

QUICK GUIDE FOR USING THE NTG- EDSD BY FAMILIES

The NTG-EDSD is a brief checklist that families or other caregivers can use to record behaviors that they suspect may be changing and want to discuss with a doctor, nurse, or other person.



National Task Group
on Intellectual Disabilities
and Dementia Practices

www.the-ntg.org

What is the EDSD? The EDSD is an easy-to-use checklist to record suspected behavioral changes and differences observed in a family member with an intellectual disability. The information gathered can be used as a baseline and/or to track changes as the individual ages. This information can be shared with doctors and other professionals to help determine if the changes are something about which to be concerned. For ease of use, the EDSD has been translated into many languages including English, Spanish, and French.

What information is collected? The form helps you record information about medical or behavioral conditions, how the person acts when doing common things, whether he/she is having memory problems or forgetting how to do things, what medications he/she takes, and whether his/her behaviors are new or have been there for some time. Most of the information you fill out on the form is something you note from your observations or from others who know the person. Some of the information may come from an organization that provides the person's community services or a health provider. Your family member may also provide answers to some of the questions.

How can you use it? Just complete the form as best as you can, and then check with anyone else who knows the person to get any other input. Then review the information to see if you have some questions for his/her doctor, nurse, or other health care provider. Take the form with you to a medical appointment and share the form and your questions with the doctor. This will help you discuss any concerns or suspicions.

Can it diagnose? No. The doctor is the one who will diagnose what is responsible for any notable changes in thinking or behavior. A doctor will need to run some tests before making a diagnosis. Although this form is not used for diagnosing, it can help point to some areas that may need further examination. This, and your personal observations, will be helpful to the doctor. The form is a starting point. From there the doctor will need to determine whether there are changes in thinking or behavior and what can be done to treat the person.

When should you use the EDSD? It has been recommended that the first use with adults with Down syndrome be around age 35. For adults with another intellectual disability, usually the first use would be in the mid-50s. These 'first uses' are called 'baselines.' If you don't note any areas of concern on the first use, then you can redo it every year or every other year. If you do note areas of concern then redo it more frequently, perhaps every six months or so or as recommended by a health care provider.

The EDSD can be downloaded at www.the-ntg.org/ntg-edsd. More information is also available on this website.

The mission of the NTG is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease and dementias.
