

INSTRUCTIONS FOR DECISION TREE FOR “FEDERAL DEFINITION OF DEVELOPMENTAL DISABILITY” TARGET GROUP ON WI LONG TERM CARE FUNCTIONAL SCREEN

The attached decision tree was developed to assist qualified screeners¹ to complete the target group question on the Wisconsin Long Term Care Functional Screen (LTC FS), which asks whether the applicant meets the federal definition of developmental disabilities (DD). In some cases, deciding whether someone meets the federal definition of DD can be complicated. It requires accurately answering numerous questions in the right order.

This decision tree is the product of a workgroup from the Department of Health Services including staff from the Bureau of Long Term Support and the Division of Mental Health and Substance Abuse Services who have over 40 years combined experience in determining DD levels of care, consulting on DD levels of care, writing guidelines and handling appeals. See the Federal DD Definition Decision Tree, its instructions, and accompanying Questions & Answers document.

This decision tree incorporates guidelines previously developed to help DHS staff make consistent decisions on whether people meet the federal definition of DD. The federal definitions of DD are open to interpretations. Different states have somewhat different interpretations. To complicate matters, diagnoses like mental retardation are quite often misapplied. In the past, waiting lists and program funding limits acted as “gate-keepers” to the long-term care system. Because Family Care is an entitlement with no waiting lists and monthly capitation payments, eligibility determination (including the target group question) must be precise and accurate.

This decision tree has been tested on several dozen cases—some that obviously meet the definition of DD, and many that are unclear. A few pragmatic decisions were made to fit unusual situations.

This decision tree only works if you follow it in order, top to bottom, and follow every arrow. Focus on one box at a time. Answer each separate question as accurately as possible using the definitions provided. Following are an overview of the DD Decision Tree, an outline of the general process for using it, contact information for DHS staff, and some key points on the decision tree.

¹ To be qualified to complete the WI LTC FS, the screener must be (a) an employee approved by WI DHS to perform screens, (b) meet educational and experience requirements, (c) participate in DHS screen training, and (d) pass the online screen certification exams. For Home and Community Based Waiver counties, people screening DD individuals must be qualified as QMRPs.

PART 1 - OVERVIEW OF FEDERAL DEFINITION OF DD DECISION TREE

A. WHY THE DD DECISION TREE WAS DEVELOPED

Since Family Care started, Aging and Disability Resource Centers have been inundated by school systems referring 18 year olds with learning disabilities, mental illness, and emotional disturbances. Others have received many referrals of people with average or low-average intelligence who need monitoring to prevent criminal activities, people with cognitive impairments due to alcohol or drug abuse, or people living unfortunate lives due to socioeconomic deprivation, choices, self-neglect, etc. These conditions do not in themselves meet the federal definition of DD. Screeners completing the LTC FS needed clear, succinct instructions to guide them through what has turned out to be a difficult determination.

All screeners must be certified to administer the WI LTC FS. Screeners are to contact the WI Bureau of Long-Term Support for consultation as needed on DD cases (see page 4 for contact information). Screeners are to refer people for further evaluation whenever it might impact their eligibility.

B. WHAT THE DECISION TREE CAN DO

- a. Shows that people with normal IQ--including those with learning disabilities, emotional disturbances, mental illness, or substance abuse--do not meet federal definition of DD.
- b. Shows that people whose cognitive impairment is not developmental--e.g., that result from substance abuse or mental illness--do not meet federal definition of DD.
- c. Shows that someone with normal intelligence who needs 24-hour monitoring to prevent pedophilia or other behaviors--including those misdiagnosed with mental retardation (MR)--do not meet federal definition of DD.
- d. Can handle misdiagnoses and missing diagnoses, which turn out to be very common.
Example: Person with IQ of 87 misdiagnosed as mentally retarded; person with IQ of 59 (at age 9) diagnosed "learning disabled" instead of MR; person diagnosed with Pervasive Developmental Disability who has IQ of 94 and no significant limitations (PDD is misdiagnosed).
- e. Can handle multiple diagnoses---e.g., autism plus MR plus learning disability plus emotional disability.
Box 4 asks that at least one of the multiple diagnoses meets the criteria listed in 4 a-e.
If person's IQ is below 75 (and that low IQ is developmental and not due to substance abuse or mental illness and appears accurate), then that fact "overrides" the fact that they were misdiagnosed as learning disabled instead of MR.

- f. Shows that people who do not have substantial functional limitations in at least three of six major life areas (defined in Box 5) do not meet the federal definition of DD-- regardless of diagnosis. Due to this, a change has been made to the DD decision tree that takes a “Yes” answer in Box 1 to Box 5, instead of automatically saying the person meets the federal DD criteria. Regardless of an individual meeting a DD level of care in the past five years, they still must have a substantial functional limitation in 3 or more of the areas defined in Box 5 and a need for ongoing support.
- g. Presents questions in the right order. Provides more objective, reliable, and accurate decision process than old method of having individual professionals using their professional judgment. Controls for excessive subjectivity in the question of “other neurological condition similar to mental retardation” found in federal definition of DD. Allows for—requires—detailed assessment of person’s abilities in Box 5 (functional limitations) and Box 6 (support needed).

C. DECISIONS SHAPING THE DECISION TREE

- a. We are forced to use full-scale IQ scores as a way to address the over-use and under-use of the diagnosis of mental retardation (MR). We are aware of the limitations of IQ testing. The federal definition of MR is a full-scale IQ below 70. Federal guidelines do acknowledge an IQ score error range of 5 points. We have chosen to use 75 as a “cut-off” point instead of 70 in recognition of that error range. We did research other states’ eligibility determination methods, and most of them do use IQ as a factor in determining whether a person meets federal definition of DD.
- b. A person with cerebral palsy (CP) or other neurological/ physical disability with no cognitive impairment would be determined with this decision tree to not meet the federal definition of DD. (They would meet the state definition of DD.) Federal language varies on this issue, and there is variation among states and within Wisconsin on whether adults with CP or other physical disabilities should be considered “DD.” This decision tree was developed to determine a target group on the LTC Functional Screen. People with cerebral palsy or other neurological/ physical disability could meet the Physical Disability target group on the LTC Functional Screen.

Box 5 of the decision tree says that the person must have substantial functional limitation in three or more of the six listed areas. A person with a physical disability but no cognitive disability would probably only meet criteria a (capacity for independent living) and b (self-care), but be independent—with adaptive aids if uses them—in the other 4 criteria (communication, learning, mobility, and self-direction).

Box 6 c says help must be “to address social, intellectual and behavioral deficits.” Persons with CP or other neurological/ physical disabilities and normal IQ would thus not make the Federal definition of DD target group. They could make the “Physical Disability” target group.

- c. Autism spectrum disorders override IQ scores. A person with any of the autism spectrum disorders would pass the decision tree if the condition satisfies criteria in Boxes 5 (functional limitations in 3 or more areas) and 6 (on-going support needed). A high-functioning person with such a diagnosis--or misdiagnosis (which are common)--would not pass Box 5 or 6.
- d. People with traumatic brain injury before age 22 might make the Federal definition of DD. People with traumatic brain injury after age 22 would not make the federal definition of DD. On the LTC FS, brain injury is considered a physical disability, if it meets the statutory definition of physical disability. The screener could check "State definition of DD" target group as well.

PART 2 - USING THE DD DECISION TREE

A. GENERAL PROCESS AND CONTACT INFORMATION

1. When the person has multiple diagnoses including mental illness, substance abuse, learning disorders, emotional disturbances, behavioral diagnoses, or dementia, a second screener should be consulted.
2. When two screeners do not have consensus in a particular case, or when the decision tree result seems incorrect for a given individual, or when the screener has full information but is not clear on how to apply the decision tree in a given case, the screener (or agency's screen lead staff) should contact the following:
 - Kim Nelson, WI Bureau of Long Term Support (BLTS) 608-267-7803
Kimberly.Nelson@wisconsin.gov
3. In Home and Community Based Waiver counties, people screening DD individuals must be qualified as QMRPs.

B. SOME DETAILED POINTS

Diagnoses and Misdiagnoses

The federal definition of DD refers to mental retardation (MR), which is in turn defined by IQ test scores and functioning. The cognitive impairment must be developmental—meaning that it occurs before the age of 22 and is not due to mental illness or substance abuse. Sometimes IQ scores do not match the person's functioning, and sometimes diagnostic labels are misapplied. We have seen people with normal intellectual functioning labeled mentally retarded. That is why the decision tree uses both IQ scores and diagnoses so that it works when mental retardation was properly diagnosed, missed, or inappropriately diagnosed.

We have found that misdiagnoses are common. Generally speaking, mental retardation (MR) should be given when the person has full scale IQ scores less than 70; learning disability should only be diagnosed when the person has a full scale IQ above the MR range.

Learning disability is appropriate diagnosis only if person's full scale IQ is above the range for mental retardation.

Per DSM-III, "mixed specific developmental disorder" should not be diagnosed if IQ is above 70.

Emotional disturbance is appropriate diagnosis only if others above do not apply, and IQ is above 75.

Multiple Diagnoses

In practice, it is often extremely difficult to draw the line between DD and mental illness, substance abuse, or emotional, behavioral, or learning disorders. If the person has multiple diagnoses including mental illness or substance abuse, their effects must be ignored to ask whether the DD condition alone causes "substantial limitations in at least three areas of life..." and requires active treatment. This "thought experiment" is the most difficult part of deciding whether someone meets the federal definition of DD. It is unavoidable. When the person has multiple diagnoses including the ones specifically excluded in Box 4 e, then the screener should consult with another QMRP. If the two QMRPs are not clear, the screener should contact DHS staff for advice.

The federal definition of DD includes conditions "similar to mental retardation." To avoid overly broad interpretation here, the decision tree excludes other types of diagnoses--namely, psychiatric diagnoses, behavioral diagnoses, learning disability, emotional disturbances, substance abuse diagnoses, and dementia/senility. Psychiatric diagnoses here includes any mental illness diagnoses, e.g.,

- Schizophrenia, psychoses;
- Anxiety disorder, dissociative disorder, sleep disorder, eating disorders, somatoform disorders, or impulse-control disorders;
- Mood disorders--including bi-polar (or "manic-depressive") disorder, depression; and
- Personality disorders (PD)--e.g., schizoid PD, borderline PD, antisocial PD, paranoid PD.

Behavioral Disorders include but are not limited to:

• Impulse-control disorder	• Oppositional defiant disorder
• Hyperactivity	• Pica
• Attention deficit disorder	• Obsessive-compulsive disorder (OCD)
• Attention-deficit, hyperactivity disorder (ADHD)	• Conduct disorder

School Assignments Do Not Reveal DD Status

School placement (e.g., special ed) does not mean the person meets federal definition of DD. Schools' categories of ED, LD, and CD (emotional disabilities, learning disabilities, and cognitive disabilities) are often based on local conditions (funding & staff) and stigma avoidance.

Criminal System Does Not Reveal DD Status

Whether or not the legal system considers a person competent enough to stand trial and be imprisoned cannot be used to decide whether a person meets federal definition of DD.

Brain Injury

Screener should ALSO check Physical Disabilities Target group question. Both the brain injury and the Cerebral Palsy in this case appear to meet statutory definition of physical disability.

Cerebral Palsy

Note that Box 6, criteria c requires that on-going support is “to address social, intellectual and behavioral deficits.” A person with moderate to severe CP who has no cognitive impairments would fail to meet criteria 6. A person with milder CP might fail to meet 3 areas of limitation required in Box 5.

Moderate to severe CP would probably meet the statutory definition of Physical Disability, so PD target group should be checked. . Mild CP might not meet the statutory definition of PD.

Other Target Groups

Screeners should always check to see if other health conditions are severe enough to meet the statutory definition of physical disability.

Special Consideration of Young Adults

It is common that young adults--especially males--have not yet had the chance to learn to handle their own meal prep, laundry, chores, money management, or even learning to ride the bus, because their parents have been doing many things for them.

Screeners need to ask whether the applicant is in fact able to do those things alone now. If not, they may currently meet the federal definition of DD. If they eventually learn to develop all possible skills, some of them may no longer meet the federal definition of DD.

Be cautious when considering young adults against this tree. An SSA determination based on a learning disability or emotional disturbance does not meet the criteria for federal DD.

Box 5 – Substantial Limitations in 3 or more areas.

Remember Box 5 asks if MR or conditions 4 a through 4 e cause(s) substantial limitations. Screeners should ignore problems caused by other excluded diagnoses listed in 4 e.

Being unemployed does not in itself indicate an inability to manage money or economic self-sufficiency. A person may be unemployed for other reasons, including socioeconomic and cultural factors.

Note that driving or vehicular transportation is not included among six areas listed in Box 5.

Economic self-sufficiency is no longer present in the federal definition of DD used for home and community-based waiver eligibility determinations. It may be included under “capacity for independent living,” but only if the person is unable to work because of MR or condition(s) 4 a-e; not for any other reasons such as socioeconomic or cultural factors, motivation, mental illness or substance abuse. People can be unemployed for reasons having nothing to do with developmental disability. Unemployment does not necessarily mean the person is unable to manage money.

In most cases if the person is unable to work due to cognitive limitations (not due to lack of motivation or depression, a substance abuse problem, an economic recession, etc.), you would determine that the substantial limitation to working is due to problems in learning. If this is the case, it may be appropriate to say that this also is evidence of a substantial limitation to capacity for independent living. However, it is important to see if there are other issues causing the substantial limitation in capacity for independent living (e.g., budgeting, grocery shopping, etc.). While it is not easy to make these distinctions, it is critical to do so. The overall picture of the person should make sense as a description of a person with a developmental disability.

Box 6 – On-Going Treatment

All four criteria must be met. Note that 6c (“Is to address social, intellectual and behavioral deficits”) excludes people with only physical impairments, such as those with cerebral palsy. “Support” here does not have to occur every day, but does have to meet all four criteria in Box 6.

“No Active Treatment” (NAT) is a separate question. See DD Decision Tree Questions & Answers document for more information on NAT.

PART 3 – QUESTIONS & ANSWERS ON THE DECISION TREE

1. What about “No active treatment?”

This decision tree is designed to answer one and only one question: "Does the person meet the ‘federal definition of DD’ target group on the LTC FS?" This decision tree does not answer other questions. For instance, if both DD and physical disability target groups apply, the decision tree does not indicate which is “primary.” In counties without Family Care MCOs, this decision tree does not indicate whether the person would be better served in the DD or physical disability system. The decision tree does not indicate whether someone would be “no active treatment” (NAT) or whether a nursing home could or would admit them. It only answers the question of whether a person meets the federal definition of DD.

2. What about persons with Downs Syndrome who develop Alzheimer’s disease before age 60? At what age does someone become aged?

There are several questions here.

- “Frail Elder” should be checked only if person is age 65 or older.
- If the person has a verified diagnosis of Alzheimer’s disease (or another irreversible dementia), then the “Alzheimer’s disease” (or the “Other irreversible dementia”) target group should be checked, regardless of the person’s age. So a 40-year-old person with Downs Syndrome and mental retardation and early Alzheimer’s could meet both the “Federal definition of DD” and the “Alzheimer’s disease” target groups.

Again, the question of “no active treatment” or NAT goes beyond the scope of this decision tree. A 67-year-old person with moderate mental retardation could pass all steps of this decision tree and would meet the federal definition of DD target group on the LTC FS. NAT

determination is a separate, secondary question to decide which waiver the person should be on.

3. Can a screener check “Frail Elder” or “dementia” target group when someone with a developmental disability no longer meets the standard for active treatment (on-going support?)

Only if the person has a condition that meets the statutory definition of “Frail Elder” or has a confirmed diagnosis of Alzheimer’s disease or irreversible dementia. Not all cognitive impairment is “dementia.”

If the person really doesn’t need any support, then the criteria in Boxes 5 and 6 would not be met, so the person would not meet the federal definition of DD. If they do meet the federal definition of DD, then the question of NAT (e.g., due to medical problems) is a separate question. (See question 2 above for discussion of NAT.)

4. What about persons diagnosed with Prader-Willi syndrome as found in Wisconsin’s definitions?

Prader-Willi syndrome is specifically mentioned in Wisconsin’s definition of DD, which is broader than the federal definition of DD. Prader-Willi syndrome is not mentioned in the federal definition of DD, so is not specifically mentioned in Box 4. It can be considered a condition similar to mental retardation (Box 4). The majority of people with Prader-Willi would meet all criteria of this decision tree, and so meet the federal definition of DD. Only a few, with milder limitations, would fail at Box 5 and Box 6.

5. Is contacting the Social Security Administration for disability determination records optional?

Yes. In most cases, continuing with the decision tree will yield positive results faster. If a person does not pass the decision tree, the screener should consider any other avenues that might render the person eligible. This includes requesting SSA records if disability determination may show developmental cognitive disability. A SSA determination does not automatically make an individual meet the federal definition of DD.

6. State statutes define brain injury very precisely. How does that fit in this decision tree?

For purposes of this decision tree, the screener needs a confirmed medical diagnosis of “head injury” or “traumatic brain injury.” Reports of suspected brain injury do not count. To meet the federal definition of DD, the brain injury must be documented to have occurred before the age of 22, and must meet all criteria in boxes 5 and 6 of the DD decision tree.

This decision tree does not determine whether someone is eligible for the brain injury waiver program. Brain injury waiver program eligibility is more clinically complex,² and will retain a separate eligibility review process in home and community based waiver counties. In Family

² For example, brain injury waiver eligibility must consider complex questions about the person’s prognosis for rehabilitation, and whether behavior or cognitive problems were present before the brain injury.

Care counties, there is not a brain injury waiver program, however individuals with brain injury may be served in Family Care under the physical disability target group with traumatic brain injury after the age of 22.

7. Is a brain tumor a physical disability? Is it a physical disability when the tumor occurs within the developmental period?

A brain tumor is a condition that may or may not meet the statutory definition of physical disability. If the brain tumor occurred after the age of 22, of course it does not meet the federal definition of developmental disability. If the brain tumor occurred before the age of 22, it might pass the federal DD decision tree in one of two ways. One, the child may have been diagnosed mentally retarded and/or have a full-scale IQ of less than 75 (Box 2). If the MR or low IQ satisfy all criteria in Boxes 3, 4, 5, 6, the federal definition of DD is met. (In this case, the cause of the MR or low IQ is less important than the MR or low IQ.)

Another person with a brain tumor might not have the diagnosis of MR or IQ scores. In this case, the brain tumor might be considered a “neurological condition [possibly] similar to MR” (Box 4). If that condition meets all criteria in Boxes 4, 5 and 6, then the federal definition of DD is satisfied.

If the brain tumor occurs after the age of 22, it does not meet the federal definition of developmental disability.

Whether or not the person meets the federal definition of DD, the screener should also ask whether the brain tumor--or, more precisely, conditions it might cause, such as paralysis--meets the statutory definition of physical disability. (This is not very important if the person met the federal definition of DD target group and if screener properly indicates traumatic brain injury in diagnosis table.)

8. Is epilepsy synonymous with seizure disorder?

Yes, it is.

9. Is epilepsy a physical disability if there exists no sub-average intelligence (IQ < 75)?

Only if it meets the statutory definition of physical disability. In most cases, it would not.

10. Can cerebral palsy be considered a physical disability?

Yes, of course--if it meets the statutory definition of physical disability. Some people have mild CP which does not “significantly limit activity in at least one major life area.”

11. How do “other neurological disorders” relate to the neurological disorders allowed in the definitions of a physical disability (simply because of similarity to mental retardation)? Still not sure what some these disorders would be.

The statutory definition of physical disability is “a physical condition, including...neurological ...which results from injury, disease, or congenital disorder and which significantly interferes with or significantly limits at least one major life activity of a person.”

So, a particular neurological condition might satisfy the definition of physical disability and also be used in the federal definition of DD (Box 4 of the decision tree) as an “other neurological condition similar to mental retardation.” In other words, a neurological condition might meet both DD and physical disabilities target group.

A few examples of such neurological conditions that might satisfy both definitions, if they occur before age 22 and cause significant limitations, include hydrocephalus, spina bifida, traumatic brain injury (including shaken baby syndrome), encephalitis, brain tumor, etc.

The “other neurological condition similar to mental retardation” can involve some subjectivity. But note that Box 4 specifically excludes mental illness, behavioral diagnoses, learning disabilities, emotional disturbances, dementia (also called senility), and substance abuse.

A neurological disorder might meet several target groups. Screeners need to consult with a health care professional to obtain the diagnoses and to understand their effects on the person’s functioning.