

Effectively training professional caregivers to screen and refer persons with dementia and intellectual disability



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BACKGROUND

By age 40, almost all people with Down syndrome, the most common cause of intellectual disability (ID), have neuropathological changes consistent with Alzheimer's disease; by age 60, about half have dementia. Detecting dementia in persons with ID can be challenging because baseline cognitive impairment can be severe and because persons with ID may have difficulty reporting symptoms.

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) was developed to aid detection of cognitive impairment in adults with ID. We implemented an educational curriculum using the NTG-EDSD to increase the ability of professional caregivers to identify and support persons with ID and dementia.

METHODS

From November 2018 to April 2019, we held five in-person training sessions for professional caregivers of persons with intellectual disability, partnering with various managed care organizations and social services agencies across the State of Wisconsin. We assessed knowledge and attitudes at baseline, immediately after training, and one week, one month and six months after training.

RESULTS

154 direct care workers, case managers, healthcare providers, and other social services staff participated in the training (demographics in **Table 1**). Though 98 participants indicated that their organizations already used NTG-EDSD, only 20.1% indicated they were "very" or "quite confident" using the tool. Other screening tools they reported using to detect cognitive impairment included animal naming (11.0%) and the Mini-Cog (11.0%).

Satisfaction with the NTG-EDSD training was very high (**Figure 1**), and 94.0% of participants agreed or strongly agreed that they could use the NTG-EDSD tool with their clients. Participants reported a marked increase in confidence in their ability to track various health circumstances and detect functional decline in their clients (pre-training vs immediately after the training) (**Table 2**). At one-month follow-up (compared with prior to training), participants found the NTG-EDSD questionnaire to be feasible to use on a wide variety of measures (**Table 3**). Participants' gains in confidence were generally not sustained at 6-month follow-up. Some feasibility gains were sustained at 6 months, but few measures reached statistical significance due to only a small portion of the sample completing both baseline and 6-month follow-ups.

Following the training, one managed care organization, serving 62 of 72 counties in Wisconsin, made the NTG-EDSD a standard part of its assessment of adults with Down syndrome starting at age 40.

CONCLUSIONS

A wide variety of social services and healthcare professionals can be effectively trained to detect dementia in persons with intellectual disability (ID) using a standardized screening tool, the NTG-EDSD. Participants were highly satisfied with the training, experienced an increase in confidence in their care of person with ID, and found the NTG-EDSD feasible to use. This educational intervention can lead to changes in practice at a systems level. Some gains were not sustained over time, suggesting that repeated interventions may be necessary.

We plan on disseminating our training materials through the Wisconsin Alzheimer's Institute website. Other next steps could include (1) assessing the impact of this training on healthcare outcomes in persons with ID, and (2) ensuring that the tool is applicable to persons from a wide range of ethnic, racial and socioeconomic backgrounds.

REFERENCES

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FIGURES & TABLES

Table 1. Demographics of participants

| Characteristic | N(%) / M±SD |
|-------------------------------------|-------------|
| Professional role | |
| - case manager or care coordinator | 92 (59.7%) |
| - direct care worker | 11 (7.1%) |
| - healthcare provider | 20 (13.0%) |
| - health educator | 10 (6.5%) |
| - other | 21 (13.7%) |
| Years in role | 7.8 ± 8.2 |
| Years in field of aging or dementia | 11.7 ± 8.0 |
| Years in field of ID | 11.3 ± 8.6 |
| Gender | |
| - female | 144 (93.5%) |
| Ethnicity | |
| - Not Hispanic/Latino | 147 (95.5%) |
| - Hispanic/Latino | 7 (4.5%) |
| Race | |
| - American Indian/Alaskan Native | 1 (0.6%) |
| - Asian/Asian-American | 3 (1.9%) |
| - Black/African-American | 7 (4.5%) |
| - Hawaiian Native/Pacific Islander | 1 (0.6%) |
| - White | 138 (89.6%) |
| - 2 or more races | 2 (1.3%) |
| Educational level | |
| - 6-12 years | 8 (5.25%) |
| - technical/4-yr college | 98 (63.6%) |
| - graduate school | 45 (29.2%) |

Figure 1. Satisfaction with training

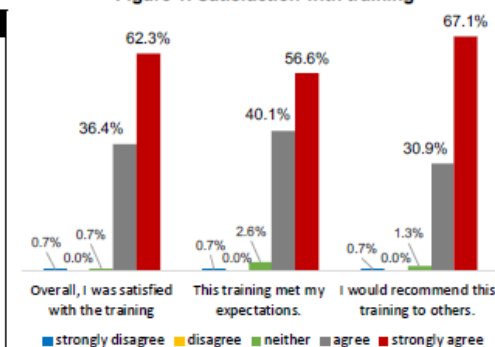


Table 3. Feasibility of using NTG-EDSD questionnaire

| (0=strongly disagree, 4=strongly agree) | pre | 1-mo post | p-value |
|--|------|-----------|---------|
| Questions allow for an accurate representation of the person | 2.69 | 3.15 | 0.08 |
| I have sufficient experience w/ person with ID to complete questionnaire | 2.77 | 3.23 | 0.027 |
| Questions are comprehensible | 2.38 | 2.92 | 0.012 |
| Instructions for using the tool are comprehensible* | 2.46 | 3.08 | 0.005 |
| Tool is complicated | 1.77 | 1.15 | 0.04 |
| The purpose of the questionnaire is clear* | 2.38 | 3.23 | 0.01 |
| Using the questionnaire for periodic reassessments would be meaningful | 2.69 | 3.38 | <0.001 |

* also statistically significant change at 6-month follow-up

Table 2. Confidence in ability to track health circumstances & functional decline

| (0=not at all, 3=very confident) | pre | post | p-value |
|--|------|------|---------|
| Intellectual disability | 2.10 | 2.33 | 0.003 |
| Changes in mental health | 2.24 | 2.39 | 0.032 |
| Significant life events | 2.30 | 2.54 | <0.001 |
| Diagnosis of mild cognitive impairment or dementia | 2.03 | 2.32 | <0.001 |
| Declines in ADLs | 2.39 | 2.56 | 0.002 |
| Changes in memory | 2.11 | 2.48 | <0.001 |
| Changes in behavior & affect | 2.20 | 2.48 | <0.001 |