

# Being Proactive FOR FAMILIES

DEMENTIA DETECTION FOR INDIVIDUALS  
WITH DOWN SYNDROME AND OTHER  
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES



The University of Kansas Alzheimer's Disease Research Center (KU ADRC) is one of 33 nationally recognized National Institute of Health Alzheimer's Disease Research Centers in the United States. The KU ADRC has several special interests, one of which is the advancement of early detection and intervention for those from higher risk populations, including the intellectual and developmental disabilities (IDD) community. The KU ADRC's detection efforts are inspired by The Mission Project, an organization serving individuals with IDD in Mission, Kansas, and incorporate current evidence-based practices coming from National Institutes of Health (NIH)—supported Down Syndrome (DS) initiatives and the National Task Group (NTG). Education efforts around this protocol are a part of the Kansas Care Ecosystem Project.

## A PROACTIVE PROTOCOL FOR FAMILIES

**THIS PROTOCOL IS TO HELP FAMILIES RECOGNIZE COGNITIVE CHANGES IN INDIVIDUALS WITH DS AND OTHER IDDs EARLY IN ORDER TO ENSURE APPROPRIATE CARE AND TREATMENT.**

### COMPLETE NTG EDSD FORM ANNUALLY

- Individuals with DS starting at age 35
- Individuals with an IDD, other than DS, starting at age 50

### PROVIDE A COPY OF THE NTG EDSD

- Key IDD providers
- Successors
- Primary Care Providers
- Neurology if at point of baseline

### BASELINE DEMENTIA EVALUATION

- Individuals with DS at age 35
- Individuals with an IDD, other than DS, if change noted on NTG EDSD

### FOLLOW UP

- Individuals with DS, annually after baseline
- Individuals with an IDD, other than DS, annually after diagnosis
- Can be more often depending on need and practitioner

**/ START HERE. START NOW.**

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