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Executive Summary

This report provides Optumas' final recommendations on the assessment tools and criteria used for Adult and Child Intermediate Care Facility Level of Care (ICF LOC) determination in Nebraska. Based on extensive research of other states’ tools, national best practices, and interviews with Nebraska’s Department of Health and Human Services (NE DHHS) staff, Optumas recommends that NE DHHS: (1) fully align the criteria used for Medicaid Home and Community Based Services waiver and institutional ICF LOC determinations; (2) modify the existing ICF LOC criteria, consistent with best practices and peer states; and (3) leverage existing standardized assessments to determine ICF LOC.

Optumas, in partnership with Alvarez & Marsal (A&M), undertook a review of ICF LOC tools and criteria in other states to understand the way ICF LOC determinations were being done across the country. Seven peer states’ ICF LOC assessment tools and criteria were evaluated in further depth. A series of options for altering or replacing the existing criteria and tool used for both Adult and Children ICF LOC determination were evaluated.

Through this process, it was determined that:

1. Nebraska’s ICF LOC is not aligned for the Medicaid Home and Community-Based Services (HCBS) waivers and institutional settings;
2. Nebraska’s definition of developmental disabilities is more restrictive than the federal definition, peer states, and best practice;
3. The ICF LOC criteria for significant functional limitations in major life activities is more limited than the federal definition, peer states, and best practice;
4. Nebraska’s homegrown tool for measuring ICF LOC for Medicaid HCBS lacks technical properties characteristic of standardized commercial tools, including testing to demonstrate inter-rater reliability, criterion-related and construct validity, among other issues; and
5. Nebraska has no single tool for measuring ICF LOC for initial ICF LOC determinations for institutional placements.

This report will provide an outline of the criteria and tools used in ICF LOC eligibility determinations for adults and children. Based on research of other states’ criteria, Optumas recommends that NE DHHS change the current criteria (both Adult and Child) used in Nebraska for determining ICF LOC eligibility and the tool used to determine LOC.

NE DHHS has the following options. Optumas’ recommendations within the options are italicized below.

- Intermediate Care Facility Level of Care Regulations for Medicaid HCBS and ICF for Adults and Children. Nebraska’s definition of intellectual and developmental disabilities is not consistent for waiver and institutional LOC and includes references to ICF admissions requirements.
  - Options from Review of Other States’/Federal Regulations (adoption of Option 2 would require rules/regulation changes):
    - Option 1: No change to regulations, or
    - Option 2: Align administrative code requirements for institutional and Medicaid HCBS ICF LOC consistent with Federal Regulations, use a single definition of intellectual and developmental disabilities (I/DD) for waiver and institutional LOC, and amend ICF LOC criteria for facilities to eliminate references to active treatment and mental illness.
Intermediate Care Facility Level of Care Criteria for Medicaid Home and Community-Based Services (HCBS) and Institutional (Intermediate Care Facility - ICF) for Adults and Children: Definition of Developmental Disability. Nebraska’s definition for developmental disability is not consistent with best practices or peer states.

- Options from Review of Other States’ Definitions of Developmental Disability (adoption of Option 2 below would require rules/regulation changes):
  - Option 1: No change to definition, or
  - Option 2: Refine the statutory definition of developmental disability to align with best practice and peer states which include requiring significant functional limitations in two of the following three areas (current definition requires three of three) of adaptive functioning: conceptual, social, and practical.

Intermediate Care Facility Level of Care Criteria in Nebraska Administrative Code (NAC) for Medicaid HCBS and Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) for Adults: Requires Level of Service Provided in an ICF/IID. Nebraska’s adult criteria for developmental disabilities is not consistent with best practice or peer states.

- Options from Review of Other States’ Criteria (adoption of Option 2 would require rules/regulation changes, e.g., reference the requirements in both the ICF/IID and Medicaid HCBS waiver ICF LOC regulations):
  - Option 1: No change to criteria, or
  - Option 2: For adults, require limitations in at least four of the following eight major life activities (current is three of six): self-care, receptive and expressive language, learning, mobility, self-direction, social skills, capacity for independent living, and economic self-sufficiency.

Intermediate Care Facility Level of Care Criteria in NAC for Medicaid HCBS and ICF/IID for Children: Part 2, Requires Level of Service Provided in an ICF/IID. Nebraska’s children criteria for developmental disabilities is not consistent with best practice or peer states.

- Options from Review of Other States’ Criteria (adoption of Option 2 would require rules/regulation changes, e.g., reference the requirements in both the ICF/IID and Medicaid HCBS waiver ICF LOC regulations):
  - Option 1: No change to criteria, or
  - Option 2: For children, require limitations in at least four of the following seven major life activities (current is three of six): self-care, receptive and expressive language, learning, mobility, self-direction, social skills, and capacity for independent living.

Additional Considerations for Intermediate Care Facility Level of Care Criteria

- Technical Corrections: We have identified two types of technical corrections that DHHS should undertake as part of this process:
  - As part of amending the statutory definition of developmental disabilities and the ICF LOC criteria for facilities, make technical changes for consistent language in Nebraska Administrative Code Title 471 Chapter 31 (471 NAC 31-003.04D).

Initial ICF LOC Assessment Process for Medicaid HCBS Waivers. Nebraska’s homegrown tool is not consistent with best practice.

- Options from Review of the Literature and Other States’ ICF LOC Assessment Tools:
Executive Summary

- **Option 1**: No change to current tool, or
- **Option 2**: Streamline the initial LOC assessment process by using the initial eligibility determination for the Developmental Disabilities Division (DDD) to also determine LOC (do not use the Developmental Index tool for initial LOC determinations). If the initial eligibility assessment was done externally and sub-scores are not available, use the Inventory for Client and Agency Planning (ICAP) for initial LOC determinations.

- **ICF LOC Redetermination Assessment Process for Medicaid HCBS Waivers.** Nebraska’s homegrown tool is not consistent with best practice.
  - Options from Review of the Literature and Other States’ ICF LOC Assessment Tools:
    - **Option 1**: No change to current tool, or
    - **Option 2**: Streamline the redetermination LOC assessment process for Medicaid HCBS by using the ICAP assessment that DDD already administers to people to redetermine LOC (do not use the Developmental Index tool for LOC redeterminations), supplementing with clinical assessments, as needed.

- **Initial ICF LOC Assessment Process for Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) settings.** There is no single tool currently in use to determine initial ICF LOC for institutional placements.
  - Options from Review of the Literature and Other States’ ICF LOC Assessment Tools:
    - **Option 1**: No change to current practice, or
    - **Option 2**: Create a more uniform process for initial ICF LOC for ICF/DD settings. Require all people who are seeking admission to an ICF/DD to first establish eligibility with the DDD. Streamline the initial LOC assessment process by using the initial eligibility determination for DDD services to also determine LOC.

- **Additional Recommendation for Initial ICF LOC Assessments and Redeterminations for Medicaid HCBS Waivers and Institutional Settings:** Create an abbreviated review process for people at or below a benchmark IQ score.

This report provides background information on ICF LOC, including details on best practice and peer states. Each of the options presented above is discussed in greater detail, as well as a discussion of and recommendations for tools to assess ICF LOC and alignment of the recommended criteria with those tools. These recommended changes to criteria will appear throughout the report in italics. Please note that any changes in criteria will have subsequent population impacts which must be evaluated before changes in criteria are implemented. Changes in criteria will also require changes in statute and regulation. A summary of Optumas’ recommendations can be found in the section titled Final Recommendations.

Understanding the population impacts of any change to ICF LOC assessment criteria or tools is critical when evaluating the next steps in implementation. Evaluating the LOC status of a sample of the existing population, under the current and proposed tools and criteria, will offer the State insight into whether groups of people are gaining or losing ICF LOC status under the proposed changes. Any changes in tools or criteria should be evaluated for potential population impacts utilizing available data. Optumas has partnered with a DHHS-DDD Licensed Psychologist on an initial population impact study that includes data analysis of a sample of more than 7,000 individuals receiving Medicaid HCBS Waiver and institutional services, as well as people on the waiting list, and found limited population impact, discussed below.
Addressing and implementing the recommendations included in this report will require significant buy-in from State staff. It is Optumas’ position that the recommended changes included in this report would represent a significant improvement and alignment with national best practices. Optumas would also recommend that the State continue to evaluate opportunities to improve the ICF LOC determination process.
Purpose and Background

The Department of Health and Human Services (DHHS) provides funding and oversight for the Medicaid Home and Community-Based Services (HCBS) waivers. This oversight includes the assessment of people’s Intermediate Care Facility Level of Care (ICF LOC) to determine eligibility for waivers, the provision of service coordination for eligible individuals, and the monitoring and paying of providers.

The Division of Medicaid and Long-Term Care (MLTC) oversees the Nebraska Medicaid program, including Intermediate Care Facilities for People with Developmental Disabilities (ICF/DDs). Medicaid provides health care services to a wide variety of eligible people, including those who are disabled or elderly, as well as low-income pregnant women, children, and parents. DHHS is working to design the most appropriate and effective ICF LOC assessment tools to achieve their mission of ‘helping people live better lives’.

This report presents Optumas’ findings regarding Nebraska’s current ICF LOC Assessment Tools and Criteria. The results of Optumas’ analyses and subsequent recommendations regarding the LOC Assessment Tools are included herein. All information reported here is intended to support DHHS in examining, evaluating, and redesigning the ICF LOC Assessment Tools and Criteria.

The variety of options and recommendations for DHHS presented here are based on the following:

- **ICF LOC in Other States** – The Optumas team reviewed literature to identify other states’ tools, criteria, and current best practices in LOC assessment tools for Medicaid populations potentially eligible to receive ICF services.

- **Independent Evaluations of Other States’ LOC Assessment Tools** – To ensure a comprehensive review of LOC assessment tools for ICF settings, the Optumas team reviewed meta-analyses across multiple states’ LOC assessment tools as well as independent evaluations of Medicaid LOC assessment tools for ICF settings.

- **Review of NE ICF LOC Assessment Tools and Processes** – The Optumas team reviewed the current NE ICF LOC assessment tools and processes for adults and children to determine if they comport with best practices and achieve Nebraska’s policy goals for those potentially eligible to receive ICF services.

- **Other States’ ICF LOC Assessment Tools and Criteria** – The Optumas team compiled ICF LOC assessment tools and criteria from other states, identified the parts of those tools that are consistent with Nebraska ICF LOC eligibility criteria, and stated policy goals for placement in ICF settings.
Intermediate Care Facility Level of Care Criteria

A person must meet two types of eligibility criteria to receive Medicaid Long Term Services and Supports (LTSS), regardless of whether he or she will receive supports in the community through Medicaid HCBS or in an institutional setting. The two types are financial eligibility (including income and asset limitations) and functional eligibility, also called level of care criteria. This memo will focus on functional eligibility.

States may only provide HCBS waiver services for people with I/DD to people who are determined to need the level of care furnished in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). The waiver application itself specifies the level(s) of care that is required to receive services under the waiver. In this way, level of care is part of how a state specifies the target population of people who may utilize Medicaid HCBS waiver services. LOC is determined initially prior to admission to an institutional setting or waiver program and then recertified at least annually for people receiving Medicaid HCBS.

The overall goal of LOC determinations is to ensure that the right people are getting the right amount of care, in the right setting. That is, that the assessment ensures access to LTSS for people most in need; that finite state resources are used to provide LTSS for that population of people; and that those people have the opportunity to receive LTSS in the least restrictive environment that meets their needs.

Federal Regulations limit eligibility for ICF/IID to people with intellectual disabilities or related conditions. Intellectual disability is not defined by the Federal Regulations. People with related conditions, more commonly referred to as developmental disabilities, are defined, in part, by resulting functional limitations.

The definition of related condition is primarily functional, rather than diagnostic. The underlying cause must have been manifested before age 22 and be likely to continue indefinitely. Specifically, related condition is defined as follows:

“a severe, chronic disability that meets all of the following conditions:
It is attributable to -
(1) Cerebral palsy or epilepsy; or
(2) Any other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of [persons with intellectual disabilities], and requires treatment or services similar to those required for these persons.
It is manifested before the person reaches age 22.
It is likely to continue indefinitely.

2 NB, The acronym for Intermediate Care Facilities differs in the Federal Regulations (ICF/IID) and Nebraska regulations (ICF/DD). For consistency, this memorandum uses the federal acronym unless specifically referring to the Nebraska regulations.
4 42 CFR 442.302(c).
It results in substantial functional limitations in three or more of the following areas of major life activity:
(1) Self-care
(2) Understanding and use of language
(3) Learning
(4) Mobility
(5) Self-direction
(6) Capacity for independent living.”


Eligibility for Medicaid HCBS waivers for people with I/DD is directly linked to ICF/IID level of care. For both eligibility and ICF LOC, states must find that the person has a diagnosis of intellectual disability or related condition and that the person requires the level of services provided by an ICF/IID. Additionally, for HCBS waiver services, the states must determine that the person, “but for the provision of waiver services, would otherwise be institutionalized in such a facility.” Thus, states “are required to use level of care evaluation instruments or processes for waivers that yield equivalent outcomes to those used for the [ICF/IID] program.”

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5 42 CFR 435.1010
6 42 CFR 435.1010; 42 CFR 441.302.
Intermediate Care Facility Level of Care Criteria: Best Practice Definitions, Federal Definition, and Peer States

Intellectual Disability Definition: The American Association on Intellectual and Developmental Disability and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

The American Association on Intellectual and Developmental Disability (AAIDD) and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) definitions of intellectual disability characterize the disability by deficits that may impact a person in three categories of adaptive behavior: conceptual, social, and practical (see Table 1: Intellectual Disability Definitions: Adaptive Behavior Deficit Categories). Each gives different definitions of major life activities in which a person may have significant functional limitations. Of note, while both definitions indicate that an intellectual disability may impact adaptive functioning in the three domains (conceptual, social, and practical), neither requires substantial limitations in all three areas to meet the criteria.

Table 1: Intellectual Disability Definitions: Adaptive Behavior Deficit Categories

<table>
<thead>
<tr>
<th>Adaptive Functioning</th>
<th>AAIDD</th>
<th>DSM-5</th>
</tr>
</thead>
</table>
| **Conceptual**       | • Language and literacy  
|                      | • Money, time, and number concepts  
|                      | • Self-direction  | • Language  
|                      | • Reading  
|                      | • Writing  
|                      | • Math  
|                      | • Reasoning  
|                      | • Knowledge  
|                      | • Memory  |
| **Social**           | • Interpersonal skills  
|                      | • Social responsibility  
|                      | • Self-esteem  
|                      | • Gullibility  
|                      | • Naïveté (i.e., wariness)  
|                      | • Social problem solving  
|                      | • Ability to follow rules/obey laws and to avoid being victimized  | • Empathy  
|                      |  | • Social judgment  
|                      |  | • Interpersonal communication skills  
|                      |  | • Ability to make and retain friendships  
|                      |  | • Similar capacities  |
| **Practical**        | • Activities of daily living (personal care)  
|                      | • Occupational skills  
|                      | • Healthcare  
|                      | • Travel / transportation  
|                      | • Schedules / routines  
|                      | • Safety  
|                      | • Use of money  
|                      | • Use of the telephone  | Self-management in areas such as:  
|                      |  | • Personal care  
|                      |  | • Job responsibilities  
|                      |  | • Money management  
|                      |  | • Recreation  
|                      |  | • Organizing school and work tasks  |

8 AAIDD Definition of Intellectual Disability, available on-line at: https://www.aaidd.org/intellectual-disability/definition.
Federal Definition of Developmental Disability

As with the federal definition of related condition, listed above, the federal definition of developmental disability looks to a person’s substantial functional limitations in three or more areas of major life activities, listed below in “Table 2: Federal Definition of Developmental Disability” (see Appendix B: 45 CFR § 1325.3 – Definitions, Developmental Disability). These major life activities fall into two areas of the three categories of adaptive functioning, discussed above: conceptual and practical. A person may meet the federal definition of developmental disabilities regardless of whether the person demonstrates significant limitations in one or two areas of adaptive functioning. For example, a person with significant limitations in only receptive and expressive language, learning, and self-direction would meet the criteria, even though he or she had deficits in only one of three areas of adaptive functioning.

Table 2: Federal Definition of Developmental Disability

<table>
<thead>
<tr>
<th>Adaptive Functioning</th>
<th>Major Life Activities in the Federal Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual</td>
<td>• Receptive and expressive language</td>
</tr>
<tr>
<td></td>
<td>• Learning</td>
</tr>
<tr>
<td></td>
<td>• Self-direction</td>
</tr>
<tr>
<td>Social</td>
<td>N/A</td>
</tr>
<tr>
<td>Practical</td>
<td>• Self-care</td>
</tr>
<tr>
<td></td>
<td>• Mobility</td>
</tr>
<tr>
<td></td>
<td>• Capacity of independent living</td>
</tr>
<tr>
<td></td>
<td>• Economic self-sufficiency (included in the federal definition of developmental</td>
</tr>
<tr>
<td></td>
<td>disability, but not related condition)</td>
</tr>
</tbody>
</table>

Peer States Definitions of Developmental Disability as Applied to Intermediate Care Facility Level of Care

Optumas researched ICF LOC criteria and tools in seven peer states: Colorado, Idaho, Iowa, Kansas, Missouri, North Dakota, and South Dakota. The federal definition of developmental disability is currently being used as a part of ICF LOC determinations in four of the seven peer states reviewed: Idaho, Missour, North Dakota and South Dakota. Additionally, Kansas has a slight variation on the definition, but also requires limitations in three or more of the seven major life activities, listed above.

Iowa uses different categories of major life activities (academic skills, social/community skills, behavior, mobility, musculoskeletal skills, activities of daily living, domestic skills, toileting, eating skills, vision, hearing or speech or both, gross/fine motor skills, sensory-taste, smell, tactile, health care, vocational skills), but likewise requires limitations in three or more major life activities, regardless of the adaptive functioning category.

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10 Idaho Code 66-402(5).
12 N.D.A.C. 75-04-01-01.17.
13 SDLR 27B-1-18.
14 K.S.A. 39-1803(f).
15 IAC 441-83.60 (249A).
Colorado, the seventh peer state reviewed, uses a cross-disability assessment, discussed below, that evaluates a person’s activities of daily living and instrumental activities of daily living, which is not comparable for the purposes of this discussion.\textsuperscript{16}

\textsuperscript{16} See Colorado’s Home and Community Based Services waivers, available on-line at: \url{https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html}. 
Aligning Nebraska’s Developmental Disability Definition for Level of Care Criteria per Federal Regulations

As discussed above in the Background section, eligibility for Medicaid HCBS waivers is directly linked to ICF/IID LOC and must be limited to those who require a LOC equivalent to that provided in an institution. In practice, this means that a state can have only one standard for LOC, regardless of whether a person is entering a Medicaid HCBS waiver or an institutional program. Nebraska ICF LOC regulations for Medicaid HCBS waiver and ICF/IID settings currently differ in two ways: (1) There are two different definitions of intellectual and developmental disabilities, and (2) the ICF LOC regulations contain admissions criteria that are not relevant to LOC.

**Optumas** recommends that the State align administrative code requirements for institutional and Medicaid HCBS ICF LOC in a manner consistent with Federal Regulations, using a single definition of intellectual and developmental disabilities (I/DD) for waiver and institutional LOC, and amending ICF LOC criteria for institutional settings to eliminate references to active treatment and mental illness.

**Definition of Developmental Disability Applied to Criteria for Intermediate Care Facility Level of Care for Medicaid Home and Community-Based Services Waivers**

Level of care for Nebraska’s Medicaid HCBS waivers for people with I/DD is governed by 403 NAC 2.001, Eligibility Requirements (see Appendix C). The regulations require that:

“In order to be eligible for Medicaid Home and Community Based Waiver Services for individuals with developmental disabilities, an individual must:

(1) Be eligible for Medicaid benefits;
(2) Be age 21 for the adult day waiver;
(3) Have a developmental disability as defined in the Developmental Disabilities Services Act; and
(4) Require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter.”

Developmental disability is defined in the Developmental Disabilities Services Act as follows:

“substantial functional limitations in one of each of the following areas of adaptive functioning:
(a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;
(b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and
(c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living.”

(See Appendix D: Nebraska Revised Statute 83-1205, Developmental Disability, Defined.)

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18 403 NAC 2.001, Eligibility Requirements.
19 Nebraska Revised Statute 83-1205.
Intermediate Care Facility Level of Care Criteria

Definition of Developmental Disability Applied to Criteria for Intermediate Care Facility Level of Care for Facility-Based Placements

Level of care for Nebraska’s ICF/IIDs is governed by 471 NAC 31-003.04D, ICF/DD Level of Care Criteria (Appendix E). The regulations require that the person “has a diagnosis of mental retardation or a related condition which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR.”

To align requirements for institutional and Medicaid HCBS ICF LOC, Optumas recommends the State update 471 NAC 31-003.04D to require that the person “has a diagnosis of developmental disability as defined in the Developmental Disabilities Services Act.” This would result in a single definition of intellectual and developmental disabilities (I/DD) across waiver and institutional ICF LOC.

Amend Intermediate Care Facility Level of Care Criteria for Facilities to Eliminate Inappropriate References to Admission Criteria

Regulatory requirements for ICF facility-based level of care include two ICF admission criteria that are not relevant to Medicaid HCBS waiver services: Active Treatment and references to mental illness.

Requirement for Active Treatment

One of the requirements for institutional ICF LOC is that the person “can benefit from "active treatment" as defined in 42 CFR 483.440(a) and 471 NAC 31-001.02. "Benefit from active treatment" means demonstrable progress in reducing barriers to less restrictive alternatives.” Optumas recognizes the importance of requiring that anyone admitted to an ICF setting must require and be able to benefit from active treatment. In fact, it is a requirement that all ICF/IID facilities must provide active treatment to their residents. However, this important admission criteria should be separate from LOC determinations because it is not applicable to Medicaid HCBS waivers.

Active Treatment is the aggressive, consistent implementation of a program of specialized and generic training, treatment, health- and related services as described in 42 CFR Part 483, Subpart D. In contrast, habilitation is the core of Medicaid HCBS waivers for I/DD. In promulgating the final rule which defined active treatment, the Centers for Medicare and Medicaid Services (CMS, previously known as the Health Care Financing Administration (HCFA)) drew a distinction between habilitation and active treatment, finding that active treatment is broader, encompassing habilitation as well as “the whole range of services necessary for clients to achieve maximum possible independence.” (See Appendix F: Excerpt from CMS Comments on the Final Rule that Defined Active Treatment, 42 CFR Parts 431, 435, 440, 442 and 483, (53 FR 20448-01, 1988 WL 261421(F.R.)))

The aggressive nature and consistent application of active treatment may be comparable to the habilitation provided in some intensive Medicaid HCBS settings; however, not everyone receiving Medicaid HCBS would

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20 471 NAC 31-003.04D.
21 471 NAC 31-003.04D.
22 471 NAC 31-003.04D. 2.
24 42 CFR Parts 431, 435, 440, 442 and 483, (53 FR 20448-01, 1988 WL 261421(F.R.)).
require active treatment. By making it an ICF LOC requirement, people in need of less than daily supports, for example, would likely not meet Active Treatment criteria.

Of note, none of the seven peer states reviewed include Active Treatment in ICF LOC criteria. For the reasons discussed above, Optumas recommends removing this reference from the ICF LOC criteria. Instead, the requirement for Active Treatment should be moved to ICF admission criteria. It could also be captured through the person-centered planning process, as is done in the peer state of South Dakota. If Active Treatment is removed from ICF LOC criteria, the State should ensure that regulatory language is sufficient to require the provision of Active Treatment in an ICF/IID. Optumas notes that the regulations related to the preadmission evaluation process, as well as Interdisciplinary Team responsibilities, among others, reference the need for Active Treatment in an ICF.

**Reference to Mental Illness**

The institutional ICF LOC criteria also include specific requirements for people dually diagnosed with I/DD and mental illness:

“A Medicaid-eligible individual has a dual diagnosis of mental retardation or a related condition and a mental illness (i.e., mental retardation and schizophrenia). The mental retardation or related condition has been verified as the primary diagnosis by both an independent QMRP and a mental health professional (i.e., psychologist, psychiatrist); and:

1. Historically there is evidence of missed developmental stages, due to mental retardation or a related condition;
2. There is remission in the mental illness and/or it does not interfere with intellectual functioning and participation in training programs, i.e., the individual does not have active hallucinations nor exhibit behaviors which are manifestations of mental illness; and
3. The diagnosis of mental retardation or related condition takes precedence over the diagnosis of mental illness.”

Optumas recommends excluding this entire section from the ICF LOC regulations. As with Active Treatment, a person’s mental health status may be relevant to ICF admissions criteria. For example, a person who is actively psychotic may not be able to benefit from Active Treatment until his or her mental health has stabilized. However, including it in ICF LOC could inadvertently exclude otherwise qualified people with dual diagnoses of developmental disability and mental illness.

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26 471 NAC 31-002.03, Preadmission Evaluation Process.
27 471 NAC 31-005.07 IDT Responsibilities.
28 See also (non-exhaustive list): 471 NAC 31-001, Standards for Participation; 471 NAC 31-001.02, Active Treatment Defined; 471 NAC 31-002.02 Role of Department; 471 NAC 31-003.04D1, Inappropriate Level of Care; 471 NAC 31-005.08G, Discharge; 31-007.05, Items in Per Diem Rates; and 471 NAC 31-008.06CD, Personnel Operating Cost.
29 471 NAC 31-003.04D.
Nebraska’s Developmental Disabilities Definition as Applied to Intermediate Care Facility Level of Care Criteria

Developmental disability is defined in the Developmental Disabilities Services Act, which governs the Department of Health and Human Services, Developmental Disabilities Division (DHHS-DDD) and Medicaid HCBS Waiver programs, including ICF LOC criteria to participate in the programs. The definition of developmental disability specifically includes intellectual disability. Above, Optumas recommends that this definition also apply for institutional ICF LOC criteria, so that there is a common definition of intellectual and developmental disability.

Nebraska’s statutory definition of developmental disabilities is more restrictive than those of peer states, limiting access to DHHS-DDD services, and Medicaid HCBS waiver programs for people with I/DD. Optumas recommends that the State refine the statutory definition of developmental disability to align with best practice and peer states, requiring significant functional limitations in two of the following three areas of adaptive functioning: conceptual, social, and practical.

Legislative History

In 2016, Nebraska updated its definition of developmental disabilities. The aim of the legislative change was to align “the seven major life activities with best practices within the categories... identified by the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), and the International Classification of Diseases (ICD-10)” (see Appendix G: LB 1038, Supporting Testimony of Courtney Miller, Director DHHS-DDD, Health and Human Services Committee, February 4, 2016). This aim also included efforts to streamline and clarify “eligibility determinations based on this best practice methodology, using the source of reference for clinicians in their area of expertise” (Appendix G).

The bill, which has become Nebraska Revised Statute 83-1205, uses the tenets from best practice federal definitions of I/DD, but is significantly more stringent than those definitions, requiring substantial functional limitations in each of the following areas of adaptive functioning: conceptual skills, social skills, and practical skills. Requiring a person to demonstrate substantial functional limitations in each of the categories of adaptive functioning, conceptual, social and practical skills, is more restrictive than the federal definition of developmental disabilities, and those of peer states (see Appendix H: I/DD Definitions). This may result in inadvertently limiting eligibility for DHHS-DDD services to people with I/DD.

Prevalence Data

To evaluate Optumas’ hypothesis that Nebraska’s definition of developmental disability is restrictive and might limit access to DHHS-DDD and Medicaid HCBS services, the team reviewed I/DD prevalence data and the number of people being served by peer states. According to a recent study, there are approximately 7.37 million people with I/DD living in the United States, of whom an estimated 20 percent were known to or served by state I/DD

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30 Nebraska Revised Statute 83-1201.
31 Id.
32 Nebraska Revised Statute 83-1205.
33 This Appendix has been updated for the Final Report.
The population prevalence is estimated at 22.8 per 1,000 of the population, or 2.28%. The “vast majority” of those people are supported through Medicaid HCBS waivers.

Optumas reviewed the Residential Information Systems Project (RISP) data for Nebraska and the seven peer states with the US Census Bureau population statistics for 2016, the most recent year for which RISP data are available, to determine an estimated I/DD population prevalence for each state, as well as percentage known to the state system (see Table 3: Summarized Residential Information Systems Project Data for Peer States).

### Table 3: Summarized Residential Information Systems Project Data for Peer States

<table>
<thead>
<tr>
<th>Jurisdiction</th>
<th>Population</th>
<th>Estimated Prevalence of I/DD</th>
<th>People Known to I/DD System</th>
<th>% Known to I/DD System</th>
<th>People Served by I/DD System</th>
<th>% Served by the I/DD System</th>
</tr>
</thead>
<tbody>
<tr>
<td>US</td>
<td>324 B</td>
<td>7.37 MM</td>
<td>1.49 MM</td>
<td>20%</td>
<td>1.23 M</td>
<td>17%</td>
</tr>
<tr>
<td>NE</td>
<td>1,906,000</td>
<td>43,457</td>
<td>7,979</td>
<td>18%</td>
<td>5,684</td>
<td>13%</td>
</tr>
<tr>
<td>CO</td>
<td>5,539,000</td>
<td>126,289</td>
<td>19,567</td>
<td>15%</td>
<td>13,111</td>
<td>10%</td>
</tr>
<tr>
<td>ID</td>
<td>1,683,000</td>
<td>38,372</td>
<td>10,151</td>
<td>26%</td>
<td>4,020</td>
<td>10%</td>
</tr>
<tr>
<td>IA</td>
<td>3,131,000</td>
<td>71,387</td>
<td>14,557</td>
<td>20%</td>
<td>11,623</td>
<td>16%</td>
</tr>
<tr>
<td>KS</td>
<td>2,911,000</td>
<td>66,371</td>
<td>12,223</td>
<td>18%</td>
<td>10,287</td>
<td>15%</td>
</tr>
<tr>
<td>MO</td>
<td>6,078,000</td>
<td>138,578</td>
<td>34,802</td>
<td>25%</td>
<td>18,704</td>
<td>13%</td>
</tr>
<tr>
<td>ND</td>
<td>754,434</td>
<td>17,201</td>
<td>7,204</td>
<td>42%</td>
<td>3,383</td>
<td>20%</td>
</tr>
<tr>
<td>SD</td>
<td>862,996</td>
<td>196,76</td>
<td>4,604</td>
<td>23%</td>
<td>4,604</td>
<td>23%</td>
</tr>
</tbody>
</table>

Data from 2016

Estimated prevalence = 2.28%

Sources: Residential Information Systems Project; US Census Bureau

In Nebraska, approximately 18% of people with I/DD are known to DHHS-DDD’s system. This is 2% lower than the federal average, and a lower percentage than five of the seven peer states. This may indicate that some people with I/DD are not be able to become eligible for the DHHS-DDD services and the Medicaid HCBS waivers (“known to the I/DD system”), given the State’s restrictive definition of developmental disability.

Based on Optumas’ experience, expanding the definition of developmental disability to require only two of three areas of adaptive functioning will likely have a significant impact on people with autism. These are individuals who may struggle with varying types of adaptive functioning (e.g. social skills, communications, activities of daily

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34 Medicaid Innovation Accelerator Program: Value-Based Payment for Home and Community-Based Services: Intellectual and Developmental Disability Systems (CMS October 2019).
36 Id.
According to the 2017 Family & Individual Needs for Disability Supports (FINDS) Community Report, nearly half of people with I/DD living with family caregivers have a diagnosis of autism spectrum disorder. Caregivers struggle with planning for the future for their adult children with autism; 65% of caregivers of people with autism spectrum disorder do not have a future plan for their adult children. This is concerning because many people with I/DD are living with aging caregivers. The National Core Indicators Adults Family Survey data from 2016-2017 found that 60% of caregivers were between the ages of 55-74, with 11% age 75 or older. Given these findings, adult children with autism who are living with aging caregivers may be at higher risk of homelessness, which leads to a greater likelihood of poor health outcomes and higher health care costs.

To align with best practice and peer states, Optumas recommends that Nebraska refine its statutory definition of developmental disability to require significant functional limitations in at least two of the three areas of adaptive functioning (current is three of three). The relatively low differential in percentage points of people known to state developmental disability system indicates that this change may be a narrow and targeted loosening of restrictions. Optumas also recommends a review of past and current eligibility data to determine the potential impact of this change, specifically looking at people who did not meet functional limitation criteria to determine whether this change would impact their eligibility and then project an estimated increase in number of people who might be found eligible each year.

Optumas notes that the definition of developmental disability is replicated in statute at § 71-1107, the Developmental Disability Court-Ordered Custody Act, which may need to be amended for consistency. The definition of developmental disability is also referenced in other sections of the Nebraska Revised Statutes, including: Neb. Rev. Stat. 20-162, Terms Defined; Neb. Rev. Stat. 37-404.01, Hunting permit; Neb. Rev. Stat. 37-424, Special fishing permit for resident who is physically or developmentally disabled; and Neb. Rev. Stat. 77-3508, Homesteads. The State would have to evaluate the projected impact of this change on each of these laws.


40 National Core Indicators, Data Highlight on Aging Caregivers, available online at: https://www.nationalcoreindicators.org/upload/aidd/Older_caregivers.pdf.

41 Paradise J. and Ross D., Linking Medicaid and Supportive Housing: Opportunities and On-the-Ground Examples, (Kaiser Family Foundation 2017), available online at: https://www.kff.org/report-section/linking-medicaid-and-supportive-housing-issue-brief/
Additional Criteria for Intermediate Care Facility Level of Care

In addition to requiring that a person meets the statutory definition of developmental disabilities, the Medicaid HCBS waiver eligibility regulations require that the person “require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter.” Nebraska currently requires that a person demonstrate substantial functional limitations in three or more major life activities, described below.

**Optumas recommends that the State align administrative code requirements for institutional and Medicaid HCBS ICF LOC criteria with the Nebraska definition of developmental disability, as well as peer states and best practice:**

- For adults, require limitations in at least four of the following eight major life activities (current is three of six): self-care, receptive and expressive language, learning, mobility, self-direction, social skills, capacity for independent living, and economic self-sufficiency; and
- For children, require limitations in at least four of the following seven major life activities (current is three of six): self-care, receptive and expressive language, learning, mobility, self-direction, social skills, and capacity for independent living.

**Nebraska Regulatory Intermediate Care Facility Level of Care Criteria: Substantial Functional Limitations in Major Life Activities**

Based upon interviews with DHHS-DDD staff and a review of a process map provided by the Division, Nebraska interprets the federal requirement that a person needs the level of services provided by an ICF/IID to require that the person meet the requirements at 471 NAC 31-003.03D for institutional ICF LOC (see Appendix I: Developmental Disabilities Level of Care Process Map). Specifically, the person must demonstrate that he or she has an intellectual or developmental disability that results in:

“substantial functional limitations in three or more of the following areas of major life activity:

1. self-care;
2. receptive and expressive language;
3. learning;
4. mobility;
5. self-direction; or
6. capacity for independent living.”

This is currently assessed through administration of the Developmental Index (DI) for Medicaid HCBS waiver LOC (see Appendix J: Developmental Index). There is no standard assessment tool or form used to document the initial institutional LOC determination.

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42 403 NAC 2.001 Eligibility Req.
43 These recommendations have been updated from the Preliminary Options for Intermediate Care Facility (ICF) Level of Care (LOC) Assessment Criteria and Preliminary Documentation of Alignment of ICF LOC Tools and Criteria dated June 1, 2020, based upon Optumas’ population impact analysis.
44 471 NAC 31-003.03D,
These six major life activities noted above align with either the conceptual or practical adaptive categories (see Table 4: Major Life Activities and Developmental Disability Definition).

Table 4: Major Life Activities and Developmental Disability Definition

<table>
<thead>
<tr>
<th>#</th>
<th>Major Life Activities</th>
<th>Developmental Disability Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>471 NAC 31-004.04D.3.a.(1) –(6)</td>
<td>Conceptual</td>
</tr>
<tr>
<td>(1)</td>
<td>Self-care</td>
<td>X</td>
</tr>
<tr>
<td>(2)</td>
<td>Receptive and expressive language</td>
<td>X</td>
</tr>
<tr>
<td>(3)</td>
<td>Learning</td>
<td>X</td>
</tr>
<tr>
<td>(4)</td>
<td>Mobility</td>
<td></td>
</tr>
<tr>
<td>(5)</td>
<td>Self-direction</td>
<td></td>
</tr>
<tr>
<td>(6)</td>
<td>Capacity for independent living</td>
<td>X</td>
</tr>
</tbody>
</table>

This means that ICF LOC for waiver and institutional settings criteria does not assess a person’s limitations in adaptive social skills, although it is specifically referenced in the statutory definition of developmental disability. Social skills are included in the peer states of Iowa, Kansas, and North Dakota, as well as in the AAIDD and DSM-5 definitions. ICF LOC determinations also do not consider a person’s limitations in the practical adaptive skill of economic self-sufficiency. As discussed above, economic self-sufficiency is included as a major life activity in the federal definition of developmental disability, as well as six of the seven peer states (see Appendix J: Comparison of Areas of Major Life Activity).

To better align the regulatory criteria for ICF LOC with the Nebraska definition of developmental disability, Optumas recommends adding the major life activities of social skills and, for adults only, economic self-sufficiency. To minimize population impact for people currently receiving services through a Medicaid HCBS waiver or in an ICF/IID, Optumas recommends that an adult would have to demonstrate substantial functional limitations in four or more of the eight areas of major life activities, and youths ages 17 or under would have to demonstrate substantial functional limitations in four or more of the seven areas of major life activities.

Given that this recommendation adds criteria without removing any existing criteria, there should be no impact on the current population because of this change. However, there may be an impact for new people applying for DDD and ICF/IID services, as this provides additional criteria by which a person may demonstrate that he or she meets LOC. Additionally, any change in tool to measure substantial functional limitation in these areas may have a population impact, as discussed below. Optumas recommends that DHHS-DDD review applicants who have been denied LOC to determine whether they would meet LOC under these new criteria.

Additional Technical Corrections to the Statutory Definition of Developmental Disability and the Regulatory Intermediate Care Facility Level of Care Criteria

If the State decides to amend the Developmental Disability Services Act and the ICF LOC regulations for institutional services, Optumas recommends that the State take advantage of the opportunity to make technical corrections and offers several technical changes for consideration.
Change Substantial to Significant

As suggested by DHHS-DDD’s Licensed Psychologist, Optumas recommends changing the term “substantial” to “significant” as it modifies functional limitations. Significant functional limitations are those that are interpreted as statistically valid at two standard deviations from the mean. This change would apply to both Neb. Rev. Stat. 83-1205(4); and 471 NAC 31-003.04D (2): “Results in significant substantial functional limitations.”

Update Language in the Developmental Disability Definition to Reference Adaptive Functioning

There is language in Neb. Rev. Stat. 83-1205(5) that refers to “three or more major life activities.” This is a reference to a requirement in the previous definition of developmental disability. Optumas recommends that it be removed and replaced with language that references adaptive functioning as required by the statute. This would read as follows:

“An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting showing significant functional limitations in at least two of the three areas of adaptive functioning: three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.”

Remove Requirement that Diagnostic Evaluations/Standardized Tests Occur Prior to Admission to the ICF/IID

Level of care regulations for ICF/IID’s require that the person establish that he or she has a diagnosis of I/DD “which has been confirmed by prior diagnostic evaluations/standardized tests.” Based upon discussions with DHHS-DDD staff, including the Licensed Psychologist, the Division’s practice allows needed flexibility, based upon availability of prior evaluations and standardized tests. The Division has experience with older adults entering the developmental disability system who do not have any developmental paperwork – school and pediatric records would be from decades ago and are no longer available. In these instances, the Division Licensed Psychologist reviews current evaluations and standardized tests and conducts interviews to determine whether the person has a social history that supports evidence of an onset of a developmental disability prior to age 22. Therefore, Optumas recommends removing the term “prior” from the regulation. With other recommended changes, discussed above, the section would then read as follows:

(1) The individual has a diagnosis of intellectual disability, mental retardation or a related condition developmental disability as defined in the Developmental Disabilities Services Act, which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR;

Use of People First Language

Nebraska Administrative Code, Title 471, Nebraska Medicaid Program Services, Chapter 31, Services in Intermediate Care Facilities for the Mentally Retarded, contains many uses of the term “mental retardation” which is outdated diagnostic terminology that many people with I/DD consider offensive. The corresponding

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45 471 NAC 31-003.04D (1) (emphasis added).
Federal Regulations contain updated modernized, People First Language, including the use of: “intellectual disability” instead of “mental retardation”; “Intermediate Care Facility for Individuals with Intellectual Disability” in place of “Intermediate Care Facility for the Mentally Retarded”; and “Qualified Intellectual Disability Professional” instead of “Qualified Mental Retardation Professional.” Given the many repetitions of this term throughout the regulations, Optumas has not provided a mark-up of the entire chapter, but does recommend making this update to the regulations.


Summary of Optumas’ Recommendations Regarding Intermediate Care Facility Level of Care Criteria

DHHS has the opportunity to unify its ICF LOC criteria for waiver and institutional services, lessen restrictions to align with best practices and peer states, use modern, People First Language, and make technical changes to improve its regulatory and statutory framework for level of care.

Below is a mark-up of the complete set of Optumas’ recommended changes to statute and regulation. These changes are also attached, along with an explanation, as Appendix L: Intermediate Care Facility Level of Care Statutory and Regulatory Authority Recommendations.


Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which:

1. Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;

2. Is manifested before the age of twenty-two years;

3. Is likely to continue indefinitely;

4. Results in significant substantial functional limitations in one of each at least two of the following three areas of adaptive functioning
   a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;
   b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and
   c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living; and

5. Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting showing significant functional limitations in at least two of the three areas of adaptive functioning three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.
403 NAC 2.001 Eligibility Req.

In order to be eligible for Medicaid Home and Community Based Waiver Services for individuals with developmental disabilities, an individual must:

(1) Be eligible for Medicaid benefits;

(2) Be age 21 for the adult day waiver;

(3) Have a developmental disability as defined in the Developmental Disabilities Services Act; and

(4) Require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter, as defined in 471 NAC 31-003.04D (2).

471 NAC 31-003.04D ICF/DD Level of Care Criteria

The Department applies the following criteria to determine the appropriateness of ICF/MRDD services on admission and at each subsequent review:

(1) The individual has a diagnosis of intellectual disability, mental retardation or a related condition as defined in the Developmental Disabilities Services Act, which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR; and

(2) The individual can benefit from "active treatment" as defined in 42 CFR 483.440(a) and 471 NAC 31-001.02. "Benefit from active treatment" means demonstrable progress in reducing barriers to less restrictive alternatives; and

(3) In addition, the following criteria shall apply in situations where:

(a) The individual has related condition and the independent QMRP for individuals aged 18 or older, an assessment identifies that the person related condition has resulted in significant functional limitations in three or more of the following areas of major life activity:

1. self-care;
2. receptive and expressive language;
3. learning;
4. mobility;
5. self-direction; or
6. social skills;
7. capacity for independent living; or
8. economic self-sufficiency.

(3) For individuals aged 17 or under, an assessment identifies that the person has significant functional limitations in four or more of the following areas of major life activity:
(a) self-care;
(b) receptive and expressive language;
(c) learning;
(d) mobility;
(e) self-direction; or
(f) social skills; or
(g) capacity for independent living.

These substantial significant functional limitations indicate that the individual needs a combination of individually planned and coordinated special interdisciplinary care, a continuous active treatment program, treatment, and other services which are lifelong or of extended duration; and/or

(b) A Medicaid-eligible individual has a dual diagnosis of mental retardation or a related condition and a mental illness (i.e., mental retardation and schizophrenia). The mental retardation or related condition has been verified as the primary diagnosis by both an independent QMRP and a mental health professional (i.e., psychologist, psychiatrist); and

(1) Historically there is evidence of missed developmental stages, due to mental retardation or a related condition;

(2) There is remission in the mental illness and/or it does not interfere with intellectual functioning and participation in training programs, i.e., the individual does not have active hallucinations nor exhibit behaviors which are manifestations of mental illness; and
(3) The diagnosis of mental retardation or related condition takes precedence over the diagnosis of mental illness.
Intermediate Care Facility Level of Care Assessment Tools

There is no federally mandated standard, formula, tool, or set of factors to measure ICF LOC. As a result, there is great variation in LOC definitions and tools used to collect and analyze information on a person’s condition and functional limitations. 47 There is also variation in who completes the LOC assessments as it may be the state Medicaid or HCBS operating agency, a local health department or Aging and Disability Resource Center, county board, a state vendor, or others. 48 Regardless, the LOC assessment is typically done face-to-face and in the person’s home. 49

States often use different assessment instruments for different populations. For example, a state may use one tool for people with intellectual and developmental disabilities and another for people with physical disabilities. 50 Tools vary in length and complexity. They may be paper-based, electronic, or web-based. Tools may be homegrown, customized, or standardized. 51

Most states use at least one tool that they developed themselves, called a homegrown tool. A 2015 Medicaid and CHIP (Children’s Health Insurance Program) Payment and Access Commission (MACPAC) study of all 50 states and the District of Columbia found that:

“Nearly every state (49 of 51) used at least one tool for either eligibility determination or care planning that was state-specific. Only two states used independently developed tools exclusively. However, 28 states used one or more tools developed independently, such as the Supports Intensity Scale (American Association on Intellectual and Developmental Disabilities) and the interRAI Home Care Assessment System (interRAI), alongside the state-specific tools. Another five states used a combination of nationally used tools and tools adapted by the state from existing tools.” 52

Four of the seven peer states use homegrown tools for ICF LOC, one being a cross-disability tool and the remaining being specific to I/DD:

- Colorado: Uniform Long-Term Care Instrument (cross-disability assessment) 53
- Kansas: Developmental Disability Profile 54
- Missouri: Missouri Critical Adaptive Behavior Inventory 55

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47 MACPAC at p 74-75.
48 MACPAC at p 75.
49 Id.
50 Id.
52 MACPAC at p 75.
At the same time that homegrown tools are frequently used, there is also interest in and movement towards use of a standardized tool across states, because they are validated, have training materials available, and generally are “perceived [by States] as easier to implement.” There are two categories of standardized tools: those that are cross-disability, like the interRAI Suite of Assessments and the Functional Assessment Standardized Items (FASI), and standardized tools designed for the I/DD systems like the Supports Intensity Scale (SIS) and the Inventory for Client and Agency Planning (ICAP).

Of the peer states using standardized tools, none use a cross-disability assessment, instead using standardized tools designed to assess people with I/DD.

- Idaho: Scales of Independent Behavior-Revised (SIB-R)
- Iowa: Supports Intensity Scale (SIS)
- South Dakota: Inventory for Client and Agency Planning (ICAP)

**Cross-Disability Assessment Tools**

There is interest at the federal level, and in some states, in developing a single cross-disability assessment tool that can be used across populations to determine level of care, as well as supporting care planning, resource allocation, and more.

The Kansas University Research and Training Institute on Independent Living describes the value of a universal, standardized assessment:

“A universal, standardized assessment is a critical tool for streamlining access to care for people seeking services. A well-designed assessment instrument can be used to not only determine eligibility for public programs, but may also provide other functions such as care planning, data collection, rate setting and quality assurance. A universal assessment can also: promote choice for customers when the assessment determines eligibility for multiple programs; reduce administrative burdens by decreasing the need for staff to perform multiple assessments; promote equity by using the same assessment criteria for all individuals in need of services; and capture standardized data that will help policymakers analyze program effectiveness.”

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57 MACPAC at 78.
The interRAI Suite of Assessments

The interRAI Suite of Assessments is a promising future option for cross-disability level of care, with the tools “either used, piloted or at some point considered in 25 states.” Currently, however, the tools are primarily used for Aging and Disability waivers, with only one state, Connecticut, using the interRAI Home Care tool for cross-disability assessments. There is an I/DD assessment tool in the interRAI Suite; however, no state is using it yet for LOC. For this reason, Optumas does not recommend using the interRAI tools for ICF LOC at this time. However, it will be worthwhile to continue to follow the development and use of these tools over time for cross-disability assessment, especially because the interRAI-HC and interRAI-PEDS-HC tools will be used for Nursing Facility LOC.

Functional Assessment Standardized Items

The Centers for Medicare and Medicaid Services (CMS) has developed and piloted a set of assessment questions, called the Functional Assessment Standardized Items (FASI) through the Testing Experience and Functional Tools (TEFT) demonstration project. The FASI was designed through a variety of Medicare program assessment tools, state assessment tools, and newly developed mobility items aimed at testing functional community tasks common for people receiving HCBS. The target population of the FASI items is composed of individuals who may need nursing facility or other institutional level of care.

The TEFT project built on national efforts to create exchangeable data across Medicare and Medicaid programs and developed the FASI from three sources:

- Self-care items and a majority of the mobility items included came from existing CMS assessment tools and have been standardized across the Medicare program assessment tools, including the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI), MDS 3.0, Long-Term Care Hospital Continuity Assessment Record and Evaluation (LTCH-CARE), and Outcome and Assessment Information Set (OASIS).

- The second set of items was adapted from existing state assessment tools to reflect the needs of individuals living in the community and receiving Community-Based Long Term Services and Supports (CB-LTSS). Instrumental activities of daily living (IADLs), living arrangements, and caregiver availability were adapted from items in the home health-based assessment and the OASIS. Assistive devices were adapted from state CB-LTSS assessment tools.

- The final group of items contained additional mobility items developed specifically for inclusion in the FASI set and was designed to reflect a broader range of functional community mobility tasks for which an individual receiving CB-LTSS may need supports or services.

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The FASI output provides standardized items for monitoring and improving CB-LTSS quality. These standardized items support reliable and valid measures of CB-LTSS recipients’ functioning.

The TEFT project conducted a FASI field test across six states between March 2017 and September 2017 in order to test the reliability, validity, and usefulness of items to capture an individual’s need for assistance with daily activities and to serve as a basis for quality performance measures. The TEFT national evaluation report found the FASI to have effective on-line training and high interrater reliability. The assessment itself was found to be well suited to evaluating needs for assistance with task completion, with more development needed to address a person’s needs for “planning, coordinating, and sustaining daily activities routinely over time.” However, it did not assess all needed domains.

Overall, the evaluation found that:

“The FASI field test represents a significant first step in developing standardized, interoperable data elements for use across [Community-Based Long Term Services and Supports] CB-LTSS programs. The FASI set is just one component of a comprehensive, standardized assessment that informs an individual’s CB-LTSS service plan and supports necessary for successful community living. Throughout testing, the FASI team heard from individuals, assessors, caregivers, and program managers that FASI was a good place to start in conducting a comprehensive, standardized, person-centered assessment, but it did not provide all information needed to determine an individual’s service plan (e.g., behavioral health needs). These comments highlight the importance of future development of a complete, standardized assessment tool for CB-LTSS.”

Given the current state of development, the FASI is not yet used by any state for LOC evaluations. For this reason, Optumas does not recommend use of the FASI currently. However, it will be worthwhile to continue to follow the development and use of the FASI over time for cross-disability assessment, especially as other states begin to use this tool, creating the opportunity for comparable population data analysis.

Homegrown Cross-Disability Assessment Tools

Several states have developed a cross-disability assessment tool for use within their state. Minnesota uses MnCHOICES, a person-centered, web-based assessment used for assessment and support planning across all LTSS, and across the lifespan. Colorado uses the Uniform Long Term Care instrument for all its waiver LOC evaluations and re-evaluations, as well as all institutional placements. This homegrown tool was developed in 2006 and validated by Colorado Medicaid Agency staff. Colorado pairs this assessment tool with other

65 Id.
standardized assessments like the Supports Intensity Scale (SIS) for supports planning. Both tools were first implemented for seniors and people with physical disabilities with implementation for people with I/DD in the nascent stage. While promising for the future, adaption of these tools for use in ICF LOC determinations in Nebraska is premature.

**Standardized Tools for Assessments in I/DD Systems**

**Supports Intensity Scale**

The SIS was developed through the American Association on Intellectual and Developmental Disabilities (AAIDD) and was first published in 2004. It measures a person’s support needs in personal, work-related, and social activities to identify and describe the types and intensity of the supports the person requires. The SIS was designed to be part of person-centered planning processes by assisting teams in developing individual support plans (ISPs) that are responsive to the needs and choices of people with disabilities.

The SIS is a standardized tool, with available training materials, on-line functionality, validity, and interrater reliability. Unlike many functional assessments, it does not measure adaptive or maladaptive behavior. To that end, it is normed with people with intellectual disabilities across the lifespan, rather than the general population.

The strength of the SIS is that it is a person-centered, strength-based approach assessment, designed by experts in the I/DD field. It is based upon the assumption that people with I/DD should have the opportunity to engage in activities and life experiences just like any other person. As an example, the SIS has a strong scale for employment supports. This makes it a good candidate for an assessment tool to inform person-centered planning, and it is used in several states for this purpose.

The main weakness of the SIS is that it was not designed for LOC or eligibility determinations, making it a mismatch for the LOC process. Additionally, the SIS can take significantly longer to administer and is a proprietary tool with significant costs for training assessors, use of the tool, and for web-based software. Because of these factors, **Optumas does not recommend using the SIS for ICF LOC assessments in Nebraska.**

**The Inventory for Client and Agency Planning Assessment**

The ICAP is a comprehensive, standardized tool, designed to assess adaptive functioning and gather additional information to determine the type and amount of services that people with disabilities may need. The ICAP is used in states for determining eligibility, planning services, evaluating, reporting progress, and for use in resource allocation.

The ICAP compiles demographic information, diagnoses, and other information relevant to determining service needs. It is a needs-based assessment, which means that it measures how a person would do if he or she had no

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supports in place. Specifically, the ICAP measures and identifies information about a person’s ability to function in four categories of adaptive skills:

- Motor Skills
- Social and Communication Skills
- Personal Living Skills
- Community Living Skills

The ICAP also measures problem behaviors. A typical ICAP assessment will take 45 minutes, with a range of 30 minutes to 1.5 hours per assessment.

The strength of the ICAP is that it has strong psychometric properties (reliability and validity) for measuring adaptive and problem behavior, a normative sample across the lifespan, straightforward administration and scoring, and sensitivity to differences among individuals with varying degrees of behavioral functioning. Beyond the standardized data obtained from the ICAP, the instrument also compiles demographic information, diagnoses, and other information relevant to determining service needs.

The main concern about using the ICAP is that the tool was published in 1986 and is no longer being updated. While the ICAP is still in use in thirteen states and readily available, at some point the tool’s publisher may elect to retire the tool and cease distribution. 69

DHHS currently uses the ICAP for the Objective Assessment Process (OAP). In the past year, DDD has made substantive improvements to ICAP protocols, providing additional training for assessors, and creating training for case managers and service providers. To enhance the integrity of ICAP data, DDD has issued updated assessment guidelines and implemented new quality assurance protocols. Recent public feedback demonstrates increased confidence in ICAP results. Below, Optumas provides recommendations about how DHHS can leverage this process for the annual HCBS waiver LOC redeterminations.

69 In addition to Nebraska, the ICAP is currently being used in the following states: Alabama, Alaska, Colorado, Delaware, Hawaii, Indiana, Louisiana, Massachusetts, Mississippi, South Dakota, Texas, West Virginia, Wyoming. See The Rehabilitation Research and Training Center on HCBS Outcome Measurement, Inventory for Client and Agency Planning, available online at: https://rtcom.umn.edu/database/instruments/icap.
DHHS currently uses the Developmental Index (DI) tool to determine whether a person meets ICF/DD LOC criteria for the Developmental Disabilities (DD) waiver. The DI was developed internally by NE DHHS staff for use in Nebraska and has been in use for many years. While the tool was initially designed for the adult population, it is currently being used across all ages.

The DI is used both for new applicants and for annual redeterminations for people receiving Medicaid HCBS to determine whether a person meets LOC criteria for the DD waivers, in accordance with 403 NAC 2.001, Eligibility Requirements. The DI is also used to perform an annual assessment of people on the waiting list for HCBS waiver.

The DI assesses whether a person has substantial limitations in a three or more of the following areas:

1. Self-care includes six Activities of Daily Living (ADLs). The person must meet the criteria in at least three of the following ADLs to have a substantial limitation in selfcare.
   a. Feeding/Eating
   b. Meal Preparation/Clean-up
   c. Toileting
   d. Bathing
   e. Grooming
   f. Dressing
2. Receptive and Expressive Language
3. Learning
4. Mobility
5. Self-Direction
6. Capacity for Independent living
7. Social Skills and Personality
8. Economic Self Sufficiency

A review of the tool and observations of its administration identified its strength and weaknesses. The main advantages of using the DI are that it works well within DDD’s existing staffing and budget allocations and can be completed over the telephone, often in fifteen minutes or less. Additionally, staff and many family members are familiar with the tool, given years of experience using it. However, there are several challenges:

1. The tool lacks technical properties characteristic of standardized commercial tools, including testing to demonstrate inter-rater reliability, criterion-related and construct validity.
2. Developed for use with adults, the DI is currently being used across all ages, but has not been normed for age differentiation, i.e. is not indexed for children’s developmental stages.
3. The tool itself contains scoring guidance and has accompanying scoring instructions that are confusing, inconsistent, and diminish inter-rater reliability.
4. The tool lists eight major life activities and has not been updated to align with revised LOC regulations that assess six major life activities (see Appendix M: Crosswalk between DD Three Domains and LOC Six Major Life Activities).

5. ‘Adaptive skills’ is the only major life activity that is scored on a Likert scale. Four major life activities rely on professional judgement to determine if a substantial limitation is present.

6. There is no option to skip questions, even when the assessor knows they are not appropriate based upon what has been learned from the interview, or when asking questions that are clearly not applicable (e.g. due to the child’s age).

7. The DI is a paper tool. Assessors hand-write responses to the interview questions, then type out the responses, then upload the information, and shred the paper version. There is no supported software to gather, aggregate, or analyze DI data.
Current Methodology for Determining Eligibility for DDD Services

DDD currently determines eligibility for developmental disability services through a psychological assessment to establish that the person has a developmental disability as defined in the Developmental Disabilities Services Act, Neb. Rev. Stat. 83-1205.

DDD typically uses the Vineland Adaptive Behavior Scales or the Adaptive Behavior Assessment System (ABAS) to assess an applicant’s eligibility, but will also accept current psychological assessments, such as those done through the educational system, like the Scales of Independent Behavior - Revised (SIB-R). Each tool assesses the person for deficits in the three broad domains required by statute: conceptual, practical, and social (see Table 5: Statute to Adaptive Test Score Translation for Eligibility Determination). All these tools are standardized and widely accepted in the field for supporting diagnoses of intellectual and developmental disabilities and assessing adaptive skills.

Table 5: Statute to Adaptive Test Score Translation for Eligibility Determination

<table>
<thead>
<tr>
<th>Statute SFL</th>
<th>ABAS-II Scale</th>
<th>SIB-R Cluster Score</th>
<th>Vineland-3 Domain Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual Skills</td>
<td>Conceptual</td>
<td>Community Living Skills</td>
<td>Communication</td>
</tr>
<tr>
<td>Social Skills</td>
<td>Social</td>
<td>Social/Communication Skills</td>
<td>Socialization</td>
</tr>
<tr>
<td>Practical Skills</td>
<td>Practical</td>
<td>Personal Living Skills</td>
<td>Daily Living</td>
</tr>
</tbody>
</table>

Key:
SFL: Substantial Functional Limitations
ABAS: Adaptive Behavior Assessment System
SIB-R: Scales of Independent Behavior - Revised

Option for Streamlining DHHS-DDD Eligibility and Initial Level of Care Determinations

By regulation, LOC determinations for Medicaid HCBS require, in part, that a person demonstrate developmental disability as defined in the Developmental Disabilities Services Act – the same criteria a person must meet for DDD eligibility. Additionally, a person must “require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter.”

Currently, this requirement is assessed by a DHHS Disability Specialist, who conducts a Developmental Index, applying the criteria in 471 NAC 31-003.04D.3.a.(1)-(6). This criteria requires the applicant to have substantial

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70 403 NAC 2.001 Eligibility Req.
71 Id.
limitations in three or more of the following areas of major life activities: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, (5) self-direction (6) capacity for independent living. However, the use of the DI is repetitive. The requirement to demonstrate substantial limitations in three or more major life activities is also tested during the eligibility assessment, as indicated in the crosswalk directly below (see Table 6: Crosswalk of Major Life Activities and Current Areas of Adaptive Functioning), through the assessment of the person’s conceptual and practical adaptive functioning.

Table 6: Crosswalk of Major Life Activities and Current Areas of Adaptive Functioning

<table>
<thead>
<tr>
<th>DD Level of Care Assessment</th>
<th>Major Life Activities 471 NAC 31-004.04D.3.a.(1)–(6)</th>
<th>DD Eligibility Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Self-care</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>(2) Receptive and expressive language</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>(3) Learning</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>(4) Mobility</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>(5) Self-direction</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>(6) Capacity for independent living</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>

The DDD eligibility determination is also sufficient for ICF LOC initial assessments, using the recommended criteria that adds two Major Life Activities: social skills and economic self-sufficiency. Each of these maps to the existing adaptive functioning categories, as illustrated below (see Table 7: Crosswalk of Major Life Activities and Optumas' Recommended Areas of Adaptive Functioning Tested During Eligibility).

Table 7: Crosswalk of Major Life Activities and Optumas' Recommended Areas of Adaptive Functioning Tested During Eligibility

<table>
<thead>
<tr>
<th>Recommended DD Level of Care Assessment Criteria</th>
<th>Major Life Activities 471 NAC 31-004.04D.3.a.(1)–(6)</th>
<th>DD Eligibility Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Self-care</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>(2) Receptive and expressive language</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>(3) Learning</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>(4) Mobility</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>(5) Self-direction</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>(6) Social Skills</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>(7) Capacity for independent living</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(8) Economic Self-Sufficiency (adults only)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Given the similarity in requirements for establishing eligibility for DDD services and for Medicaid waiver ICF LOC initial determination, and the strength of the assessment tools used during the eligibility process, Optumas recommends taking advantage of the opportunity to streamline these processes. The assessment used for initial eligibility determination for DDD services could also be used to determine the person’s LOC for DD waiver services.
If the initial eligibility assessment were done externally and sub-scores are not available, the Inventory for Client and Agency Planning (ICAP) could also be for initial LOC determinations. The follow-up initial LOC assessment using the DI tool could then be eliminated, as repetitive.
Intermediate Care Facility Level of Care Redeterminations: Opportunity to Streamline Waiver Level of Care using the Inventory for Client and Agency Planning Assessment

Current Use of the ICAP by DDD

DDD currently uses the ICAP tool to measure a person’s needs, skills, and abilities for OAP purposes, the results of which are used to determine the participant’s annual Individual Budget Amount (IBA), as required by Neb. Rev. Stat. 83-1216(1). DDD completes an ICAP when a person is new to services, prior to the person’s first ISP meeting, and then repeats the assessment at least every other year, and more frequently, as needed, based upon a change in circumstances.

DDD Disability Specialists and Community Coordinator Specialists are trained on how to administer the ICAP, and Service Coordinators are trained on the ICAP and protocols. Training materials are available as needed. Additionally, DDD’s stakeholders are familiar with this tool.

Option for Streamlining DDD OAP and Level of Care Redeterminations

While the ICAP is currently used by DDD to determine a person’s IBA, information gathered during the existing assessments could also be used for ICF LOC redeterminations for people receiving Medicaid HCBS. Specifically, the ICAP provides information on whether the person has an intellectual disability, measures adaptive functioning, and can be calculated to determine an ICAP adaptive behavior score called the broad independence score.

Of note, DDD typically re-administers the ICAP every two years for the OAP. By comparison, HCBS must be re-evaluated no less frequently than annually. Nonetheless, without increasing the frequency of the ICAP, DDD could determine LOC by using a process in which service coordinators review the most recent ICAP data annually with the person and his or her support team, as part of the ISP pre-planning process. If the team confirms that the person’s functioning largely stayed the same, DDD could rely on the existing ICAP data for LOC. Given the lifelong nature of intellectual and developmental disabilities (I/DD) and accompanying support needs, most people’s ICAP data will remain relevant over a two-year cycle. This relative consistency of need is why ICAP data can be used on a biennial cadence for the OAP.

Optumas recommends that DHHS streamline the redetermination LOC assessment process for Medicaid HCBS by using the ICAP assessment that DDD already administers to people to redetermine LOC. It is likely, given the nature of the I/DD population, that most people will continue to meet LOC, year over year, as they do now. There may be a small percentage of people who will need further assessment to determine LOC: for example, people who have an IQ within the standard error of measure for intellectual disability (i.e. IQ of 70 or below). In these instances, Optumas recommends that DDD use the existing DDD eligibility assessment process to do a clinical assessment of continuing eligibility for HCBS services.

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72 Center for Medicaid Services Application for a 1915(c) Home and Community-Based Services, Instructions, Technical Guide and Review Criteria, January 2015, Appendix B-6-g.
Institutional Level of Care: No Single Tool for Institutional Level of Care Determinations

There is currently no designated standard assessment tool or form that is used in Nebraska to document the initial institutional LOC determination or utilization review reassessments. Instead, each ICF/DD has its own policies and procedures for admissions and ongoing utilization review. The ICF/DD shares documentation with the state demonstrating that the person met the standard provided in 471 NAC 31-003.04D. The ICF/DD review team then reviews all submitted documentation and determines whether the ICF/DD level of care is appropriate and will be approved for Medicaid payment based on level of care criteria.

DDD staff report that State Qualified Intellectual and Developmental Disabilities Professionals (QIDDPs) have developed their own “cheat sheets” to document LOC findings. One such form that was developed for applicants who have “other related conditions” is used by multiple QIDDPs. An example of an unnumbered/unnamed form used to summarize the information used to make the LOC decision is provided in Appendix N: Form used to Summarize Information used in the Institutional LOC Decision. Because there is no standardized tool, the current process does not consistently specify or document the components of the LOC criteria described in 471 NAC 31-003.04D.3.a.(1)-(6) that are met/not met, including which of the six (6) major life areas have substantial functional limitations.

Initial Intermediate Care Facility Level of Care Determinations: Opportunity to Streamline Institutional Level of Care with DDD Eligibility Determinations

Intermediate care facilities are currently administered by the Medicaid and Long-Term Care Division (MLTC) of DHHS, in accordance with Neb. Rev. Stat. 68-911(2)(b). In practice, this means that some people who are seeking ICF institutional services first establish eligibility with DDD; others go directly to the ICF itself. Optumas recommends that DHHS require all people who are seeking admission to an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) to first establish eligibility with the DDD. This would create one process by which people become eligibility for services through the DD system of care and would create a unified system in which information about eligibility is collected and stored.

Creating a single point of entry would allow DHHS to streamline the initial LOC assessment process for all people applying for admission to an ICF/DD by using the initial eligibility determination for DDD services to also determine LOC. Therefore, for people seeking institutional services, as with those seeking Medicaid HCBS, Optumas recommends that the DDD eligibility determination be used to determine initial ICF LOC. No further initial LOC determination would be required. DDD would still need to determine ICF admission criteria, specifically, whether the person required active treatment, as defined by 471 NAC 31-001.02.

Intermediate Care Facility Level of Care Prior Authorization Reviews

Unlike Medicaid HCBS LOC, there is no comparable process for annual ICF LOC determinations. Instead, as required by 42 CFR 456 Subpart F and 471 NAC 31-005.08J, the Central Office review team completes a “utilization review” of people residing in an ICF every six months, using forms specifically applicable to ICF services that assess, in part, that the person has an ongoing need for active treatment. While this utilization

review is outside the scope of the LOC project, Optumas notes that based upon conversations with DHHS staff, the Technical Advisory Group, and stakeholders, this process works effectively and efficiently.
Use IQ Scores as a Benchmark to Further Streamline the Intermediate Care Facility Level of Care Redetermination Process

DDD could further streamline the ICF LOC redetermination process by creating an abbreviated process, based upon severity of condition, that if, for example, a person has an IQ score that is at or below a certain number, he or she meets LOC. For example, if a person’s primary disability is an intellectual disability with an IQ of 60 or less, that person would be presumed to have ongoing functional deficits and supports needs, such that they are determined to meet ICF LOC.

LOC must still be redetermined on an annual basis for HCBS waiver services, and a utilization review must be conducted every six months for facility-based services. However, for a person who meets an identified benchmark IQ standard, there could be a “short form” process in which the person’s service coordinator documents the person’s IQ, the support team’s confirmation that the person’s needs have not significantly changed, and that the person continues to meet LOC. This could occur during the ISP pre-planning process.
Annual Reassessments for People on the Waiting List

DDD currently performs an annual assessment of people on the Medicaid HCBS waiver waiting list using the DI tool. Disability Specialists contact each person (or the person’s family) on the waitlist to complete the DI by phone. This is neither a federal nor state requirement but appears to be done to ensure that a person who is waiting for services will likely meet LOC when the time comes to enroll in the waiver. Families seemed uncertain of the purpose of these contacts. Assessors note that scheduling these calls is a time-consuming activity, many people do not return calls, and they have a high incidence of “no-shows.” Assessors also employ “cold-calling” to track people down and, once they do connect, there is some fear of scams and sharing personal information over the phone.

While outside the scope of this work, it is worth noting that many of the recommendations above regarding LOC could apply to managing the waiting list population. For example, having an IQ benchmark would divide the population such that DHHS and their stakeholders could be assured that a certain number of people on the waiting list, who are otherwise eligible, will qualify for the DD waivers. Likewise, using the initial eligibility determination (and the redeterminations that are done at age nine and eighteen), DHHS can make assumptions about the person’s likelihood of meeting waiver LOC.74 The ICAP could be used for waiting list management as well. Then, each year the Disability Specialist or Service Coordination, for people receiving Targeted Case Management, could talk with the families about what, if anything, has changed rather than repeating the DI year over year.

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74 See 403 NAC 2.004, Developmental Disability Redetermination
Impact of Process

Finally, it is worth considering the impact of process and procedure on level of care determinations. There may be some natural variation in the application of the level of care tool, resulting in possibly subjective or inconsistent results. Applicants may also be coached to help them meet level of care.75 These issues can occur regardless of which tool is used. When a state switches level of care instruments and does the accompanying training of staff, some of these issues may (at least temporarily) be abated. This could result in people who would have been found to meet level of care previously to not meet level of care and not because of a change in the tool, point system or algorithm, but because of a correction in process.

75 See, e.g., Report to MO DSDS at p 40.
Summary of Optumas’ Recommendations Regarding Intermediate Care Facility Level of Care Tools

DHHS can strengthen its ICF LOC determinations and streamline assessment processes by eliminating the DI and leveraging existing standardized assessments. At the front door to services, DHHS can use the eligibility assessment process already in place to determine initial LOC, eliminating the need for a follow-up telephone review with the Disability Specialist for Medicaid HCBS and for institutional services for people who have established eligibility with DDD. Once a person is receiving Medicaid HCBS, DDD can utilize information from the ICAP, which is already being done to determine a person’s funding level, to redetermine LOC.

Optumas estimates that most people will continue to meet LOC, as they do now, year over year, given the lifelong nature of I/DD and people’s typical support needs throughout their lifespan. For people for whom there may be a question regarding LOC redeterminations, DHHS can use the existing DDD eligibility assessment process to do a clinical assessment and review of continuing eligibility for Medicaid HCBS services. Finally, DDD can streamline LOC redetermination process further, by creating an abbreviated review process that people at a certain IQ level will have ongoing functional deficits and supports needs, such that they qualify for ICF LOC.
Alignment of Recommended Intermediate Care Facility Level of Care Criteria and Tools

This section of the memo assumes that the State has accepted Optumas’ recommendations regarding changes to the ICF LOC criteria and use of the recommended tools, discussed above.

Initial Determinations for Medicaid HCBS Waivers for People with I/DD and for ICF/IIDs when People Establish Eligibility Through DHHS-DDD

Optumas recommends that DHHS-DDD leverage the assessment used for initial eligibility determination for DHHS-DDD services to determine the person’s LOC for Medicaid HCBS waiver services for people with I/DD and for people who use ICF/IID services, who also establish eligibility with DHHS-DDD. DHHS-DDD typically uses the Vineland Adaptive Behavior Scales (Vineland) or the Adaptive Behavior Assessment System (ABAS) to assess an applicant’s eligibility for services.

The Vineland Adaptive Behavior Scales

The Vineland has five domains and a series of correlated subdomains. Three of the five domains are required for LOC determinations, and these are the ones typically administered by and available to DHHS-DDD for the purposes of eligibility assessments: Communication, Daily Living Skills, and Socialization. Given the limited availability of the remaining two domains, Motor Skills and Maladaptive Behavior, Optumas’ recommendations regarding use of the Vineland for ICF LOC initial determinations relies on only the three required domains, using the two additional domains, Motor Skills and Maladaptive Behavior, as available (see Table 8: Vineland Adaptive Domains and Subdomains).

Table 8: Vineland Adaptive Domains and Subdomains

<table>
<thead>
<tr>
<th>Adaptive Domains</th>
<th>Subdomains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>• Receptive</td>
</tr>
<tr>
<td></td>
<td>• Expressive</td>
</tr>
<tr>
<td></td>
<td>• Written</td>
</tr>
<tr>
<td>Daily Living Skills</td>
<td>• Personal</td>
</tr>
<tr>
<td></td>
<td>• Domestic</td>
</tr>
<tr>
<td></td>
<td>• Community</td>
</tr>
<tr>
<td>Socialization</td>
<td>• Interpersonal Relationships</td>
</tr>
<tr>
<td></td>
<td>• Play and Leisure</td>
</tr>
<tr>
<td></td>
<td>• Coping Skills</td>
</tr>
<tr>
<td>Motor Skills (Optional)</td>
<td>• Fine Motor</td>
</tr>
<tr>
<td></td>
<td>• Gross Motor</td>
</tr>
<tr>
<td>Maladaptive Behavior (Optional)</td>
<td>• Internalizing</td>
</tr>
<tr>
<td></td>
<td>• Externalizing</td>
</tr>
<tr>
<td></td>
<td>• Critical Items</td>
</tr>
</tbody>
</table>
Optumas recommends that for ICF LOC for adults, the State should require limitations in at least four of the following eight major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, social skills, capacity for independent living, and economic self-sufficiency. For children, the State should require limitations in at least four of the following seven major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, social skills, and capacity for independent living.

Seven of these eight major life activities map well to the required Vineland subdomains (see Table 9: Proposed Regulation and Vineland Crosswalk with Level of Care Thresholds), and the eighth, Mobility, maps to an optional subdomain. Optumas recommends that these are used accordingly for initial ICF LOC determinations. An alternative for Mobility will be discussed below, in the section on ICF LOC Redeterminations for the Medicaid HCBS Waivers for People with I/DD.

**Table 9: Proposed Regulation and Vineland Crosswalk with Level of Care Thresholds**

<table>
<thead>
<tr>
<th>#</th>
<th>ICF LOC Criteria: Eight Major Life Activities 471 NAC 31-003.04D(2) and 403 NAC 2.001(4) As Proposed</th>
<th>Vineland Subdomains</th>
<th>Proposed Minimum to Meet</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Receptive and Expressive Language</td>
<td>Receptive</td>
<td>Significant functional limitations in one of two: Receptive OR Expressive</td>
</tr>
<tr>
<td>2</td>
<td>Learning</td>
<td>Written</td>
<td>Significant functional limitation in Written</td>
</tr>
<tr>
<td>3</td>
<td>Self-Direction</td>
<td>Coping Skills</td>
<td>Significant functional limitation in Coping Skills</td>
</tr>
<tr>
<td>4</td>
<td>Social Skills</td>
<td>Interpersonal</td>
<td>Significant functional limitations in one of two: Interpersonal Relationships OR Play and Leisure Time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Play and Leisure Time</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Self-Care</td>
<td>Personal</td>
<td>Significant functional limitation in Personal</td>
</tr>
<tr>
<td>6</td>
<td>Mobility</td>
<td>Fine Motor</td>
<td>Use if available: Significant functional limitations in one of two: Fine Motor OR Gross Motor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gross Motor</td>
<td>If not available, use ICAP</td>
</tr>
<tr>
<td>7</td>
<td>Capacity for Independent Living</td>
<td>Domestic</td>
<td>Significant functional limitations in Domestic</td>
</tr>
<tr>
<td>8</td>
<td>Economic Self-Sufficiency Adults Only</td>
<td>Community</td>
<td>Significant functional limitations in Community</td>
</tr>
</tbody>
</table>

**The Adaptive Behavior Assessment System**

The Adaptive Behavior Assessment System (ABAS) has three adaptive domains – conceptual, social, and practical – which split into ten subdomains (see Table 10: Adaptive Behavior Assessment System Adaptive Domains and Subdomains). Each of these are typically tested as part for eligibility and are available for use for ICF LOC initial determinations.
Alignment of Recommended Intermediate Care Facility Level of Care Criteria and Tools

Table 10: Adaptive Behavior Assessment System Adaptive Domains and Subdomains

<table>
<thead>
<tr>
<th>Adaptive Domains</th>
<th>Subdomains</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual</td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Functional Academics</td>
</tr>
<tr>
<td></td>
<td>Self-Direction</td>
</tr>
<tr>
<td>Social</td>
<td>Leisure</td>
</tr>
<tr>
<td></td>
<td>Social</td>
</tr>
<tr>
<td>Practical</td>
<td>Community Use</td>
</tr>
<tr>
<td></td>
<td>Home/ School Living</td>
</tr>
<tr>
<td></td>
<td>Self-Care</td>
</tr>
<tr>
<td></td>
<td>Health and Safety</td>
</tr>
<tr>
<td></td>
<td>Work</td>
</tr>
</tbody>
</table>

Seven of the eight major life activities that **Optumas** recommends for use for ICF LOC determinations map well to the ABAS subdomains (see Table 11: Proposed Regulation and Adaptive Behavior Assessment System Crosswalk with Level of Care Threshold). **Optumas** recommends that these are used accordingly. The remaining Major Life Activity will be discussed below, in the section on ICF LOC Redeterminations for the Medicaid HCBS Waivers for People with I/DD.

Table 11: Proposed Regulation and Adaptive Behavior Assessment System Crosswalk with Level of Care Thresholds

<table>
<thead>
<tr>
<th>#</th>
<th>ICF LOC Criteria: Eight Major Life Activities 471 NAC 31-003.04D(2) and 403 NAC 2.001(4) As Proposed</th>
<th>ABAS-II Subdomains</th>
<th>Proposed Minimum to Meet</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Receptive and Expressive Language</td>
<td>Communication</td>
<td>Significant functional limitations in Communication</td>
</tr>
<tr>
<td>2</td>
<td>Learning</td>
<td>Functional Academics</td>
<td>Significant functional limitation in Functional Academics</td>
</tr>
<tr>
<td>3</td>
<td>Self-Direction</td>
<td>Self-Direction</td>
<td>Significant functional limitation in Self-Direction</td>
</tr>
<tr>
<td>4</td>
<td>Social Skills</td>
<td>Social Leisure</td>
<td>Significant functional limitations in one of two: Social OR Leisure</td>
</tr>
<tr>
<td>5</td>
<td>Self-Care</td>
<td>Self-Care Health and Safety</td>
<td>Significant functional limitation in one of two: Self-Care OR Health and Safety</td>
</tr>
<tr>
<td>6</td>
<td>Mobility</td>
<td>N/A</td>
<td>Use ICAP</td>
</tr>
<tr>
<td>7</td>
<td>Capacity for Independent Living</td>
<td>Home Living Community Use</td>
<td>Significant functional limitations in one of two: Home Living OR Community Use</td>
</tr>
<tr>
<td>8</td>
<td>Economic Self-Sufficiency Adults Only</td>
<td>Work</td>
<td>Use if available. If not available, use ICAP</td>
</tr>
</tbody>
</table>
Optumas recommends that DHHS-DDD leverage the information gathered during the Inventory for Client and Agency Planning (ICAP) assessment for ICF LOC redeterminations for Medicaid HCBS waiver services for people with I/DD. The ICAP provides information on whether the person has an intellectual disability, measures adaptive functioning, and can be calculated to determine an ICAP adaptive behavior score called the broad independence score. Specifically, the ICAP measures and identifies information about a person’s ability to function in four categories of adaptive skills: Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. The ICAP also measures problem behaviors. All ICAP Sections and Subsections appear below in “Table 12: Inventory for Client and Agency Planning Sections and Subsections”.

Table 12: Inventory for Client and Agency Planning Sections and Subsections

<table>
<thead>
<tr>
<th>Section</th>
<th>ICAP Section</th>
<th>ICAP Subsection</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Descriptive Information</td>
<td>Sex, Height, Weight, Race, Hispanic Origin, Primary Language Understood, Primary Means of Expression, Marital Status, and Legal Status</td>
</tr>
<tr>
<td>B</td>
<td>Diagnostic Status</td>
<td>Primary Diagnosis, and Additional Diagnosed Conditions</td>
</tr>
<tr>
<td>C</td>
<td>Functional Limitations and Needed Assistance</td>
<td>Level of Intellectual Disability,76 Vision, Hearing, Frequency of Seizures, Health, Required Care by Nurse or Physician, Current Medications, Arm/ Hand, Mobility, and Mobility Assistance Needed</td>
</tr>
<tr>
<td>D</td>
<td>Adaptive Behavior</td>
<td>Motor Skills Social and Communication Skills Personal Living Skills Community Living Skills</td>
</tr>
<tr>
<td>E</td>
<td>Problem Behavior</td>
<td>Hurtful to Self, Hurtful to Others, Destructive to Property, Disruptive Behavior, Unusual or Repetitive Habits, Social Offensive Behavior, Withdrawal or Inattentive Behavior, and Uncooperative Behavior</td>
</tr>
<tr>
<td>F</td>
<td>Residential Placement</td>
<td>Current Residence Recommended Change</td>
</tr>
<tr>
<td>G</td>
<td>Daytime Program</td>
<td>Current Formal Daytime Activity Recommended Change</td>
</tr>
<tr>
<td>H</td>
<td>Support Services</td>
<td>Presently Being Used Not Used Now, but Evaluation Needed</td>
</tr>
<tr>
<td>I</td>
<td>Social and Leisure Activities</td>
<td>Social and Leisure Activities within the Last Month; and Factors Limiting Social Activities</td>
</tr>
<tr>
<td>J</td>
<td>General Information and Recommendations</td>
<td>N/A</td>
</tr>
</tbody>
</table>

76 The ICAP uses the term “mental retardation.” In recognition of the movement toward People First Respectful Language, as demonstrated in the Developmental Disabilities Services Act, Neb. Rev. Stat. §§83-1202, et seq., this memo instead uses the term “intellectual disability.”
All the eight major life activities that *Optumas* recommends for use for ICF LOC determinations map well to the ICAP (see Table 13: Proposed Regulation and Inventory for Client and Agency Planning Crosswalk with Level of Care Thresholds). *Optumas* recommends that each of the following areas of the ICAP are used to redetermine ICF LOC for people in the Medicaid HCBS waivers for people with I/DD, and that for initial LOC determinations, the ICAP is used to determine whether the person has a significant functional limitation in the areas of mobility and economic self-sufficiency, except where Vineland or ABAS data is available.

### Table 13: Proposed Regulation and Inventory for Client and Agency Planning Crosswalk with Level of Care Thresholds

<table>
<thead>
<tr>
<th>#</th>
<th>ICF LOC Criteria: Eight Major Life Activities 471 NAC 31-003.04D(2) and 403 NAC 2.001(4) As Proposed</th>
<th>ICAP Sections</th>
<th>Proposed Minimum to Meet</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Learning</td>
<td>C: Functional Limitations and Needed Assistance 1: Level of Intellectual Disability</td>
<td>IQ of 70 or lower C1: Scores 2-6</td>
</tr>
<tr>
<td>3</td>
<td>Self-Direction</td>
<td>N/A</td>
<td>Broad Independence Score of 70 or less</td>
</tr>
<tr>
<td>4</td>
<td>Social Skills</td>
<td>E: Problem Behavior</td>
<td>Anything less than normal range of -11 in: (1) General Maladaptive score; OR (2) Internalized Index; OR (3) Asocial Index; OR (4) Externalized Index</td>
</tr>
<tr>
<td>6</td>
<td>Mobility</td>
<td>C: Functional Limitations and Needed Assistance 9: Mobility (all ages) OR 10: Mobility Assistance Needed (ages 4 and older)</td>
<td>C9: Scores 2-4 OR C10: Scores 3 OR 4 (not asked until the person is 4 years old)</td>
</tr>
<tr>
<td>8</td>
<td>Economic Self-Sufficiency <em>Adults Only</em></td>
<td>G: Daytime Programming 2: Recommended Change</td>
<td>Anything other than Competitive Employment (#9) would meet: G2: Scores 1-8</td>
</tr>
</tbody>
</table>
Summary of Optumas’ Recommendations Regarding Alignment of Intermediate Care Facility Level of Care Criteria and Tools

Optumas developed a comprehensive table (see Table 14: Proposed Regulation and Vineland, Adaptive Behavior Assessment System and Inventory for Client and Agency Planning Crosswalk with Level of Care Thresholds) of the mapping of each assessment tool used (i.e. Vineland, ABAS, and ICAP) to the domains appearing in Statute and ICF LOC. This table was used throughout the development of ICF LOC recommendation to ensure alignment of criteria and tools.
### Alignment of Recommended Intermediate Care Facility Level of Care Criteria and Tools

**Table 14: Proposed Regulation and Vineland, Adaptive Behavior Assessment System and Inventory for Client and Agency Planning Crosswalk with Level of Care Thresholds**

<table>
<thead>
<tr>
<th>DD Defined (Statute)</th>
<th>Vineland</th>
<th>ABAS</th>
<th>ICF Level of Care</th>
<th>ICAP Reference Manual/Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Conceptual Skills</strong></td>
<td><strong>Language</strong></td>
<td>Communication</td>
<td>Receptive OR Expressive</td>
<td>Conceptual Communication</td>
</tr>
<tr>
<td></td>
<td><strong>Literacy</strong></td>
<td>Written</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Money</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Time</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Number Concepts</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Self-Direction</strong></td>
<td>Coping Skills In Social Domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Skills</strong></td>
<td><strong>Interpersonal</strong></td>
<td>Socialization</td>
<td>Interpersonal relationships OR Play and Leisure time</td>
<td>Social OR</td>
</tr>
<tr>
<td></td>
<td><strong>Social Response</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Self esteem</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Gullibility</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Wariness</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Problem Solving</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Follow laws/rules</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Avoid victimize</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Practical Skills</strong></td>
<td><strong>ADLs</strong></td>
<td>Daily Living Skills</td>
<td>Personal</td>
<td>Practical Self-care OR</td>
</tr>
<tr>
<td></td>
<td><strong>Personal care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Healthcare</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Mobility</strong></td>
<td>Only available under age 9</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Independent Living</strong></td>
<td>Domestic</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Occupational skills</strong></td>
<td>Community</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please see Appendix P: Developmental Disabilities Criteria Crosswalk for additional details on Scoring and Scoring Guidelines.
### Final Recommendations

**Table 15: Final Optumas Intermediate Care Facility Level of Care Recommendations**

<table>
<thead>
<tr>
<th>Page Number</th>
<th>ICF LOC Category</th>
<th>Decision Point</th>
<th>Recommended Option</th>
<th>Recommended Option Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>Adult and Child LOC</td>
<td>Medicaid HCBS waiver and institutional ICF LOC alignment</td>
<td>Option 2</td>
<td><strong>Optumas</strong> recommends that the State align administrative code requirements for institutional and Medicaid HCBS ICF LOC consistent with Federal Regulations, using a single definition of intellectual and developmental disabilities (I/DD) for waiver and institutional LOC, and amending ICF LOC criteria for institutional settings to eliminate references to active treatment and mental illness.</td>
</tr>
<tr>
<td>17</td>
<td>Adult and Child LOC</td>
<td>Medicaid HCBS waiver and institutional ICF LOC alignment</td>
<td>Option 2</td>
<td>To align requirements for institutional and Medicaid HCBS ICF LOC, <strong>Optumas</strong> recommends that the State update 471 NAC 31-003.04D to require that the person “has a diagnosis of developmental disability as defined in the Developmental Disabilities Services Act.” This would result in a single definition of intellectual and developmental disabilities (I/DD) across waiver and institutional ICF LOC.</td>
</tr>
<tr>
<td>18</td>
<td>Adult and Child LOC</td>
<td>Medicaid HCBS waiver and institutional ICF LOC alignment</td>
<td>Option 2</td>
<td>Of note, none of the seven peer states reviewed include Active Treatment in ICF LOC criteria. For the reasons discussed above, <strong>Optumas</strong> recommends removing this reference.</td>
</tr>
<tr>
<td>19</td>
<td>Adult and Child LOC</td>
<td>Medicaid HCBS waiver and institutional ICF LOC alignment</td>
<td>Option 2</td>
<td>The institutional ICF LOC criteria also include specific requirements for people dually diagnosed with I/DD and mental illness. <strong>Optumas</strong> recommends excluding this entire section from the ICF LOC regulations.</td>
</tr>
<tr>
<td>20</td>
<td>Adult and Child LOC</td>
<td>Criteria: Definition of developmental disability</td>
<td>Option 2</td>
<td><strong>Optumas</strong> recommends that the State refine the statutory definition of developmental disability to align with best practice and peer states, requiring significant functional limitations in two of the following three areas of adaptive functioning: conceptual, social, and practical.</td>
</tr>
<tr>
<td>Page Number</td>
<td>ICF LOC Category</td>
<td>Decision Point</td>
<td>Recommended Option</td>
<td>Recommended Option Text</td>
</tr>
<tr>
<td>-------------</td>
<td>---------------------------</td>
<td>--------------------------------------------------------</td>
<td>--------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| 23          | Adult and Child LOC       | Criteria: Limitations in Major Life Activities         | Option 2           | **Optumas** recommends that the State align administrative code requirements for institutional and Medicaid HCBS ICF LOC criteria with the Nebraska definition of developmental disability, as well as peer states and best practice:  
- For adults, require limitations in at least four of the following eight major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, social skills, capacity for independent living, and economic self-sufficiency; and  
For children, require limitations in at least four of the following seven major life activities: self-care, receptive and expressive language, learning, mobility, self-direction, social skills, and capacity for independent living. |
<p>| 24          | Adult and Child LOC       | Criteria: Definition of developmental disability       | Option 2           | To better align the regulatory criteria for ICF LOC with the Nebraska definition of developmental disability, <strong>Optumas</strong> recommends adding the major life activities of social skills and, for adults only, economic self-sufficiency. |
| 24          | Adult and Child LOC       | Criteria: Definition of developmental disability       | Option 2           | To minimize population impact for people currently receiving services through a Medicaid HCBS waiver or in an ICF/IID, <strong>Optumas</strong> recommends that an adult would have to demonstrate substantial functional limitations in four or more of the eight areas of major life activities; and youths ages 17 or under would have to demonstrate substantial functional limitations in four or more of the seven areas of major life activities. |
| 24          | Adult and Child LOC       | Population Impact                                      | N/A                | <strong>Optumas</strong> recommends that DHHS-DDD review applicants who have been denied to determine whether they would meet LOC under this new [ICF LOC] criteria.          |</p>
<table>
<thead>
<tr>
<th>Page Number</th>
<th>ICF LOC Category</th>
<th>Decision Point</th>
<th>Recommended Option</th>
<th>Recommended Option Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>Adult and Child LOC</td>
<td>Criteria: Technical change</td>
<td>Option 2</td>
<td>As suggested by DHHS-DDD’s Licensed Psychologist, Optumas recommends changing the term “substantial” to “significant” as it modifies functional limitations. This change would apply to both Neb. Rev. Stat. 83-1205(4); and 471 NAC 31-003.04D (2): “Results in <strong>significant</strong> functional limitations.”</td>
</tr>
<tr>
<td>25</td>
<td>Adult and Child LOC</td>
<td>Criteria: Technical change</td>
<td>Option 2</td>
<td>There is language in Neb. Rev. Stat. 83-1205(5) that refers to “three or more major life activities.” This is a reference to a requirement in the previous definition of developmental disability. <strong>Optumas</strong> recommends that it be removed and replaced with language that references adaptive functioning as required by the statute.</td>
</tr>
<tr>
<td>25</td>
<td>Adult and Child LOC</td>
<td>Criteria: Technical change</td>
<td>Option 2</td>
<td>Level of care regulations for ICF/IID’s require that the person establish that he or she has a diagnosis of I/DD “which has been confirmed by <strong>prior</strong> diagnostic evaluations/standardized tests.” <strong>Optumas</strong> recommends removing the term “prior” from the regulation.</td>
</tr>
<tr>
<td>40</td>
<td>Adult and Child LOC</td>
<td>Assessment tool: Initial ICF LOC determinations for Medicaid HCBS waivers</td>
<td>Option 2</td>
<td>Given the similarity in requirements for establishing eligibility for DDD services and for Medicaid waiver ICF LOC initial determination, and the strength of the assessment tools used during the eligibility process, <strong>Optumas</strong> recommends taking advantage of the opportunity to streamline these processes. The assessment used for initial eligibility determination for DDD services could also be used to determine a person’s LOC for DD waiver services. If the initial eligibility assessment was done externally and sub-scores are not available, the Inventory for Client and Agency Planning (ICAP) could also be for initial LOC determinations. The follow-up initial LOC assessment using the DI tool could then be eliminated, as repetitive.</td>
</tr>
<tr>
<td>Page Number</td>
<td>ICF LOC Category</td>
<td>Decision Point</td>
<td>Recommended Option</td>
<td>Recommended Option Text</td>
</tr>
<tr>
<td>-------------</td>
<td>----------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>--------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>41</td>
<td>Adult and Child LOC</td>
<td>Assessment tool: ICF LOC redeterminations for Medicaid HCBS waivers</td>
<td>Option 2</td>
<td>Optumas recommends that Nebraska streamline the redetermination LOC assessment process for Medicaid HCBS by using the ICAP assessment that DDD already administers to people to redetermine LOC.</td>
</tr>
<tr>
<td>41</td>
<td>Adult and Child LOC</td>
<td>Assessment tool: ICF LOC redeterminations for Medicaid HCBS waiver</td>
<td>N/A</td>
<td>There may be a small percentage of people who will need further assessment to determine LOC, such as people who have an IQ within the standard error of measure for intellectual disability (i.e. IQ of 70 or below). In these instances, Optumas recommends that DDD use the existing DDD eligibility assessment process to do a clinical assessment of continuing eligibility for HCBS services.</td>
</tr>
<tr>
<td>41</td>
<td>Institutional Admissions for Adults and Children</td>
<td>Process</td>
<td></td>
<td>Optumas recommends that DHHS require all people who are seeking admission to an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) to first establish eligibility with the DDD. This would create one process by which people become eligible for services through the DD system of care and would create one system in which information about eligibility is collected and stored.</td>
</tr>
<tr>
<td>41</td>
<td>Adult and Child LOC</td>
<td>Assessment tool: Initial ICF LOC determinations for institutional settings</td>
<td>Option 2</td>
<td>For people seeking institutional services, as with those seeking Medicaid HCBS, Optumas recommends that the DDD eligibility determination be used to determine initial ICF LOC. No further initial LOC determination would be required.</td>
</tr>
<tr>
<td>49</td>
<td>Adult and Child LOC</td>
<td>Alignment of criteria with tool: Vineland</td>
<td>N/A</td>
<td>Seven of the eight major life activities map well to the required Vineland subdomains, and the eighth, Mobility, maps to an optional subdomain. Optumas recommends that these are used accordingly for initial ICF LOC determinations.</td>
</tr>
<tr>
<td>50</td>
<td>Adult and Child LOC</td>
<td>Alignment of criteria with tool: ABAS</td>
<td>N/A</td>
<td>Seven of the eight major life activities that Optumas recommends for use for ICF LOC determinations map well to the ABAS subdomains. Optumas recommends that these are used accordingly.</td>
</tr>
</tbody>
</table>
### Final Recommendations

<table>
<thead>
<tr>
<th>Page Number</th>
<th>ICF LOC Category</th>
<th>Decision Point</th>
<th>Recommended Option</th>
<th>Recommended Option Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>52</td>
<td>Adult and Child LOC</td>
<td>Alignment of criteria with tool: ICAP</td>
<td>N/A</td>
<td>All the eight major life activities that <strong>Optumas</strong> recommends for use for ICF LOC determinations map well to the ICAP. <strong>Optumas</strong> recommends that each of the following areas of the ICAP are used to redetermine ICF LOC for people in the Medicaid HCBS waivers for people with I/DD, and that for initial LOC determinations, the ICAP is used to determine whether the person has a significant functional limitation in the areas of mobility and economic self-sufficiency, except where Vineland or ABAS data is available.</td>
</tr>
<tr>
<td>64</td>
<td>Eligibility</td>
<td>Population Impact</td>
<td>N/A</td>
<td><strong>Optumas</strong> recommends that Nebraska evaluate all people who are denied eligibility for DHHS-DDD services for a six month period, to determine how many of those people would be eligible if the criteria were two of three adaptive deficits, instead of the current three of three requirement.</td>
</tr>
</tbody>
</table>
Population Impact Study

Optumas’ recommendations are based upon an initial population impact analysis using a sample of the latest ICAP assessments provided by the State for individuals who previously met ICF LOC criteria. Optumas received ICAP assessments of the NE DDD population in March 2018, November 2019, and May 2020. The data and analysis were reviewed through conversation with the DHHS-DDD team, including the Licensed Psychologist. Initial population impact study findings are detailed below.

Initial Population Impact Study for Adults

Population Impact of Using the ICAP to Determine Intermediate Care Facility Level of Care for Adults

The results of Optumas’ initial population impact study for adults indicate that less than 1% of individuals who currently meet ICF LOC would fail to meet ICF LOC under the updated tools and criteria (see Figure 1: Adult Population Impact). All individuals who appeared to lose ICF LOC or fall close to the threshold set by the new tools and criteria were submitted to the State for clinical review.

Of a total sample population of 8,409 adults who currently meet ICF LOC, Optumas determined that there were 57 adults who, using the ICAP to test ICF LOC, qualified for ICF LOC but were one functional limitation away from being found ineligible (see Figure 1: Adult Population Impact). These adults were determined to have substantial functional limitations in four of eight subdomains. A DHHS-DDD Licensed Psychologist studied twenty of these fifty-seven adults and, in her clinical judgment, agreed that all would meet ICF LOC, but were on the threshold of establishing eligibility. None of these individuals are currently in an ICF setting.

From the same sample population, Optumas determined that twenty-four adults currently meeting ICF LOC would not continue to do so under the proposed changes. A DHHS-DDD Licensed Psychologist studied three of these adults and, in her clinical judgment, determined that they would not meet eligibility for DDD under the current statute and should not meet ICF LOC. None of these individuals are currently in an ICF setting. An overview of the results of Optumas’ Adult Population Impact Study, including the two groups noted above, can be found below in “Figure 1: Adult Population Impact”.

Please see Appendix Q for additional information on the individuals reviewed.
Figure 1 identifies the number of adults meeting each quantity of subdomains. For example, there are 5,455 individuals who meet LOC on seven subdomains. Fifty-seven individuals are on the cusp of eligibility in column four. All 24 individuals not meeting ICF LOC fall to the left of the vertical gray line. This figure indicates that the relative number of individuals impacted is minimal.
Initial Population Impact Study for Children Age Seventeen and Younger

Population Impact of Using the ICAP to Determine Intermediate Care Facility Level of Care for Children

The results of Optumas' initial population impact study for children indicate that less than 1% of individuals who currently meet ICF LOC fail to meet ICF LOC under the updated tools and criteria (see Figure 2: Child Population Impact). All individuals who appeared to lose ICF LOC or fall close to the threshold set by the new tools and criteria were submitted to the State for clinical review.

Of a total sample population of 445 children age 17 or younger who currently meet ICF LOC, Optumas determined that there were six youth who, using the ICAP to test ICF LOC, qualified for ICF LOC but were one functional limitation away from being found ineligible (see Figure 2: Child Population Impact). These youth were determined to have substantial functional limitations in four of seven subdomains. A DHHS-DDD Licensed Psychologist studied five of these six youth and, in her clinical judgment, agreed that all would meet ICF LOC, but were on the threshold of establishing eligibility.

From the same sample population, Optumas determined that there are four youth who, using the ICAP to test ICF LOC, would have substantial functional limitations in two or three of seven subdomains. Two of the youth are under nine years old and have not yet had to establish adaptive deficits for DDD eligibility. A DHHS-DDD Licensed Psychologist studied one of these four youth and determined that the child is on the cusp on eligibility, with needs that are more physical than adaptive. An overview of the results of Optumas' Child Population Impact Study, including the two groups noted above, can be found below in “Figure 2: Child Population Impact”.

Please see Appendix Q for additional information on the individuals reviewed.
Figure 2 identifies the number of children meeting each quantity of subdomains. For example, there are 332 individuals who have six subdomains. Six children are on the cusp of eligibility in column four. All four individuals not meeting ICF LOC fall to the left of the vertical gray line. This figure indicates that the relative number of individuals impacted is minimal.
Recommendations for Additional Population Impact Study

Eligibility

Optumas recommends that, while DHHS is working to promulgate proposed changes into statute and regulations, DHHS evaluate all people who are denied eligibility for DDD services to determine how many of those people would be eligible under the proposed criteria requiring two of three adaptive deficits, instead of the current three of three requirement. This would help the State project the potential impact of expanding the definition of developmental disability.

Intermediate Care Facility Level of Care

Optumas recommends that during the time the statutory changes are pending, approximately through July 1, 2021, DHHS administer the ICAP once a person has been found eligible for services, to project whether that population of people would meet ICF LOC, and whether any adjustments are needed to the proposed standards.

Optumas analyzed the results of more than 8,000 ICAPs as part of the Initial Population Impact Study; however, there were limited data available for people at the Beatrice State Development Center (BSDC). To better understand the potential population impact on people residing at the BSDC in both the long term care unit and the crisis stabilization unit, Optumas recommends that DHHS complete ICAPs for the population of people residing at the BSDC and analyze the results to determine whether this population would continue to meet ICF LOC using the recommended criteria.
Next Steps

DHHS should evaluate this memorandum and determine if the changes described align with the mission of the State. Additionally, DHHS should determine the most appropriate course of action for each of the decision points identified in this document. Of note, there are a number of steps required for implementation, including but not limited to the statutory and regulatory changes described above; ongoing population impact studies as data become available; waiver amendments to modify level of care criteria and tools; staff training; and an analysis of impact on staffing needs.
Conclusion

DHHS’ work to design the most appropriate and effective Intermediate Care Facility Level of Care (ICF LOC) criteria and assessment tools will certainly help them to achieve their mission of ‘helping people live better lives’. Optumas has greatly appreciated the opportunity to work with DHHS on this very important initiative. Optumas is ready to assist DHHS in the effort of implementing any of the above recommendations.
Appendices

*Persons with related conditions* means individuals who have a severe, chronic disability that meets all of the following conditions:

(a) It is attributable to -

   (1) Cerebral palsy or epilepsy; or

   (2) Any other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons.

(b) It is manifested before the person reaches age 22.

(c) It is likely to continue indefinitely.

(d) It results in substantial functional limitations in three or more of the following areas of major life activity:

   (1) Self-care.

   (2) Understanding and use of language.

   (3) Learning.

   (4) Mobility.

   (5) Self-direction.

   (6) Capacity for independent living.
Appendix B: 45 CFR § 1325.3 – Definitions, Developmental Disability

The term “developmental disability” means a severe, chronic disability of an individual that:

(1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
(2) Is manifested before the individual attains age 22;
(3) Is likely to continue indefinitely;
(4) Results in substantial functional limitations in three or more of the following areas of major life activity:
   (i) Self-care;
   (ii) Receptive and expressive language;
   (iii) Learning;
   (iv) Mobility;
   (vi) Self-direction;
   (vii) Capacity for independent living; and
   (viii) Economic self-sufficiency.
(5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life.
Appendix C: 403 NAC 2.001, Eligibility Requirements

TITLE 403: MEDICAID HOME AND COMMUNITY-BASED WAIVER SERVICES (HCBS) FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

CHAPTER 2: APPLICATION, ELIGIBILITY, FUNDING, WAITLIST AND APPEALS
001. ELIGIBILITY REQUIREMENTS.

In order to be eligible for Medicaid Home and Community Based Waiver Services for individuals with developmental disabilities, an individual must:

1) Be eligible for Medicaid benefits;
2) Be age 21 for the adult day waiver;
3) Have a developmental disability as defined in the Developmental Disabilities Services Act; and
4) Require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter.
Appendix D: Nebraska Revised Statute 83-1205, Developmental Disability, Defined

83-1205. Developmental disability, defined.

Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which:

(1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;

(2) Is manifested before the age of twenty-two years;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in one of each of the following areas of adaptive functioning:

(a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;

(b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility, wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and

(c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living; and

(5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.
Appendix E: 471 NAC 31-003.04D, ICF/DD Level of Care Criteria

31-003.04D ICF/MR Level of Care Criteria:

The Department applies the following criteria to determine the appropriateness of ICF/MR services on admission and at each subsequent review:

1. The individual has a diagnosis of mental retardation or a related condition which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR; and
2. The individual can benefit from "active treatment" as defined in 42 CFR 483.440(a) and 471 NAC 31-001.02. "Benefit from active treatment" means demonstrable progress in reducing barriers to less restrictive alternatives; and
3. In addition, the following criteria shall apply in situations where -
   a. The individual has a related condition and the independent QMRP assessment identifies that the related condition has resulted in substantial functional limitations in three or more of the following areas of major life activity:
      (1) self-care;
      (2) receptive and expressive language;
      (3) learning;
      (4) mobility;
      (5) self-direction; or
      (6) capacity for independent living;
   These substantial functional limitations indicate that the individual needs a combination of individually planned and coordinated special interdisciplinary care, a continuous active treatment program, treatment, and other services which are lifelong or of extended duration; and/or
   b. A Medicaid-eligible individual has a dual diagnosis of mental retardation or a related condition and a mental illness (i.e., mental retardation and schizophrenia). The mental retardation or related condition has been verified as the primary diagnosis by both an independent QMRP and a mental health professional (i.e., psychologist, psychiatrist); and -
      (1) Historically there is evidence of missed developmental stages, due to mental retardation or a related condition;
      (2) There is remission in the mental illness and/or it does not interfere with intellectual functioning and participation in training programs, i.e., the individual does not have active hallucinations nor exhibit behaviors which are manifestations of mental illness; and
      (3) The diagnosis of mental retardation or related condition takes precedence over the diagnosis of mental illness.

“Comment: Several commenters stated that the provision of habilitation services is the cornerstone of active treatment. Therefore, they recommended specifically that the proposed definition be amended to include the term “habilitation”, as it is used in the context of the Home and Community-Based Services Waiver program (as provided in section 1915(c)(5) of the Act, that was added by section 9502(a) of the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), Public Law 99-272).”

Response: We do not agree that the term habilitation, as defined for purposes of the home and community-based waiver program, should be included in the definition of Active Treatment at § 435.1009. Although Congress provided a definition of habilitation services in section 1915(c)(5) of the Act, that definition focuses on clients who otherwise would have been institutionalized rather than strictly those currently in an ICF/MR. By its own terms, it refers to “individuals who receive such services after discharge from a skilled nursing facility or intermediate care facility,” and not to inpatients. While active treatment may include some services that are defined as being habilitative, we do not believe that it is feasible to attempt to identify in our definition of active treatment every type of service that must be provided to ICF/MR residents to assist them to reach maximum possible independence. Nevertheless, we believe our definition of active treatment is sufficient in scope to encompass the whole range of services necessary for clients to achieve maximum possible independence.”
Appendix G: LB 1038, Supporting Testimony of Courtney Miller, Director DHSS-DDD, Health and Human Services Committee, February 4, 2016

Courtney Miller, Director
Division of Developmental Disabilities
Nebraska Department of Health and Human Services

Good morning Senator Campbell and members of the Health and Human Services Committee, my name is Courtney Miller (C-O-U-R-T-N-E-Y M-I-L-L-E-R). I am the Director for the Division of Developmental Disabilities in the Department of Health and Human Services.

I am testifying today in support of LB 1039 which standardizes the definition of Intellectual Disability and allows the Department to use best practice methodology in making fair and equal Developmental Disability eligibility determinations. I want to thank Senator Coash for introducing this bill on the Department’s behalf.

In order to be eligible for services through the Developmental Disability Services Act (DDSA), which provides for a state-funded entitlement, an individual must meet two standards: have a diagnosis of a developmental disability and have adaptive functional limitations that meet a need for an institutional level of care.

Currently, the term “Intellectual Disability” is not consistently defined in statute in a manner that is objective or that accurately reflects medical or psychological practice.

Under the DDSA, an intellectual disability is defined as sub-average intellectual functioning, referring to activities such as learning, reasoning and problem solving. One way to measure intellectual functioning is an IQ test. A person would not qualify for a diagnosis unless they are significantly sub-average, generally having an IQ of 70 or below on a valid IQ test, on which 100 is considered average. As the statute is currently written, and generally interpreted, Nebraskans who do not meet this sub-average standard may qualify for services.

LB 1039 standardizes the definition and also makes clear that an intellectual disability, for purposes of the programs administered through the Division of Developmental Disabilities, is a sub-category of a developmental disability.

LB 1039 also uses the term adaptive function, which means one’s ability to adjust to a situation. In order to qualify for services from the Division of Developmental Disabilities under the federally-approved waiver, an individual must meet institutional level of care criteria which are determined by the adaptive functioning of the individual based on seven major life activities that are included in the federal code.
LB 1039 aligns the seven major life activities with best practices within the categories of practical skills, social skills, and conceptual skills, as identified by the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), and the International Classification of Diseases (ICD-10).

Practical skills include areas such as personal care, occupational skills, safety, use of money and telephones. Social skills include those such as interpersonal skills, social responsibility, self-esteem, and the ability to follow rules and obey laws. Conceptual skills include areas such as language and literacy, use of money, use of telephone, time and self-direction.

LB 1039 streamlines and clarifies eligibility determinations based on this best practice methodology, using the source of reference for clinicians in their area of expertise.

In closing, LB 1039 is aligned with our mission of helping people live better lives as it standardizes the definition of Intellectual Disability, promotes the use of best practice, aligns the statute with the relevant source documents in this area of clinical expertise, and provides clarity on eligibility for the individual, their family, advocates, our federal partners, and the public to ensure appropriate utilization of tax dollars to serve those individuals who qualify for services. This bill will not impact those individuals currently receiving services through the division.

I am happy to answer any questions.
Appendix H: IDD Definitions
## Intellectual or Developmental Disability: Definition

Intellectual disability is a disability characterized by significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifested during the developmental period. It is attributable to:  
1. Cerebral palsy or epilepsy; or  
2. Any other condition, other than mental illness, found to be closely related to intellectual disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disabilities, and requires treatment or services similar to those required for these persons.  
It is manifested before the person reaches age 22.  
It is likely to continue indefinitely.  
It results in substantial functional limitations in three or more of the following areas of major life activity:  
- **Conceptual:** The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.  
- **Practical:** The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.  
- **Social:** The social domain relies on empathy, social judgment, interpersonal communication skills, and the ability to make and retain friendships, and similar capacities.

### Federal IDEA Definition

NFEDD means significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period; that adversely affects a child’s educational performance.  
It is intellectual disability that results in subaverage intellectual functioning (approximately less than the 2.3rd percentile), present in many mental and behavioral disorders based on appropriately normed, individually administered standardized tests.  
Where (e.g., Schizophrenia, Bipolar disorder), only disorders whose core features are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioral indicators.

### Adaptive: Conceptual

- Conceptual skills — language and literacy, money, time, and number concepts, and self-direction.

### Adaptive: Social

- Social skills — interpersonal skills, social responsibility, self-esteem, empathy, social problem solving, and the ability to follow rules/laws and to avoid being victimized.

### Adaptive: Practical

- Practical skills — activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

### Adaptive: Motor

- Mobility

### Federal Related Condition

- Seizures and epilepsy
- Hypothyroidism
- Malnutrition
- Hemophilia
- Cerebral palsy
- Fragile X syndrome
- Other chronic medical conditions
- Neurogenic bladder
- Duchenne muscular dystrophy
- Down syndrome
- Autism spectrum disorder
- Williams syndrome
<table>
<thead>
<tr>
<th>Intellectual or Developmental Disability Definition</th>
<th>NE Statute: DO</th>
<th>NE Statute: ID</th>
<th>NE Regs: IDF LOC</th>
<th>NE Regs: Waiver LOC</th>
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<tr>
<td>Developmental disability means a severe, chronic disability of a person which: A. is attributable to a mental or physical impairment or combination of mental and physical impairments; B. is manifested before the person attains age twenty-two years; C. is likely to continue indefinitely; D. results in one or more of the following areas of major life activity: (1) self-care, (2) receptive and expressive language, (3) learning, (4) mobility, and (5) self-direction; E. reflects the person's need for a combination and coordination of medical, psychological, and social services that are of lifelong or extended duration and are individually planned and coordinated.</td>
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<td>The individual has a diagnosis of a mental illness, which: (1) is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness; (2) is manifested before the age of twenty-two years; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity: (a) conceptual skills, including language, literacy, money, time, number concepts, and self-direction; (b) social skills, including interpersonal skills, social problem solving, and the ability to follow laws and rules and to avoid being victimized; (c) practical skills, including activities of daily living, personal care, occupational skills, health care, mobility, and the capacity for independent living; (d) self-care; (e) mobility; (f) capacity for independent living;</td>
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<td>Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which: (1) is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness; (2) is manifested before the age of twenty-two years; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity: (a) conceptual skills, including language, literacy, money, time, number concepts, and self-direction; (b) social skills, including interpersonal skills, social problem solving, and the ability to follow laws and rules and to avoid being victimized; (c) practical skills, including activities of daily living, personal care, occupational skills, health care, mobility, and the capacity for independent living; (d) self-care; (e) mobility; (f) capacity for independent living;</td>
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<td>Intellectual disability means significant subaverage general intellectual functioning which is associated with significant limitations or impairments in adaptive functioning manifested before the age of twenty-two years.</td>
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<td>Disabilities Services Act [impact adaptive functioning in three domains, inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting three or more of the major life activities described in subdivision (6) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.</td>
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<td>The individual has a severe, profound, or other substantial intellectual disability which is attributable to a mental or physical impairment which is manifested before the age of twenty-two years; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (a) conceptual skills, including language, literacy, money, time, number concepts, and self-direction; (b) social skills, including interpersonal skills, social problem solving, and the ability to follow laws and rules and to avoid being victimized; (c) practical skills, including activities of daily living, personal care, occupational skills, health care, mobility, and the capacity for independent living;</td>
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<td>The individual is in need of a combination of medical, psychological, and social services that are of lifelong or extended duration and are individually planned and coordinated. The individual has a related condition and the independent QMRP assessment identifies that the related condition has resulted in substantial functional limitations in three or more of the following areas of major life activity: (a) conceptual skills, including language, literacy, money, time, number concepts, and self-direction; (b) social skills, including interpersonal skills, social problem solving, and the ability to follow laws and rules and to avoid being victimized; (c) practical skills, including activities of daily living, personal care, occupational skills, health care, mobility, and the capacity for independent living;</td>
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<td>Intellectual or Developmental Disability</td>
<td>Intellectual disability is defined as: a diagnosis of intellectual disability (intellectual developmental disorder), global developmental delay, or unspecified intellectual disability (intellectual developmental disorder) which shall be made only when the onset of the person’s condition was during the developmental period and shall be based on an assessment of the person’s intellectual functioning and level of adaptive skills. The diagnosis shall be made in accordance with the criteria provided in the DSM-5.</td>
<td>(a) intellectual disability; or (b) a severe, chronic disability, which: (1) is attributable to a mental or physical impairment or combination of mental and physical impairments; or (2) is manifested before the person attains age twenty-two; or (3) Is likely to continue indefinitely; or (4) results in substantial functional limitations in three or more of the following areas of major life activity: communication, self-care, self-direction, functional academic skills, social/civic skills, economic self-sufficiency; and (5) does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as a result of the infirmities of aging;</td>
<td>Intellectual disability is defined as having substantial limitations in present functioning that is manifested during the period from birth to age eighteen years and is characterized by significantly subaverage intellectual functioning existing currently with deficits in adaptive behavior including related limitations in two or more of the following major adaptive skill areas [see below]:</td>
<td>Intellectual and developmental disability means a disability that manifests before the person reaches twenty-two years of age, that constitutes a substantial disability to the affected person, and that is attributable to a mental or physical impairment or combination of mental and physical impairments; or a condition which has received a dual diagnosis of intellectual disability and mental retardation. Unless otherwise specifically stated, the federal definition of “developmental disability” listed in 42 U.S.C. c. 3401 at osc. shall apply.</td>
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Appendix I: Developmental Disabilities Level of Care Process Map

Developmental Disabilities Level of Care Process Map

1. A DSS determines eligibility for developmental disabilities services, yes or no.

2. A DSS sends notice through IFocus for eligibility or ineligibility.

3. If the DSS determines eligibility, the person is eligible for services.

4. If the DSS determines ineligibility, the person is not eligible for services.

Level of Care (LOC) Requirements for Medicaid HOBDS Developmental Disabilities waivers must meet:
1. The person must need and benefit from an active treatment program.
2. The person must have developmental disabilities without meeting those criteria described in subparts (1) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.
Appendix J: Developmental Index

This section gauges the individual's level of dependence in 6 activities of daily living. Mark all that describe the individual's ability.

A. **Feeding/Eating**: The ability to take nourishment. This may include the act of getting food from the plate to the mouth or self use of mechanical feeding devices.

- [ ] Independent.
- [ ] Intermittent supervision or reminders but individual can feed self.
- [ ] Needs constant supervision and/or partial assistance in setting up meals (i.e. cutting meat, pouring fluids) but individual could feed self.
- [ ] Needs and receives total assistance from another. Individual is unable to participate.

Comments:

B. **Meal Preparation/Clean-up**: The ability to open cans, boxes, or packages; read simple cooking instructions, set temperature correctly, operate appliances; and clean cookware, dishes, and eating utensils thoroughly.

- [ ] Independent.
- [ ] Intermittent supervision or reminders for preparing simple meals and using kitchen appliances.
- [ ] Needs constant supervision and/or partial assistance during some or all steps of preparation and clean-up.
- [ ] Totally dependent on another for meal preparation or clean-up. Individual is physically or cognitively unable to participate.
- [ ] Individual is physically unable to perform tasks but is able to make choices and direct preparation and clean-up as needed.

Comments:
C. **Toileting:** The ability to get to and from the toilet, commode, bedpan, or urinal, including transfer to and from the toilet; management of clothing, cleansing; and the ability to get to the toilet to empty the bladder/bowel, including changing incontinence pad/briefs, cleansing and disposing of soiled articles.

- Independent. (This includes bladder and bowel continence.)
- Intermittent supervision, cueing or minor physical assistance with clothes adjustment or hygiene.
- Needs constant supervision, and/or partial assistance during some or all steps of toileting.
- Totally dependent on another for all steps of toileting.

Comments:

D. **Bathing:** The ability to get to the bathing area, set correct temperature, and cleanse all parts of the body and the hair to maintain proper hygiene and prevent body odor including tub, shower, and/or sponge bath.

- Independent.
- Intermittent supervision or reminders. May need temperature set, prompting and cueing, or occasional help in and out of tub; can bathe independently.
- Needs constant supervision, and/or partial assistance during some or all steps of bathing.
- Totally dependent on another for bathing. Individual is physically or cognitively unable to participate.

Comments:

E. **Grooming:** The ability to do routine daily personal hygiene (combing hair, brushing teeth, shaving, menstrual care, and washing face and hands).

- Independent.
- Grooms self independently; may require intermittent supervision or prompting and cueing.
- Individual is physically unable to perform tasks but is able to make choices and give direction as needed.
- Constant supervision, partial or total assistance in some or all grooming needs.

Comments:

F. **Dressing:** The ability to put on and remove clothing, as needed. This includes both upper and lower body.

- Independent.
- Dresses self independently; may require prompting and cueing.
- Individual is physically unable to perform tasks but is able to make choices and give direction as needed.
- Physical assistance or presence of another at all times. Individual is physically or cognitively unable to participate.

Comments:
RECEPTIVE AND EXPRESSIVE LANGUAGE
Mark all that describe the individual's ability.

- Communication is unimpaired and readily understood.
- Has no speech but generally understands what is going on around him/her.
- Uses augmentative communication device and/or sign language (formal or informal).
- Speech is difficult for familiar others or strangers to understand.
- Indicates choices by making audible sounds, pointing, or leading others.
- Has no speech and generally does not understand what is going on around him/her or meanings.
- Doesn't express a wide range of emotions, or seems unhappy, sad, or unusually passive much of the time.
- Is unable to communicate needs in general.

Comments:

LEARNING
Mark all that describe the individual's ability.

- Does not seem to know the function of common household objects (brush, telephone, fork, microwave, coffee pot).
- Does not follow simple instructions.
- Cannot ride a bicycle.
- Has trouble eating, sleeping, or using the toilet.
- Demonstrates no reading skills.
- Reacts survival words and simple printed material and instructions (e.g. billboards, signs, recipes, etc.).
- Has no writing skill.
- Writes name, fills out checks, forms, applications, etc. independently.
- Comprehends what he/she writes and can read for enjoyment or education.

Comments:

MOBILITY
Mark all that describe the individual's ability.

- Walks independently at all times.
- Uses wheelchair or other assistive device independently.
- Needs assistance for ambulation at times when surfaces are uneven or slippery, rising from a low seat, using stairs, stepping on or curbs, etc.
- Needs constant supervision, and/or partial assistance with wheelchair maneuvering, such as negotiating doorways, elevators, ramps, locking or unlocking brakes, etc.
- Needs total assistance of another with wheelchair, turning and positioning, etc.
- Independently takes taxi or bus and safely goes about neighborhood and community (more than six blocks) alone.
- Can transfer on a bus.
- Has a learner's permit or driver's license.
SELF-DIRECTION
The individual and/or authorized representative, such as a family member or their legal guardian has the authority and responsibility to make choices, exercise decision-making, and give direction to others regarding some or all of his/her DD services. Mark all that describe the individual's ability.

☐ Stops an activity without complaints when asked to do so or when time is up.
☐ Controls temper.
☐ Completes school projects, home activities, or work tasks on time.
☐ Creates or assists in development of self-reminders or cues to initiate, finish, and/or self-check own performance.
☐ Tells time or can plan or associate events relating to time periods of the day.
☐ Is not easily distracted and able to concentrate on any single activity for more than five minutes.
☐ Can perform errands (mail letters, borrow an egg from neighbor, etc.)

Comments:

CAPACITY FOR INDEPENDENT LIVING
Mark all that describe the individual's ability.

☐ One or more indicators in Self-Direction (above) are marked.
☐ Can independently operate phone or computer.
☐ Respects property and accepts authority/directions.
☐ Avoids dangerous objects or engaging in dangerous or risky activities.
☐ Recognizes difference between fantasy and reality and acceptable and unacceptable behaviors.
☐ Independent in all aspects of medication administration and management.
☐ Needs intermittent supervision or reminders to administer medications or order medications from pharmacy.
☐ Total assistance needed with administration and management of medications.
☐ Exhibits fearful or timid behavior, resulting in avoidance or unwillingness to participate in activities.
☐ Is aggressive or self-abusive when angry or upset due to change in routine, asked to do or not do something, etc. Describe aggressive or self-abusive behaviors.

Comments:

☐ Must be supervised constantly or have supports on-site or within proximity to allow immediate on-site availability at all times due to health and/or safety concerns. Give specifics:

☐ Knowingly or unknowingly plays with dangerous objects or engages in dangerous or risky activities. Give specifics:
SOCIAL SKILLS AND PERSONALITY
Mark all that describe the individual’s ability.

☐ Usually tells the truth.
☐ Knowingly makes false statements.
☐ Always or usually recognizes when others are trying to take advantage of him or her.
☐ Seldom or never recognizes when others are trying to take advantage of him or her.
☐ Table manners are socially acceptable.
☐ Table manners are not socially acceptable.
☐ Tries to take advantage of or manipulate others. Explain:

Comments:

☐ Seems unhappy, sad, or unusually passive much of the time, and may result in having few friends or limited interactions with co-workers.
☐ Can’t differentiate between fantasy and reality.
☐ Doesn’t recognize the difference between acceptable and unacceptable behaviors.
☐ Tends to run or wander away.
☐ Does not take instructions willingly.

Comments:

ECONOMIC SELF-SUFFICIENCY
Mark all that describe the individual’s ability.

☐ Receives earned and/or unearned income.
☐ Counts change to $1.00.
☐ Handles cash (coins and currency) to $5.00 and understands value.
☐ Handles cash to $10 or more and understands value.
☐ Makes small purchases (pop, candy, etc.)
☐ Makes routine purchases (clothing, groceries, etc.)
☐ Writes or directs others to write checks or use debit card.
☐ Keeps track of balances for petty cash, checking, savings, etc.

Comments:

Additional Comments or Explanations:
### Appendix K: Comparison of Major Life Activity (MLA)

<table>
<thead>
<tr>
<th>Conceptual</th>
<th>Language</th>
<th>ICF (6 MLA)</th>
<th>Federal Definition (7 MLA)</th>
<th>Peer States</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receptive/Expressive Language</td>
<td>Receptive/Expressive Language</td>
<td>KS, MO, ID, SD, ND</td>
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<tr>
<td>Literacy</td>
<td>Learning</td>
<td>Learning</td>
<td>IA, KS, MO, ID, SD, ND</td>
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<tr>
<td>Money</td>
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<td>Time</td>
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<tr>
<td>Number Concepts</td>
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<tr>
<td>Self-Direction</td>
<td>Self-Direction</td>
<td>Self-Direction</td>
<td>KS, MO, ID, SD, ND</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>Interpersonal</td>
<td></td>
<td>IA = Social &amp; Community Skills</td>
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<tr>
<td>Social Responsibility</td>
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<tr>
<td>Self-Esteem</td>
<td></td>
<td></td>
<td>KS – ID = Social skills, community use, leisure</td>
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<tr>
<td>Gullibility</td>
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<tr>
<td>Wariness</td>
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<td></td>
<td>ND = I/DD relies upon diagnosis that assesses functioning across all 3 domains including social</td>
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<tr>
<td>Social Problem-Solving</td>
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<tr>
<td>Follows laws/rules</td>
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<tr>
<td>Practical</td>
<td>Activities of Daily Living</td>
<td>Self-care</td>
<td>Self-care</td>
<td>IA, KS, MO, ID, SD, ND</td>
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<tr>
<td>Personal Care</td>
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<tr>
<td>Occupational Skills</td>
<td></td>
<td>Economic Self-Sufficiency</td>
<td>IA, KS, MO, ID, SD, ND</td>
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</tr>
<tr>
<td>Health Care</td>
<td></td>
<td></td>
<td>IA, KS-ID</td>
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<tr>
<td>Mobility</td>
<td>Mobility</td>
<td>Mobility</td>
<td>IA, KS-DD, MO, ID, SD, ND</td>
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<tr>
<td>Independent Living</td>
<td>Independent Living</td>
<td>Independent Living</td>
<td>IA, KS, MO, ID, SD, ND</td>
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</table>
## Appendix L: Intermediate Care Facility Level of Care Statutory and Regulatory Authority Recommendations

<table>
<thead>
<tr>
<th>Statutory Definition of Developmental Disability</th>
<th>Statutory Definition of Intellectual Disability</th>
<th>ICF/DD Eligibility: Medicaid HCBS DD Waivers</th>
<th>ICF/DD Eligibility: Facility</th>
</tr>
</thead>
</table>

Developmental disability shall mean a severe, chronic disability, including an intellectual disability, other than mental illness, which:

- (1) Is attributable to a mental or physical impairment unless the impairment is solely attributable to a severe emotional disturbance or persistent mental illness;
- (2) Is manifested before the age of twenty-two years;
- (3) Is likely to continue indefinitely;
- (4) Results in significant substantial functional limitations in one of each at least two of the following three areas of adaptive functioning:
  - (a) Conceptual skills, including language, literacy, money, time, number concepts, and self-direction;
  - (b) Social skills, including interpersonal skills, social responsibility, self-esteem, gullibility;

  Intellectual disability means significant subaverage general intellectual functioning which is associated with significant impairments in adaptive functioning manifested before the age of twenty-two years. Significant subaverage general intellectual functioning shall refer to a score of seventy or below on a properly administered and valid intelligence quotient test.

In order to be eligible for Medicaid Home and Community Based Waiver Services for individuals with developmental disabilities, an individual must:

- (1) Be eligible for Medicaid benefits;
- (2) Be age 21 for the adult day waiver;
- (3) Have a developmental disability as defined in the Developmental Disabilities Services Act; which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR; and

(2) The individual can benefit from "active treatment" as defined in 42 CFR 483.440(a) and 471 NAC 31-001.02. "Benefit from active treatment" means demonstrable…

The Department applies the following criteria to determine the appropriateness of ICF/MRDD services on admission and at each subsequent review:

(1) The individual has a diagnosis of intellectual disability, mental retardation or a related condition, developmental disability as defined in the Developmental Disabilities Services Act; which has been confirmed by prior diagnostic evaluations/standardized tests and sources independent of the ICF/MR; and

(2) The individual can benefit from "active treatment" as defined in 42 CFR 483.440(a) and 471 NAC 31-001.02. "Benefit from active treatment" means demonstrable…
### Statutory Definition of Developmental Disability

wariness, social problem solving, and the ability to follow laws and rules and to avoid being victimized; and

(c) Practical skills, including activities of daily living, personal care, occupational skills, healthcare, mobility, and the capacity for independent living; and

(5) Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

An individual from birth through the age of nine years inclusive who has a substantial developmental delay or specific congenital or acquired condition may be considered to have a developmental disability without meeting showing significant functional limitations in at least two of the three areas of adaptive functioning three or more of the major life activities described in subdivision (4) of this section if the individual, without services and support, has a high probability of meeting those criteria later in life.

### Statutory Definition of Intellectual Disability

### ICF/DD Eligibility: Medicaid HCBS DD Waivers

- Disabilities Services Act; and
- (4) Require the level of services provided by an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) initially and annually thereafter, as defined in 471 NAC 31-003.04D (2).

### ICF/DD Eligibility: Facility

- Progress in reducing barriers to less restrictive alternatives; and
- (2)(3) In addition, the following criteria shall apply in situations where—
  - (a) The individual has related condition and the independent QMRRP. For individuals aged 18 or older, an assessment identifies that the person related condition has resulted in significant substantial functional limitations in three four or more of the following areas of major life activity:
    - (4a) self-care;
    - (2b) receptive and expressive language;
    - (3c) learning;
    - (4d) mobility;
    - (5e) self-direction; or
    - (6f) social skills;
    - (7g) capacity for independent living; or
    - (8h) economic self-sufficiency.
  - (3) For individuals aged 17 or under, an assessment identifies
<table>
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<tr>
<th>Statutory Definition of Developmental Disability</th>
<th>Statutory Definition of Intellectual Disability</th>
<th>ICF/DD Eligibility: Medicaid HCBS DD Waivers</th>
<th>ICF/DD Eligibility: Facility</th>
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<tr>
<th>That the person has significant functional limitations in four or more of the following areas of major life activity:</th>
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<tbody>
<tr>
<td>(a) self-care; (b) receptive and expressive language; (c) learning; (d) mobility; (e) self-direction; or (f) social skills; or (g) capacity for independent living.</td>
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</tbody>
</table>

These substantial significant functional limitations indicate that the individual needs a combination of individually planned and coordinated special interdisciplinary care, a continuous active treatment program, treatment, and other services which are lifelong or of extended duration; and/or

(b) A Medicaid-eligible individual has a dual diagnosis of mental retardation or a related condition and a mental illness (i.e., mental retardation and schizophrenia). The
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<tr>
<th>Statutory Definition of Developmental Disability</th>
<th>Statutory Definition of Intellectual Disability</th>
<th>ICF/DD Eligibility: Medicaid HCBS DD Waivers</th>
<th>ICF/DD Eligibility: Facility</th>
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</table>

**Statutory Definition of Developmental Disability**

**Statutory Definition of Intellectual Disability**

**ICF/DD Eligibility: Medicaid HCBS DD Waivers**

**ICF/DD Eligibility: Facility**

- mental retardation or related condition has been verified as the primary diagnosis by both an independent QMRP and a mental health professional (i.e., psychologist, psychiatrist); and

(1) Historically there is evidence of missed developmental stages, due to mental retardation or a related condition;

(2) There is remission in the mental illness and/or it does not interfere with intellectual functioning and participation in training programs, i.e., the individual does not have active hallucinations nor exhibit behaviors which are manifestations of mental illness; and

(3) The diagnosis of mental retardation or related condition takes precedence over the diagnosis of mental illness.

**Explanation of changes:**

- Aligns the statutory definition of developmental disability with the intent of the DSM. The DSM states that an intellectual disability impacts adaptive

**No changes proposed**

**Explanation of changes:**

- Specifically links to the regulatory requirement for

**Explanation of changes:**

- Replaces intellectual disability and related condition with developmental disability, as defined by the
<table>
<thead>
<tr>
<th>Statutory Definition of Developmental Disability</th>
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<th>ICF/DD Eligibility: Facility</th>
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<tbody>
<tr>
<td>functioning in the three domains (conceptual, social and practical) but does not require substantial limitations in ALL 3 areas to meet the criteria of developmental disability. The proposed criteria specify that rather than all 3 areas, there must be limitations in at least two areas.</td>
<td>ICF LOC used in facilities to ensure that LOC Medicaid HCBS waiver for people with developmental disabilities remains aligned with ICF LOC for facility-based services</td>
<td>Developmental Disabilities Services Act, which is inclusive of both terms.</td>
<td>- Changes substantial to significant functional limitations which is interpreted as significant statistically at two standard deviations.</td>
</tr>
<tr>
<td>- Changes substantial to significant functional limitations which is interpreted as significant statistically at two standard deviations.</td>
<td>- Reference to subdivision 4 was “clean-up to align with the three domains as opposed to the previous statute’s seven major life areas.</td>
<td>- Removes requirement for “prior” diagnostic evaluations to better reflect DHHS’s practice of not requiring an evaluation that took place during the developmental period.</td>
<td>- Remove references that apply only to ICF and not HCBS – may require updates to ICF regs</td>
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<tr>
<td>- Reference to subdivision 4 was “clean-up to align with the three domains as opposed to the previous statute’s seven major life areas.</td>
<td>- Remove references to subdivision 4 was “clean-up to align with the three domains as opposed to the previous statute’s seven major life areas.</td>
<td>- Remove references that apply only to ICF and not HCBS – may require updates to ICF regs</td>
<td>o active treatment – although provided in intense settings – not all people receiving HCBS require active treatment;</td>
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<td></td>
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<td>o Delete references to mental illness – should not apply to LOC for people seeking waiver services.</td>
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<td>o Delete references to QMRP / independent assessment</td>
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<td></td>
<td>- Changes substantial to significant functional limitations which is interpreted as significant statistically at two standard deviations.</td>
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<td>- Clarify that both people with ID and DD must meet the criteria for functional limitation of major life areas</td>
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<td>- For adults (a) Add economic self-sufficiency and social skills to the list of major life areas and (b) Require a</td>
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<tr>
<td>Statutory Definition of Developmental Disability</td>
<td>Statutory Definition of Intellectual Disability</td>
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<td>minimum of 4 rather than 3 deficits in major life areas.</td>
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<td>- For children—requirement is a minimum of 4 of 7 deficits in major life areas.</td>
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</tbody>
</table>
# Appendix M: Crosswalk between DD Three Domains and LOC Six Major Life Activities

<table>
<thead>
<tr>
<th>NE. Rev. Stat. 83-1205</th>
<th>LOC</th>
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</thead>
<tbody>
<tr>
<td>Conceptual</td>
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<tr>
<td>Language</td>
<td>Receptive/Expressive Language</td>
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<td>Literacy</td>
<td>Learning</td>
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<td>Money</td>
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<td>Number Concepts</td>
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<td>Self-Direction</td>
<td>Self-Direction</td>
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<tr>
<td>Social</td>
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<td>Interpersonal</td>
<td>Social Skills &amp; Personality</td>
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<td>Social Responsibility</td>
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<td>Self-Esteem</td>
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<td>Gullibility</td>
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<td>Follows laws/rules</td>
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<tr>
<td>Activities of Daily Living</td>
<td>Self-care</td>
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<td>Personal Care</td>
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<td>Health Care</td>
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<tr>
<td>Occupational Skills</td>
<td>Economic Self-Sufficiency</td>
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<td>Mobility</td>
<td>Mobility</td>
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<tr>
<td>Independent Living</td>
<td>Independent Living</td>
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Green Font = Major Life Activity included in ICF LOC regulation  
Blue Font = Major Life Activity not included in ICF LOC regulation but assessed by the DI
Appendix N: Form used to Summarize Information used in the Institutional LOC Decision

<table>
<thead>
<tr>
<th>Client</th>
<th>Factor</th>
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</table>

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<thead>
<tr>
<th>Annual/Cycle</th>
<th>Placement sought</th>
<th>Alternate Placement sought</th>
<th>Psych Eval &amp; Dx</th>
<th>D/H/R prior to</th>
<th>Age 22</th>
<th>most recent physician certification</th>
<th>most recent Physical therapy</th>
<th>Annual PIP</th>
<th>C/I/DD/OA</th>
<th>Completed DW-28</th>
</tr>
</thead>
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</table>

Annotations:
- We review the C/I/DD/OA level of care to determine if needed by each individual in accordance with ACRL. We review our needs at least every 6 months.
Appendix O: Excerpts from the ICAP for Nebraska Guide (2018)

Guidelines for Completing General Information
Administering the ICAP does not require an extensive background in test administration. These instructions and definitions summarize information that is useful in completing the ICAP Response Booklet. A completed ICAP will reflect current evaluations, programs, services, and recommendations as outlined on the participant’s annual Individual Service Plan (ISP).

General Protocols

Writing Instrument: Use a #2 pencil or pen with dark ink to ensure marks remain visible when the ICAP is scanned into an electronic record.

Revised Answers: When changing a response, fully erase the previous answer to ensure it is not inadvertently included in the final score.

Cover page – Identifying Information

Name: Person's last name, first name, and middle initial. Use the participant’s legal, full name. Must be the same name on N-Focus.

Address: Complete address of the participant's actual residence.

Phone: Telephone number at the participant's residence.

Residential Facility: Residential Facility is the responsible party for where a participant lives. For example, this may be a Specialized DD Provider, nursing facility, parental home or “N/A – lives alone.”

School/Day Program: School/Day Program is the responsible party for where a participant goes during the day. For example, this may be a school, Specialized DD Provider, or “N/A – works independently.” For Daytime Program, if a participant is funded under multiple service codes, choose the setting in which they spend a majority of their day.

County/District Responsible: Country/District Responsible is the Nebraska County in which the participant currently resides.

Case Manager: Name and phone number of the Case Manager. This is the participant’s DD Service Coordinator.

Parent or Guardian: Name and phone number of the participant’s parent(s) or guardian. Circle whether the person named is parent or guardian. If the participant is an independent adult with no parental oversight or no guardian, enter N/A.

Respondent: The name of the person who completed the ICAP. First and last name.

Your Phone: Complete phone number.

Relationship to Person: Job title.
**Reason for Evaluation:** Reason for Evaluation should be listed on the ICAP assignment email. Possible reasons for completion include:

- Initial ICAP
- Biennial ICAP
- Change in ICAP abilities
- Requested by DDCO

If you have difficulty with terms such as *simple*, or *clean*, or *appropriate*, ask: What is the approximate developmental level of this task for a non-handicapped person? What standard for success would a parent or teacher of a child that age apply?

How clean is a clean room? Parents of an 11 to 15 year old expect their children to begin to assume this responsibility. What would parents of an average child this age have been thinking when he said "does, but not well," or "does very well"?

Difficulty sometimes arises when assessing adults with mental or physical handicaps because a behavior's context may be different than the norm. Nevertheless, the standard for success should be the same as it was for the norming group.

**General Scoring Considerations for Adaptive Section**

**Adaptive equipment** — If the participant can independently use his/her adaptive equipment without help, score the task as it is actually performed. If he/she wears glasses, how well does he/she see with glasses? How well does he/she walk with his cane? How well does he/she eat with a spoon, even if it is an adapted spoon?

- Equipment must be owned and readily available to participant to use in all environments.

**Alternative communication methods** — For a participant who does not speak, rate on the communication system they use to relay information.

- If a participant uses sign language this should be considered equivalent to speaking. Refer back to Section A. 7. (Primary Means of Expression).
- Communication books, boards, and devices can be equivalent to speaking when they contain many words that can be combined to form unique sentences. For example, pointing to the word or symbol "where" and the separate word or symbol "coat," constitutes a simple question. Simply pointing to a symbol for jacket, or to a question mark, does not constitute a simple question.
- Any communication device used must be owned and readily available to participant to use in all environments.

**Asks permission** — A participant is not penalized for appropriately asking permission before initiating a task. Even though the participant does not begin the task entirely on his/her own, he/she is initiating the task by appropriately seeking permission.
**Awareness, motivation, and social expectations** — To receive a score of *Does very well*, the participant needs the ability to perform a task, the awareness of when the task is needed, and the motivation to perform it, given normal social expectations.

For example, for the task *Cleans bedroom*:

- A young child or severely handicapped adult who lacks the ability to make a bed will be scored *Never or rarely*, regardless of awareness or motivation.
- Someone who has the ability to clean, perhaps after step-by-step training, but who cannot follow a schedule independently and has no awareness of when or if the skill is necessary, must be scored less than *Does Very Well*. *Without being asked and without the occasional reminder*.
- An independent adult who keeps a clean house would be rated *Does Very well without being asked* and without the occasional reminder.
- An independent adult whose bedroom is often a mess, even when close friends come over, but is cleaned well before it becomes unsanitary and before receiving special company, might still be rated *Does Very Well* if the frequency of cleaning is within the range of normal social expectations for a non-handicapped adult in a similar living situation.
- A household member who has the ability to clean a room well, who always keeps it at least healthy, but who thoroughly cleans it only according to a schedule or "when company comes," might still be rated *Does Very Well* if he always or almost always complies with household expectations with no more than an occasional comment or reminder.
- Someone who has the ability to clean well but does not follow a schedule independently and typically fails to perform the skill even when social expectations clearly dictate, either for lack of awareness or for lack of motivation, perhaps related to a mental health problem, must be scored less than *Does Very Well without being asked* and without the occasional reminder.

**Being asked** — A few tasks, often easier tasks near the beginning of a domain, are typically performed only in response to a question (such as *States birth date*). In this case the behavior may be rated *Does Very Well* even though the participant is replying to a question.

**Differentiating adaptive and problem behavior** — If there is a discrepancy between the quality of the participant’s performance (such as *always or almost always does well*) and the frequency (such as *3/4 of the time*), the score should be based primarily on the quality of performance. The focus of the adaptive behavior section is on ability. Someone who, if tired, angry or impetuous, sometimes refuses to perform a task might still be rated “*Does Very Well*” without being asked if the skill is within his ability and is usually performed well. If the refusal is persistent but applies only to a few specific adaptive tasks, at most it may decrease the participant’s adaptive rating to *Does Fairly Well* on these specific tasks. In this case the occasional uncooperativeness would not also be rated as a behavior problem.

Behaviors that interfere with the participant’s day-to-day activities or with the activities of those around him/her should be rated as behavior problems, not as a lack of adaptive behavior. Refusal to perform necessary tasks that are within the participant’s ability, sometimes called non-compliance or uncooperative behavior, may be recorded in the problem behavior section of the ICAP if the refusal is common enough to create a persistent problem across many adaptive skills. In this case the participant’s uncooperativeness would not detract from his adaptive behavior task scores, which should be rated on the basis of ability rather than cooperation.
Adaptive vs. Problem Behaviors

These are complicated scenarios and respondents should consider each situation on a case-by-case basis to determine the etiology of the behavior and define it as either an adaptive, maladaptive, or uncooperative behavior.

**Medication** — Consider medications to be like adaptive equipment, like glasses or a hearing aid. How well does the participant perform with the help of his/her medication?

- If medication results in lessening adaptive skills, such as not being able to perform tasks due to lethargy, adaptive skills will need to reflect the participant’s functioning while on the medication with side effects. This is similar to considering medications as assistive devices when they benefit a participant’s skill level.

**More than one part** — If a task has more than one part and one part is rated lower than the others, the weakest part of the task is scored. For example, if a participant can perform all steps of cleaning room well except for making their bed, they would be scored on the making bed step.

- If there is one part of a task that the participant cannot do at all, the task must be rated *Never or Rarely*.

**No Opportunity** — A participant may not have the opportunity to perform a task or may not allowed to do a task for reasons other than skill level. An activity may be against facility rules or be “someone else’s job.” In these cases, estimate whether and how well the participant would complete the task if given the opportunity.

- If participant was capable of performing the task prior to current placement in a restrictive setting, a reasonable assumption can be made that they remain capable.
- If interviewee has not had an opportunity to observe the participant performing the task, ask someone else who has observed the task, or ask them to estimate whether and how well he/she could perform the task at the present time without help or additional training.
- Base a “best estimate” on information and/or observation of the participant’s performance on similar or related tasks. Place an “E” in the ICAP next to any estimated responses.

**Physical disability** — If the participant’s physical disability prevents him/her from performing a task without help, even though it is within his/her mental ability, the task must be rated "Never or Rarely" (or possibly at Does, But Not Well). A participant should be neither penalized nor rewarded because of a disability. A participant with a wheelchair, for example, might or might not receive credit for a task such as *Picks up and carries a full bag of groceries* depending on whether he/she can do so independently using his wheelchair.

**Prompt or demonstration** — There may be a task that the participant has never been asked to perform. Demonstrating a task to a participant once for the purpose of explaining the task is not considered training or supervision.
Appendices

Safety — If the participant is not allowed to perform a task because his/her level of performance and/or judgment would pose a threat to his/her safety, the task should be scored Never or Rarely (or possibly Does, But Not Well). For example, because a child can reach and turn knobs on the stove does not mean he can operate the stove independently.

Supervision — Some participants receive more supervision than their adaptive behavior dictates because of their problem behavior. Adaptive behavior should be rated based upon ability to perform tasks independently, not upon the level of supervision or facility supervision rules. If the participant could do a task such as “acts appropriately in public with friends,” he/she should receive credit for the ability even if it is against supervision for he/she to go out alone with friends.

Technology — Technology is considered like adaptive equipment. If a participant can use technology to complete a task, score the task as it is performed. How well does he/she preform the task with technology?

- The ICAP is a several decades old assessment tool. Sometimes new technology may eliminate the original task for the participant. For example, rather than locating or remembering phone numbers the participant uses speed dial, the participant doesn’t mail letters but sends emails and texts, or the participant uses the internet rather than the yellow pages or want ads.
- Tasks are rated based on completing the task without help or supervision. Technology may change the “how” but it should not change the ability of the participant to complete a task. For example, if a participant has a cell phone which stores phone numbers, are they are able to independently find numbers and make calls? If a participant can complete a task independently with technology, he/she receives a 3 (Does Very Well). If a participant uses technology, plus the help of someone else, he/she cannot score a 3 (Does Very Well) due to the need for assistance.
- Consider the overall skill being measured. This can be determined based on which section the skill is listed under: Motor Skills, Social & Communication Skills, Personal Living Skills, or Community Living Skills. For instance, “Folds a letter into three equal sections and seals in an envelope” is a Motor Skill, not a Social & Communication Skill.

Too easy — A participant may no longer perform a task because it is too easy for him/her. Tasks that are too easy for a participant should always be scored Does Very Well. For example, if the participant does very well on the task of dresses self completely and neatly then the task Holds out arms and legs while being dressed would be too easy for the participant and should be scored a 3 (Does Very Well).

Vulnerability — Vulnerability equates to a lack of adaptive behavior (identifying and avoiding dangerous situations) and should not be labeled as a problem behavior. It should be captured within a participant’s adaptive section in the form of inability to complete tasks. More information regarding vulnerability as a problem behavior is included Guidelines for Completing Problem Behavior Scale (Section E), pp. 34-39.

Pages 26 - 29

2. SOCIAL AND COMMUNICATION SKILLS
The primary focus of these tasks includes social interaction, language comprehension and language expression. This area measures interaction with others in various social settings, understanding of
language transmitted by signs, oral expression, or written symbols and communication of information through signs, oral expression or written language.

1. **Makes sounds or gestures to get attention.**
   Consideration(s): This is the beginning of communication. The participant uses sounds or gestures to obtain the attention of another person. If the participant is verbal, he/she has gone beyond the need to reach for a person and has mastered this skill, the score is a 3.

2. **Reaches for a person whom he or she wants.**
   Consideration(s): The participant has the ability to engage another person for a response, such as a physical reach. If the participant is verbal, he/she has gone beyond the need to reach for a person and has mastered this skill, the score is a 3.

3. **Turns head toward speaker when name is called.**
   Consideration(s): When a participant speaks, he/she is beyond this skill, and the score is a 3. When a participant who does not have the physical ability to turn his/her head acknowledges the speaker by making sounds/gestures/smiles when his/her name is called, the score is a 3. A participant who is hearing impaired would be scored a “0” if unable to complete task.

4. **Imitates actions when asked, such as waving or clapping hands.**
   Consideration(s): This is a pre-verbal and early social skill.

5. **Hands toys or other objects to another person.**
   Consideration(s): This task focuses on the skill of sharing or interacting with another person. If the participant hands an object, such as magazine, glass, puzzle piece to someone else, the score is a 3. If the participant does not have the cognitive skill to interact with another person in this manner, the score is a 0.

6. **Shakes head or otherwise indicates “yes” or “no” in response to a simple question such as, “Do you want some milk?”**
   Consideration(s): The participant needs to know the difference between yes and no. The participant can overtly indicate through other means, such as, gesture, pushing away, reaching towards, accepting or not accepting. When the participant is inconsistent in his/her responses, the score should reflect the accuracy of the answer.

7. **Points to familiar pictures in a book on request.**
   Consideration(s): Points to common objects in a book or magazine as they are named, such as dog, house, ball, cup, apple, tree, mom, or dad. Includes use of communication devices.

8. **Says at least ten words that can be understood by someone who knows him or her.**
   Consideration(s): The ten words do not have to be consecutive to each other or form a sentence. The participant says ten words to communicate.
   - If a participant using sign language is able to communicate at least ten words, the score is a 3.
   - When the communication device has more than ten symbols and the participant understands and uses them selectively, the score is a 3.
9. Asks simple questions (for example, “what’s that?”).
Consideration(s): Asks questions, such as beginning with what, where, why, how.
- Using sign language or a communication device is appropriate if the communication device has enough ‘symbols’ to allow the participant to ask questions by putting words/symbols together.
- Pointing to a “what’s that” symbol or a question mark to ask a question would be recorded 0. Never or Rarely.

10. Speaks in three-or four-word sentences.
Consideration(s): The participant talks in simple sentences. For example, “I want milk.” Using sign language or a communication device is appropriate if the participant uses sufficient symbols to make sentences which are understandable.

11. Waits at least two minutes for turn in a group activity (for example, taking turns at batting a ball or getting a drink of water).
Consideration(s): The participant needs to understand the concept of taking turns when playing a game or waiting in line. If prompting is needed for the participant to remain in line, move forward in a socially acceptable manner, and know when it is their turn, they would not receive a score of a 3.

12. Offers help to other people (for example, holds a door open for one whose arms are full or picks up an object dropped by someone else).
Consideration(s): Does the participant have the social awareness to recognize the needs of others. Does the participant offer help to another person? Assistance may be physical or verbal, such as giving directions. Socially the participant has anticipated a need and has offered assistance.

13. Acts appropriately without drawing negative attention while in public places with friends (for example, a movie theater or library).
Consideration(s): This task focuses on whether the participant understands social expectations of behavior when at the library or movie versus a concert or sporting event.
- If the participant does not have the skill to understand the appropriate social behavior the score is a 0.
- When they are acting appropriately without prompts the score is a 3.

14. Responds appropriately to most common signs, printed words, or symbols (for example, STOP, MEN, WOMEN, DANGER).
Consideration(s): Does the participant know at least ten common signs, words or and have the skill to respond in any environment? For example, would they know which bathroom to go into in an unfamiliar place?

15. Summarizes and tells a story so that it is understood by someone else (for example, a TV program or a movie).
Consideration(s): This task is not based on appropriate grammar but on the ability to summarize a story and make it understandable to an unfamiliar person. They need to relate the events of a story in appropriate sequence. Consider the number of questions (prompts) the participant needs to tell the story. If the participant needs prompts to complete the story or provide details, the score is not a 3.
16. Locates or remembers telephone numbers and calls friends on the telephone.
Consideration(s): Does the participant use the phone and call people, such as, relatives, staff, and friends. The phone numbers can be located in an accessible place, such as, the contact list on a cell phone, a written list on the refrigerator or next to the phone. The participant does not need to program or write down the numbers him or herself to receive a score of 3.

17. Writes, prints, or types understandable and legible notes or letters for mailing.
Consideration(s): The notes need to be created by the participant and not copied. The notes need to be legible and understandable to the reader. The participant can use a cell phone and texting or computer and computer programs such as email, social networks and twitter.

18. Locates needed information in the telephone yellow pages or the want ads.
Consideration(s): The participant needs to be able to generalize this skill to more than one situation, such as ordering pizza or finding garage sales. Information can be accessed over internet search engines, phone apps, white pages, community news circulars, or other websites.

19. Calls a repair service or the caretaker if something major such as the furnace or the refrigerator breaks down in the home.
Consideration(s): Does the participant recognize when something breaks and that he needs to follow through with getting the item fixed in an appropriate period of time. The participant needs to call the appropriate caretaker and know who to call if the caretaker is unavailable.
- The participant may be able to verbalize the skill, but if there is not follow through in assuring the item is fixed, the score is a 0.
- The participant needs to be able to generalize the skill to more than one situation. Do not score this task a 3 based on information from only one situation.
- If the participant’s response is to call a parent, they would not be scored a 3.

Pages 29 -31

3. PERSONAL LIVING SKILLS
The primary focus of these tasks includes eating and meal preparation, toileting, dressing, personal self-care, domestic skills and the maintenance of a relatively organized lifestyle and living environment. This area assesses the participant’s effectiveness in meeting the everyday demands of personal independence and autonomy, primarily in the home environment.

1. Swallows soft foods.
Consideration(s): When the participant is able to swallow ground, chopped, or bite sized food, the score is a 3.
- When the participant is able to swallow food with the consistency of baby food (pureed, pudding, applesauce, mashed bananas, thickit) the score is a 3.
- When the participant has had a swallowing evaluation which determined the participant has difficulty swallowing food with the consistency of baby food (pureed, pudding, applesauce, mashed bananas), the score is dependent on the level of assistance required to assist the participant to swallow.
- When staff needs to be present to provide a prompt as needed to take a drink, or swallow or other recommendations from the evaluation at meal times, score a 2.
• When staff needs to be present to assist throughout mealtime providing prompts to swallow between each bite of food, prompt to take a drink or other recommendations from the swallow study, score a 1.
• When the participant is not able to swallow food with the consistency of baby food (pureed, pudding, applesauce, mashed bananas) the score is a 0.

2. **Picks up and eats foods such as crackers.**
   Consideration (s): Does the participant pick up finger foods and eat them? If the participant eats with utensils, this task is too easy for the participant and the score is a 3.

3. **Holds out arms and legs while being dressed.**
   Consideration (s): The participant needs to be able to complete both parts of this task (arms and legs). If the participant dresses him/herself, this task is too easy for the participant and the score is a 3. If the participant has a physical disability limiting full extension of a limb the score is less than a 3.

4. **Holds hands under running water to wash them when placed in front of a sink.**
   Consideration (s): This is the first step in a participant learning how to wash their hands. This does not require that the participant know how to turn the water faucet on or off.
   - The score is a 3 when a participant is in front of a sink and extends their hands under the water faucet in preparation for someone else to wash the hands.
   - If a participant only has physical use of one hand and independently places their hand under running water, the score is a 3.

5. **Eats solid foods with a spoon with little spilling.**
   Consideration (s): Does a participant get most of the food in their mouth using a spoon? If the participant uses a fork this skill is too easy for the participant and the score is a 3. An example of a solid food would be mashed potatoes. Solid foods exclude soup, milk or other liquids.

6. **Stays dry for at least three hours.**
   Consideration (s): This is a pre-toileting skill to be able to control one’s bladder for at least three hours. A two-hour toileting schedule may not always indicate that a participant cannot control their bladder for at least three hours. For example:
   - The score is 3 if a participant is dry when changed every two hours and can hold their bladder for three hours.
   - The score is 0 if a participant is always wet when changed every two hours and cannot hold their bladder for at least three hours. They would not be rated a 1 or a 2.

7. **Removes pants and underpants.**
   Consideration (s): This does not require that a participant knows how to put their pants and underpants on once they have taken them off. This is a pre-toileting skill and not related to problem behavior.

8. **Uses the toilet at regular times when placed on the toilet or when taken to the bathroom.**
   Consideration (s): When a participant is taken to the bathroom at regular times and then uses the toilet when placed on the toilet, the score is a 3.
9. Puts on T-shirt or pullover shirt, although it may be on backward.
Consideration (s): This is the first step in learning how to dress. The shirt can be placed on backwards or inside out. The participant does not need to know when it is appropriate to change his shirt, such as, when dirty or torn.

10. Uses the toilet, including removing and replacing clothing, with no more than one accident per month.
Consideration (s): This task focuses on how many accidents the participant has when they use the toilet independently. If the participant uses the toilet but does not remove and replace clothing, rate the participant’s ability to remove and replace clothing. If the participant is incontinent at night this task is scored a 0. Based on the respondent’s understanding of the participant’s level of personal living skills, it would be appropriate to skip questions 6 and 8 to ask question 10 first. If a participant earns a score of 3 on question 10, they would also earn a 3 on questions 6 and 8.

11. Closes the bathroom door when appropriate before using the toilet.
Consideration (s): The participant recognizes the need for privacy and ensures the bathroom door is closed when guests are present or when using a public restroom.

12. Dresses self completely and neatly, including shoes, buttons, belts, and zippers.
Consideration (s): The participant dresses appropriately depending on the social situation or environment. The participant selects clothing from the wardrobe made available to them. Dressing self completely includes using Velcro shoes, slip on shoes, or elastic pants. Neatly is defined as zipping pants, buttoning buttons in the right holes, putting shoes on, putting pants on facing forward, and having shoes on the correct feet.

13. Cuts food with a knife instead of trying to eat pieces that are too large.
Consideration (s): A knife is a common table knife and not only a steak knife. When a participant recognizes that pieces are too large to eat and is not given a knife but is able to cut food into smaller pieces using a fork, the score is a 3.

14. Washes, rinses, and dries hair.
Consideration (s): When the participant is not able to complete any part of the task, such as never rinsing hair or always using too much shampoo, the task is scored a 0.
- When the participant washes and dries his/her hair but does not rinse the shampoo out of his/her hair well, the score is a 1 because the weakest part of the task was scored.
- Drying hair can include towel dry.
- If the participant needs prompts, the score is not a 3.

15. Washes and dries dishes and puts them away.
Consideration (s): The participant completes all parts of the task with the weakest part of the task being scored.
- If the participant washes the dishes but does not use the appropriate amount of soap, appropriate water temperature, does not completely clean the dishes but dries and puts the dishes away, the weakest part of the task, washes the dishes is scored.
- Dishes may be air dried but need to be put away.
The use of a dishwasher is scored a 3 if used properly and the dishes are dried prior to putting them away.

If the participant needs prompts, the score is not a 3, but could be a 1 or a 2.

16. Mixes and cooks simple foods such as scrambled eggs, soup, or hamburgers.
Consideration (s): The participant mixes at least two ingredients together.
- The participant needs to be able to set the appropriate temperature on the stove or microwave and determine when the food is done.
- If the participant only heats up pre-made food in a microwave or only cooks TV dinners the score is a 0.

17. Cleans bedroom, including putting away clothes, changing sheets, dusting, and cleaning the floor.
Consideration (s): If the participant is not able to complete any one part of the task, such as never changes sheets, the task is scored a 0. The participant needs to complete all parts of the task with the weakest part of the task scored. The participant needs to make the decision when it is appropriate to clean. Prompts may be used and scored accordingly. The participant who lives independently is given some latitude on the frequency at which this task is completed.

18. Prepares shopping list for at least six items from a grocery store.
Consideration (s): The participant makes the decision on what items they need to buy based upon their current supply. This does not require that food items be nutritional. The participant can prepare a shopping list without writing it down or may use a picture shopping list. Other lists, such as Christmas lists, may be used. Spelling and neatness are not important. The participant just needs to be able to read it back.

19. Loads and operates a washing machine using an appropriate setting and amount of detergent.
Consideration (s): The participant completes all parts of this task with the weakest part of the task scored.
- If the participant is not able to complete any one part of the task, such as never uses appropriate amount of soap, the task is scored a 0.
- The participant needs to know how to operate the machine using the appropriate settings to wash their clothes and the appropriate amount of clothing so the machine is not overloaded.
- If the setting option is pre-selected and the participant does not know how to operate the machine the score is not a 3.
- To receive a score of a 3, the participant can transfer this skill to use another washing machine.
- If the participant is not physically able to load and operate a washing machine and needs the physical assistance of another person to do so, the score is a 0.

20. Plans, prepares, and serves main meal for more than two people.
Consideration (s): The participant needs to decide what and how much food to prepare and serve.
- If the participant only cooks prepared microwave food or TV dinners the score is a 0.
- This task should not have a score higher than the score on tasks 16 and 18.

21. Repairs minor damage to clothing, such as tears or missing buttons, or arranges for these repairs outside the home.
Consideration (s): The participant needs to recognize that their clothing is in need of repair and make the needed repairs themselves or arrange for the repair outside the home or with a caregiver. The participant needs to ensure they get the repaired item back.

Pages 31 – 33

4. COMMUNITY LIVING SKILLS
The primary focus of these tasks includes time and punctuality, money and value, work skills, and home and community orientation. It assesses the level of independence in areas essential to successful community transition by measuring skills needed for accessing community resources, integration in employment, and other social and economic requirements encountered in community settings.

1. Finds toys or objects that are always kept in the same place.
Consideration (s): Can the participant find their belongings, such as coat, shoes, snacks, a glass to get a drink?

2. Finds own way to a specified room when told to go (for example, “Go wait in the kitchen”).
Consideration (s): When the participant is familiar within an area and can find their own way to a room, the score is a 3.

3. Indicates when a chore or assigned task is finished.
Consideration (s): The participant who is able to independently move on to the next task or get more tasks has moved past this skill and is scored a 3. The participant does not need to verbalize to indicate when the task is finished but does need to overtly indicate completion. The participant may ‘point’ or sign that a chore is finished, may tap staff on the arm, may raise his hand, or use a switch to gain staff attention.

4. Stays in an unfenced yard for ten minutes when expected without wandering away.
Consideration (s): Regardless of whether the participant can ambulate or not, the participant has to have the cognitive ability to understand that they need to stay in the yard when expected without wandering away. Staff needs to feel the participant is safe based on their level of adaptive behavior skills to be left alone in the unfenced yard with regular monitoring. If the participant is completely immobile and dependent upon staff to maneuver their wheelchair, this item would be scored a 0.

5. Uses the words “morning” and “night” correctly.
Consideration (s): The participant needs to know the difference between morning and night. The participant does not need to speak the words to get a score on this task.

6. Trades something for money or another item of value (for example, trades one book for another one or for money).
Consideration (s): The participant has the understanding that he should not give up something for nothing. This primarily tests a participant’s pre-money usage skill and the trade does not need to be for another item of equal value. However, a participant’s ability to use money to facilitate a trade would also satisfy the requirements of this test.
  - **Prerequisite/Logical Connection:** Task 6 is a prerequisite of task 7 and must be scored as equal to, or greater than task 7.
  - The participant can demonstrate ability to trade if he makes purchases using checks or cash.
7. Buys items from a vending machine (for example, candy, milk or soda pop).
Consideration (s): This is a pre-money usage skill so the participant does not need to know the correct amount of money needed to use the vending machine. When the participant is provided with the correct amount of money/coins, they place the money into a vending machine and select an item to purchase. A vending machine has more than one selection to make, versus a gum ball machine where there is no choice. Task 6 cannot be scored lower than task 7.

8. Crosses nearby residential streets, roads, and unmarked intersections alone.
Consideration (s): The participant needs to have the street safety skills to cross the street in their neighborhood. The key words in this task is “nearby residential” versus downtown or business area streets. This is crossing a less-busy street without a crosswalk signal.

9. Buys specific items requested on an errand, although may not count change correctly.
Consideration (s): The participant does not need to receive correct change. The participant can purchase additional items as long as the specified items are purchased. Examples of specific items may include bread, milk, laundry soap, or shampoo. These items do not need to be brand specific. The participant may ask for help from a store clerk. The participant needs to pick up more than one item to receive a score of 3.

10. States day, month, and year of birth.
Consideration (s): Ask the participant what day, month and year they were born.
- If the participant can never state the year but does remember the day and month of birth the score is a 0.
- If they can remember the day, month, and year of birth only once in a while, the score is a 1.
- If the participant can remember almost always the score is a 2.
- If the participant can remember the day, month, and year of his birth consistently, the score is a 3.

11. Uses a watch or a clock daily to do something at the correct time (for example, catch a bus or watch a TV program).
Consideration (s): The participant does not need to be able to tell time. The participant needs to be able to distinguish certain times that they need to know (such as when to leave for work, when to leave to go to a basketball game, shopping, going out with friends, to the library).

12. Correctly counts change from a five-dollar bill after making a purchase.
Consideration (s): If the participant cannot count change up to five dollars using dollars, quarters, nickels, dimes, and pennies the score is a 0. The participant must be able to determine the amount of change due back to them after making a purchase. This is a fundamental math skill requiring the participant be able to add and subtract small amounts.

13. Operates potentially dangerous electrical hand tools and appliances with moving parts (for example, a drill or a food mixer).
Consideration (s): The participant safely uses a variety of electrical appliances and hand tools and appliances, such as toaster, coffee maker, hair dryer, can opener, mixer, microwave, stove, oven, lawn mower, or weed eater, to receive a score of a 3. If the participant does not understand the potential dangerousness of using electrical appliances and/or hand tools the score is a 0.
14. Writes down, if necessary, and keeps appointments made at least three days in advance.
Consideration (s): The participant remembers the appointment that was made at least three days prior and keeps the appointment. Writing down the appointment is not necessary if they can remember.

15. Budgets money to cover expenses for at least one week (recreation, transportation, and other needs).
Consideration (s): The participant needs to budget multiple expenses.
- If the participant does not score (1, 2, 3) on task 12, correctly counts change from a five-dollar bill after making a purchase, the participant does not have the skill to budget money.

16. Works at a steady pace on a job for at least two hours.
Consideration (s): If the participant does not work at a job in the community, at school, in a workshop, or in the home the score is a 0.

17. Completes applications and interviews for jobs.
Consideration (s): The participant independently completes applications and interviews successfully for jobs to receive a score of a 3.

18. Receives bills in the mail and pays them before they are overdue.
Consideration (s): The participant needs to receive their bills and pay them independently before they are overdue. Payment can be made by mail or online to receive a score of 3.

Consideration (s): The participant writes checks, adds, and subtracts the balance in the checkbook register or computer and compares the total to the total on the bank statement.

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**Guidelines for Completing Problem Behavior Scale (Section E)**

A problem behavior is one which requires the attention of others in the participant’s environment to stop or minimize it. A problem behavior is something you feel compelled to address, stop, prevent or redirect. A problem behavior interferes with a participant’s everyday activities.

**Categories**

Each category on the ICAP includes six to twelve examples of behaviors that could be problems for some people. The examples of behaviors are only listed to define the category and should not be used as an all-inclusive list of problems. The problem behavior section of the ICAP classifies behaviors into the following eight categories:

1. **Hurtful to Self** - Problem behavior that inflicts physical injury to a participant’s own body and as a result requires immediate medical intervention and/or immediate staff intervention. If threats of self-harm are a problem, the threatening behavior is better recorded in another category.

2. **Hurtful to Others** - Problem behavior where a participant commits a physical act toward another person or animal that requires immediate intervention. If verbal threats of physical harm to others are a problem, this behavior is better recorded in another category, such as Socially Offensive Behavior or Disruptive Behavior.
3. **Destructive to Property** - Problem behavior in which a participant deliberately breaks, defaces, or destroys property. Accidental destruction of property is not a problem behavior. If threats of destroying property are a problem, this behavior is better recorded in another category, such as Socially Offensive Behavior or Disruptive Behavior.

4. **Disruptive Behavior** - Problem behavior that interferes with the activities of others or limits the participant’s opportunities to participate in everyday activities.

5. **Unusual or Repetitive Habits** - Problem behavior that involves stereotypical behaviors, excessive repetitive or unusual actions that interfere with a participant’s everyday activities.

6. **Socially Offensive Behavior** - Problem behavior that is offensive to the majority of other people.

7. **Withdrawal or Inattentive Behavior** - Problem behavior in which a participant has difficulty being around other people or paying attention. Expressing suicidal ideations may be considered here.

8. **Uncooperative Behavior** - Problem behavior in which a participant is being stubborn, contrary or obstinate and has difficulty in following rules or working with other people. Refusals to cooperate with rules, directives, medical treatment plans may be recorded in this category.

**Determining Problem Behaviors**

If the participant has a problem behavior, describe the problem and then select the category which best represents the problem. If the participant has more than one problem in a single category, choose the behavior that is most problematic as the primary problem. Do not write more than one example of problem behavior in any category. If the participant does not have a problem behavior in a category, write “none” and mark (0) Never for frequency and (0) Not serious; not a problem for severity.

If a very serious or an extremely serious problem behavior occurred more than a year ago, it may be rated based on the level of the behavior’s severity, providing the behavior meets all the bullets in the severity criteria. Examples include; arson, assault, murder, rape, molestation. The frequency of occurrence would then be rated as occurring less than monthly and would receive a score of 1.

The problem behavior section of the ICAP assesses problem behaviors exhibited. The goal is to identify the presence of more frequent or serious problems that may indicate poor personal and social adjustment that limits independence and requires attention similar to that required by a lack of specific adaptive behaviors.

- Problem behaviors limit independence and require attention similar to that required by lack of specific adaptive behaviors.
- The rating specifics are found in this section. Verbally explain to the interviewee what severity ratings require. For example, you could explain that **extremely serious, a critical problem** indicates that it may be life-threatening. To help interviewees understand the intended scope of the responses you may ask clarifying questions based on the Severity Scale. For example, you could ask, “Is this behavior life-threatening?”
For a participant currently receiving DD services you should review any Functional Behavioral
Assessment (FBA), Behavior Support Plan (BSP), Safety Plan documentation, and incident
reports.

Police reports and court records may provide pertinent information for anyone, regardless of
services received.

Problem behaviors can only be scored based on current conditions. If a highly structured environment or
the use of medications has reduced the frequency or severity of the behavior being rated, do not rate the
behavior based on what would happen if the supports were to be removed. Rate the behavior according
to how the behavior currently presents itself.

Behaviors that occurred within the last 90 days are used for determining if the behavior exists. If the
behavior did not occur within the last 90 days but has occurred within the last year, consideration is given
to rating the behavior if there is a formal behavior support plan in place addressing the problem behavior.

If a very serious or an extremely serious problem behavior occurred more than a year ago, it may be rated
based on the level of the behavior’s severity, providing the behavior meets all the bullets in the severity
criteria. Examples include; arson, assault, murder, rape, molestation. The frequency of occurrence would
then be rated as occurring less than monthly and would receive a score of 1.

**PRIMARY PROBLEM – Does the participant have this type of behavior problem?**

- The ICAP has eight categories of problem behavior, with examples listed within each category.
- The examples listed for these categories are only to explain what the categories mean and not
to suggest that they are a problem for a particular participant. Many behaviors, even if listed as
examples, may not be problems if they are mild, infrequent, or age appropriate.
- The examples given for each category of the Problem Behavior Scale may not include the
specific behavior of concern for a given participant. Respondents may describe other behaviors
that are not listed as long as they fall within the appropriate broad category.

**FREQUENCY – How often does this behavior usually occur?**

Mark one response that indicates how often the primary problem behavior occurs. The frequency of the
behavior is important, such as hitting people is worse if it happens ten times per day than if it happens
only once per month. **Prerequisite/Logical Connection:** Note that answers indicating a frequency of
greater than 0 (Never), must also have a corresponding answer indicating a severity of greater than 0 (Not
serious; not a problem) for that specific problem behavior.

Count the total number of episodes, based on the total of all behaviors occurring during waking hours in
all environments. Use incident reports, behavior tracking, etc. Verbal reports should not generally be
used.

- Count the actual number of occurrences, not potential occurrences.
- Count episodes of a behavior as a single occurrence.
- Count episodes as separate occurrences if they happen more than 10 minutes apart.
- Rate the behavior’s frequency based on its frequency during the most recent month. If it did not
occur every day, rate it as 1-6 times a week; if not every week, rate it as 1-3 times a month; if
not this month (but it is documented as still a problem), rate it as less than once a month.
Program data may be used to support information given in interviews.
• If the behavior occurs at least once every day (including weekends) but the frequency varies from day to day, rate the frequency on the majority of the days in the week.
• If the behavior occurs daily, but the frequency varies from hour to hour, rate the behavior as hourly if it occurs during more than half the hours in the waking day; otherwise rate it as daily.
• Regardless of how often an action occurs, if severity is rated a “0” then it has been determined that the action is not a problem behavior and its frequency must be rated “0”.
• If a behavior did not occur within the 90 day timeframe but is still documented as a problem it should be rated as “less than once a month” for frequency.

SEVERITY – How serious is the problem usually caused by this behavior?
Mark one response that indicates how serious the specific primary problem behavior is when it occurs. If the problem occurs in many environments, rate how serious that problem behavior is in the environment in which you most often observe or interact with the participant.

Factor interviews from different environments as well as documentation from all environments when making a determination. The bullets provided below are examples, not a required list of characteristics that must all first be observed before a behavior can be scored as a specific degree of severity.

0 – Not serious, not a problem
• Odd, eccentric, peculiar.
• Not everyone considers it to be a problem.
  o If you would rate the behavior a (0) for severity regardless of frequency, the behavior should not be listed as a problem, and therefore not be rated.

1 – Slightly serious, a mild problem
• Annoying, embarrassing, worrisome.
• Considered to be a problem, but only in one environment.
• Can usually be managed by common sense and a structured environment.
• Does not seriously limit activities.

2 – Moderately serious, a moderate problem
• Objectionable
• Unacceptable.
• A problem in more than one environment.
• Addressed by an individualized objective, with written procedures.
• Limits some activities.

3 – Very serious, a severe problem
• Frightening, repulsive, dangerous.
• #1 ranked individualized objective, with written procedures. Requires a formal, written Behavior Support Plan.
• Frequency reduced only with constant vigilance and a highly structured environment.
• Difficult or impossible for a single staff person to control when it occurs.
• Precludes some activities/environments that cannot be structured.
4 – Extremely serious, a critical problem

- May be life-threatening.
- Individualized objective and written record of every occurrence of the behavior. Requires a formal, written Behavior Support Plan.
- Frequency difficult to reduce.
- Consequences difficult to minimize.

Response to Problem Behaviors in any of the 8 Categories

At the end of the problem behavior section the respondent is asked about how problem behaviors are usually managed when they occur. Select the response to the most severe problem in the behavior section.

Comments

When applicable, include information regarding Functional Behavioral Assessments, Behavioral Support Plans, Safety Plans, and incident reports. Reference which of the 8 Categories involve reviewed documents.

General Scoring Considerations for Problem Behavior Section

**Behaviors requiring programing** — Per the Severity section, level 2 severity is “addressed by an individualized objective, with written procedures”. When reference is made to an “individualized objective” that usually refers to formalized habilitation training.

- Levels 3 and 4 also refer to individualized objectives, as well as a formal written Behavior Support Plan (BSP).
- Consider the rest of the clarifying information about what constitutes a score of 2, 3 or 4, behaviors that are scored with that level of severity to justify the score.
- Someone who does not have a specialized DD provider may not have the documentation required for a level 2 severity. If a school is rating at that intensity, it would be expected that they have some sort of written record. For someone coming into services, if a problem behavior is rated with a severity of 2 it will be expected that once they are receiving services the DD provider have a program in place to address the specific behavior.
- If it is clear from the supporting documentation that the team is trying options such as base-lining, environmental changes, planned intervention strategies before implementation of a formal behavioral support program, then it may be possible to rate a behavior in anticipation of the new program goal. It would be expected that data would indicate the frequency of the problem behavior. Severity of behaviors may be captured on incident reports.

**Behaviors that may be considered undesirable, but common in society, for example smoking or drinking** — Do not make a judgment of the behavior itself, but look at its actual effect on the participant’s independence.

- If a behavior is legal, albeit potentially harmful, for a typical person, it should not automatically be rated as a problem behavior.
- If a negative behavior results from the action, such as picking fights when drunk, that behavior may be rated on the Problem Behavior Scale.
- If a participant has been ordered by a physician not to engage in a specific behavior and they continue to do so, the behavior may be rated in Category 8 Uncooperative Behavior, for being uncooperative with treatment.
As always, severity should be rated strictly on the basis of actual outcomes, such as developing respiratory problems because of smoking.

**Clustered Behaviors**—Clustered or Concurrent Behaviors or Behavior Outbursts identify behaviors that usually occur together or within a few minutes of each other and should be considered to be a single problem and categorized as a single type. Do not list what is essentially one problem under more than one behavior category. Select the behavior category based on the behavior that is either the most frequent or is the most severe (evaluator discretion). Score the frequency and severity of the behavior based on that selection.

Example: On a daily basis a participant has behaviors that include refusals, screaming, stomping feet, and threatening to hit when asked or prompted to perform a task. Once a week the behavior escalates to include hitting. Record the primary problem as a behavior episode in the category describing how the behavior initially presents itself, in this example Uncooperative Behavior. In parenthesis, write the components of the behavior as they typically occur from beginning to end (refusals, screaming, stomping feet, threatening to harm, hitting). Rate the frequency as 4, One to ten times a day. Rate the severity using the severity guidelines based on the most severe component of the behavior, in this case hitting others. If the behavior category of Hurtful to Others is chosen as the primary problem category for this example, the frequency of the behavior would be scored a 3, one to six times a week as hitting is occurring once a week.

**Behaviors that may fall into multiple categories**—Look at immediacy and intensity when deciding what behavior to mark. For example, with arson: going to jail might be a long-term concern, but the immediate concern would likely be either harm to others or property destruction.

- The next consideration is intensity. In taking steps to prevent the behavior, what is the intensity of supports provided primarily due to? With the arson example: Are supports due to the potential harm to others or property destruction? The answer to that would likely be derived from the participant’s past behavior. If he or she targets abandoned buildings, then property destruction may be the primary concern. Otherwise, potential harm to others would likely be primary.

**Disabilities** Behaviors related to the participant’s disability should not be listed. Examples of this would be a person with autism who paces or a person with Prader-Willi syndrome who overeats. These are not behaviors that would necessarily respond to programming.

**Environmental factors**—For all of us, our behavior varies somewhat based on our situation. Generally our responses are not radically different from one environment to the next. We would consider this to be normal and consistent with our personality.

- If our behavior is radically different in a specific environment this is unusual and not merely a function of our personality. It is perceived that the difference was due to some aspect of that particular environment.
- When scoring the ICAP the participant cannot be rated in one environment more than one level below how they are rated in the better environment; this acknowledges that the participant actually has the skill to behave more appropriately.
- This does not shortchange the significance of the problem behavior, but minimizes the effect of environment.
Inability to learn/ Lack of adaptive behavior — This is not a behavior problem. Nor do behavior problems include behaviors that are chronologically age appropriate, such as a baby who cries or a toddler who repeatedly says “no” or digs in the cupboards.

Medication — If a participant exhibits a behavior, such as sleeping, due to a side effect of medications or health problems this should not be scored as a problem behavior. While it may appear to be inattentive behavior, such actions or reactions are beyond volitional control of the participant and should not be considered problem behaviors. If side effect behaviors are the only behaviors displayed under a category, the category should be marked “Never” under frequency of occurrence.

• Medication may, like in the adaptive section, assist the participant. Behaviors should be ranked as they actually occur regardless of medications which may affect their frequency or severity.

Vulnerability — Being vulnerable is not captured directly in the Problem Behavior section.

• “Putting self in unsafe situations” is not a specific observable behavior. If this is identified, you should ask the interviewee what this means.

Once a specific, observable behavior is identified, such as “walks into the street”, this can be categorized and rate.
Appendix P: Developmental Disabilities Criteria Crosswalk
<table>
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<tr>
<th>DD Defined (Statute)</th>
<th>Vineland</th>
<th>ABAS</th>
<th>ICF Level of Care</th>
<th>ICAP Reference Manual/Guidelines</th>
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ICAP Manual Table F, pp. 121-124

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For children under the age of 18, see ICAP manual Table F, pp.121-124 for an age in months specific criterion.
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<td><strong>ICAP Question</strong></td>
<td><strong>Learning</strong> C.1. Level of Intellectual Disability (Mark one) &lt;br&gt;1. No intellectual disability &lt;br&gt;2. Mild (IQ 52-70) &lt;br&gt;3. Moderate (IQ 36-51) &lt;br&gt;4. Severe (IQ 20-35) &lt;br&gt;5. Profound (IQ under 20) &lt;br&gt;6. Unknown, delayed, at risk</td>
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<td>Also see ICAP manual p. 11</td>
<td><strong>Mobility</strong> C.9. Mobility (Mark one) &lt;br&gt;1. Walks &lt;br&gt;2. Does not walk &lt;br&gt;3. Limited to bed most of the day &lt;br&gt;4. Confined to bed entire day</td>
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<td><strong>Mobility</strong> C.10. Mobility assistance Needed (Mark all that apply) &lt;br&gt;1. None &lt;br&gt;2. Needs assistive devices (can, walker, wheelchairs): &lt;br&gt;3. Occasionally needs help of another person &lt;br&gt;4. Always needs help of another person</td>
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<td>Also see ICAP manual p. 12</td>
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• If the participant needs assistive devices but does not require mobility assistance from another person on a typical day, do not mark either 3 or 4.

Economic Self-Sufficiency
G.2. Recommended change within next two years, if any (Mark one)
- 1. No formal daily program outside the home
- 2. Regular volunteer activities outside the home
- 3. School
- 4. Day care
- 5. Daytime activity center
- 6. Work activity center
- 7. Sheltered workshop
- 8. Supervised or supported on-site job placement
- 9. Competitive employment
- 10. Other
- 11. No change recommended

(pp.41-42) When considering Daytime Activity, select, in G.1 the environment where the participant spends the majority of time and mark this in the appropriate category on the ICAP. Mark one response in the next column that is a likely or needed alternate daytime placement within the next two years (for example, ISP team’s recommendation). If no change is recommended, mark, No change recommended.

- **No Formal Daily Program outside the Home:** Activities outside the residence include occasional social and recreational activities or shopping but no formal daytime habilitation program.
- **Regular Volunteer Activities outside the Home:** Regular volunteer work on at least one day a week outside the home environment.
- **School:** The participant attends a public or private educational program with certified teachers for people in the 3-21 age range. Use for local school programs, including public, private, and home schools.
- **Day Care:** The participant attends a program of social and leisure activities, usually for preschool children or elderly adults.
- **Daytime Activity Center:** The participant receives day habilitation services which consist of social, leisure or prevocational activities aimed at maximizing personal independence.
- **Work Activity Center:** The participant has a pre-vocational goal and participates in social activities and structured vocational training.
- **Sheltered Workshop:** The participant receives training and may work on an hourly or piece-rate basis.
- **Supervised or Supported On-Site Job Placement:** The participant receives prevocational training services and works under special supervision or with a special trainer at a competitive job site.
- **Competitive Employment:** The participant receives integrated vocational services and holds a regular job with other employees without disabilities at or above the legal minimum wage.

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## Appendix Q: Population Impact Adults and Children for Review

57 Adults identified to be on the cusp of eligibility
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### 24 Adults identified to not meet ICF LOC eligibility

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### 6 Children identified to be on the cusp of eligibility

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### 4 Children identified to not meet ICF LOC eligibility

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