

# 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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Moran JA, Rafii MS, Keller SM, et al., The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clin Proc* 2013;88:831-840.

## FIGURES & TABLES

Table 1. Demographics of participants

Characteristic	N(%) / MeanSD
<b>Professional role</b>	
- 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
<b>Gender</b>	
- female	144 (93.5%)
<b>Ethnicity</b>	
- Not Hispanic/Latino	147 (95.5%)
- Hispanic/Latino	7 (4.5%)
<b>Race</b>	
- 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%)
<b>Educational level</b>	
- 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