Sometimes Usually Always
5. The activities I do contribute to my feeling competent. Rarely Sometimes Usually Always
6. The activities I do are valued by other people. Rarely Sometimes Usually Always
7. The activities I do help other people. Rarely Sometimes Usually Always
8. The activities I do give me pleasure. Rarely Sometimes Usually Always
9. The activities I do give me a feeling of control. Rarely Sometimes Usually Always
10. The activities I do help me express my personal values. Rarely Sometimes Usually Always
11. The activities I do give me a sense of satisfaction. Rarely Sometimes Usually Always
12. The activities I do have just the right amount of challenge. Rarely Sometimes Usually Always

Total Score: 35 Moderate Engagement

Close [Save as Draft](#) [Save as Final](#)

13. Complete the assessment and then select **Save as Final** when completed.



Basic Information

Upload Photo



Number of Assessments Done

1



Number of Progress Notes Recorded

0

Assessment Name	Status	Total Score	Date Completed	Notes	Next Due Date	
DETERMINE Nutrition Assessment	Due					+ 🗑️ ✎️
Engagement in Meaningful Activities Survey (EMAS)	Completed	35 - Moderate Engagement	01/29/2026 ✔		01/29/2027	+ 🗑️ ✎️
Fall Risk/Hendrich II	Due					+ 🗑️ ✎️
Geriatric Depression Scale	Due					+ 🗑️ ✎️
Katz Index	Due					+ 🗑️ ✎️
Lawton Scale	Due					+ 🗑️ ✎️
Loneliness (UCLA Short Form)	Due					+ 🗑️ ✎️
SLUMS	Due					+ 🗑️ ✎️

+ Other Assessments

13. Here you can see the Total Score and Date Completed for the assessment you completed.

Questions?

- Tina Sadarangani trs233@nyu.edu
- William Zagorski william.zagorski@centennialadultcare.com
- Keith Anderson kaander4@olemiss.edu
- Clara J. Scher cls3002@med.cornell.edu

If you have any questions about CADCare and/or need assistance, please reach out to:

Shahrzad Siamdoust ss10680@nyu.edu

(201)-803-4872 (You can call or text)