Report on InterRAI DD Waiver Concerns & Recommendations

TO: Beneficiary Advisory Committee (BAC)
FROM: InterRAI Subcommittee of the BAC
DATE: Sept 17, 2026
RE: Comprehensive Report on Systemic InterRAI Assessment Concerns and Recommendations

1. Rationale for Committee

The BAC InterRAI Subcommittee was formed on July 16, 2026, following substantial public feedback during a presentation by Crystal Wheeler, Administrator of Eligibility and Enrollment for the InterRAI assessment. Public comments highlighted several unresolved issues, including instances where individuals did not receive pilot results, lack of data regarding appeal requests and completion rates, questions surrounding the use of the Case Mix Index (CMI) for funding decisions, internal adjudication of appeals within DHHS, factors considered in scoring (such as Therap, GERs, and FBAs), assessment execution for nonverbal individuals, and the appropriateness of using a "last 3 days" lookback window when behaviors persisted beyond that timeframe. The public comment period reflected significant emotional and procedural concerns from advocates, guardians, and providers.

Due to time constraints, the public comment segment was closed; however, the BAC voted to create a subcommittee to investigate these concerns and formally report back. This document fulfills that mandate.

2. Logistics of the Committee

The subcommittee consisted of statewide volunteers who completed an informal application process—either by submitting information through BAC/DHHS Leadership or by directly contacting the BAC/MAC chairs. Members completed a Request to Serve Form. The subcommittee was chaired by Mary Phillips (Chair of the BAC) and co-chaired by Phil Gray (Medicaid Advisory Committee). Committee members included Kathy Rohloff, Tori Sorensen, Scott Stemper, Adrienne Downs, Curt Safranek, Mike Brown, Jennifer Hansen (MAC), Cathy Martinez, and Renae Wacker (BAC). Representatives included members from the DD Advisory Committee, Autism Family Network, Disability Alliance of Nebraska, The Arc of Nebraska, B-lieve and Achieve Group Home, UCP of Nebraska, Ne APA Parent Caregiver Advocate, NEP-MAP (Nebraska Partnership for Mental Healthcare Access in Pediatrics), Olmstead Committee, ALL (Advocacy Leadership and Lived Experience) with Munroe-Meyer Institute, and the National Disability & Home Care Rights Coalition. Members serve in roles associated with mental health providers, Occupational Therapists, Psychologists, retired educators, special education administrators, and parent and guardian representatives.
Committee membership was formally presented on August 5, 2026, during the MAC/BAC

Executive Meeting.

Meetings were held on Tuesday evenings from 6:00 to 7:00 p.m. on 7/21, 7/28, 8/4, 8/11, 8/25, 9/1, 9/8, and 9/15 via Zoom. The platform was hosted by The Arc of Nebraska to avoid technical hosting challenges for BAC Leadership members who were not serving on the subcommittee.

3. Purpose of the Committee

Participation in the BAC Subcommittee provided a structured opportunity for current or former Medicaid members, guardians, independent providers, and caretakers to share lived experiences regarding the InterRAI assessment with the Division of Medicaid and Long-Term Care (MLTC). The primary objective was to identify core systemic concerns and present formal recommendations to the MLTC division.

4. Actions of the Committee

4.1 Key Findings and Systemic Concerns

On July 29, 2026, the subcommittee reviewed and categorized key operational issues within the InterRAI framework:

- **Appeal Process & Due Process Limitations:** Appeals are managed internally, where the Director approves decisions made by DHHS Legal, presenting a potential conflict of interest. The committee recommends establishing an impartial third-party review or Administrative Law Judge (ALJ) system (similar to Social Security) outside of district court, which currently forces beneficiaries to incur significant legal expenses to seek due process.
- **Adverse Action Notices:** Written notices explaining decision rationales are consistently missing or inadequate. Beneficiaries are often restricted to appealing procedural steps rather than substantive content. Additionally, when appeals are negotiated and withdrawn, individuals risk losing funding without further recourse. Adverse Action Notices were ensured with LB956 signed into law by then Governor Ricketts.
    - THE BILL SPECIFIES IN SEC 3 ITEM (2). THE INFORMATION THAT IS TO BE INCLUDED IN AND ADVERSE ACTION NOTICE.
      (2) The department shall notify an applicant for or recipient of medical assistance of any decision of the department to deny or discontinue eligibility or to deny or modify medical assistance. Except in the case of an emergency, the notice shall be mailed on the same day as or the day after the decision is made. In addition to mailing the notice, the department may also deliver the notice by any form of electronic communication if the department has the agreement of the recipient to receive such notice by means of such form of electronic communication. Decisions of the department, including the failure of the department to act with reasonable promptness, may be appealed, and the

> *appeal shall be in accordance with the Administrative Procedure Act.*
> *(3) Notice of a decision to discontinue eligibility or to modify medical assistance shall include an explanation of the proposed action, the reason for the proposed action, the information used to make the decision including specific regulations or laws requiring such action, contact information for personnel of the department to address questions regarding the action, information on the right to appeal, and an explanation of the availability of continued benefits pending such appeal.*

- **Lack of Person-Centered Planning:** Using InterRAI to establish level of care fails to satisfy person-centered planning mandates. Per federal requirements (42 CFR 441.301(c)(2)), service plans must reflect individual choices, functional needs, and settings that foster full community integration. Including regard to the individual's guardian availability to accommodate the assessment process.
- **Algorithm Appropriateness:** Questions remain regarding whether CMS or DHHS has properly evaluated the appropriateness of the algorithm for this specific population group.
- **Clinical Review Process Flaws:** While the InterRAI manual specifies a multidisciplinary clinical review team, the Nebraska implementation utilizes a single individual (a BCBA) focused primarily on behavioral analysis, lacking broader clinical expertise and operating outside of their core competency.
- **Changes in implementation rules:** The current rules feel very controlling; the public is not notified following administrative procedure changes as required under the Nebraska Administrative Procedures Act. Barriers exist to public participation or notification.

4.2 Case-Mix Index Evaluation

On July 30, 2026, the subcommittee received training on the Case-Mix Index (CMI) presented by Dr. Tori Sorensen, BS, PT, DPT, CEAS. This same presentation was provided to DHHS leadership. Comparative analysis between waivers revealed inequitable funding algorithms for individuals living in family homes. Committee findings suggest the algorithm, as applied by the state, functions as a budgetary allocation constraint rather than an objective assessment tool. While 403 Neb. Admin. Code ch. 2 § 008 states that a Case-Mix Index should not be used for "strict prescription of funding," current practice appears to violate this guideline, jeopardizing individual health and safety.

4.3 Summary of Arc of Nebraska Survey

On August 11, 2026, the subcommittee reviewed preliminary findings from an ongoing survey hosted by The Arc of Nebraska. Key findings include:

- **Inaccurate Assessment Results:** Respondents reported that InterRAI assessments fail to reflect true functional needs or safety requirements. Funding tiers were frequently reduced without functional improvement, guided by an opaque scoring algorithm.
- **Flawed Administration & Data Integrity:** Survey data highlighted missing diagnoses, unverified answers, clinical detachment, and the exclusion of guardians and advocates

from assessment sessions.

- **Inadequate Assessment Parameters:** The 3-to-7-day lookback window is insufficient to capture behavioral variability or complex developmental needs and disregards long-term medical documentation.
- **Notification & Communication Gaps:** Families cited missed appointments, last-minute cancellations, and failure to receive advance notice or clear information regarding assessment objectives and outcomes.
- **Assessor Training & Variability:** Assessor qualifications varied widely, with some receiving as little as two weeks of training. Assessors frequently failed to provide contact credentials or share scoring screens during evaluations.
- **Omission of Critical Care Factors:** Essential supervision requirements, behavioral escalation factors, and self-help deficiencies were regularly omitted, increasing health and safety risks.
- **Systemic Isolation & Advocacy Barriers:** Guardians reported feeling isolated and forced to navigate complex evaluation structures without guidance or support from state agencies or service coordinators.

4.4 DHHS Response Regarding Case-Mix Index Errors

On August 17, 2026, the subcommittee chair formally submitted inquiry questions regarding errors identified in the Case-Mix Index. DHHS responded on September 4, 2026. The exchange is summarized below:

Inquiry 1: *"With 7 errors in the 33 end buckets, this is a 21.2% change from the original Case Mix Index Research. How is Nebraska's model still reliable and valid with these many changes?"*

DHHS Response: *"Nebraska's code was accurate all along. The chart that interRAI posted was wrong – our algorithm codes were not built on that posted chart. We built ours off the information on page 5 of the article that shows the correct information. The InterRAI's CMI chart was inaccurate and we made aware of this. That is why we posted the updated CMI chart to reflect the accurate CMI scores. We did go back and look at the code and ensured that it was accurate and does correlate with algorithm code. When you look at page 5 of the interRAI publication, it shows that our corrected chart is accurate. We are not using the CMI that has the errors."*

Inquiry 2: *"Were these changes intentional? If so, what rationale were they based upon?"*

DHHS Response: *"There were no changes. It was a correction of the chart."*

Inquiry 3: *"Were these 'changes' the cause of the 3-4 cases that were overturned in appeal? If so, when was the problem discovered and has there been any changes as a result?"* **DHHS Response:** *"The overturned appeals were for procedural errors. We found the error and corrected our CMI shortly after implementing the interRAI in late summer of 2025. It was found while supervisors were doing their reviews. The errors that everyone basing this on - are not actual errors in our CMI algorithm because we used page 5 and those information is correct."*

Mislabeled Branches and Buckets: Despite the DHHS response, the *Page 5* reference in their response lists out the CMI number for each terminal "bucket." The problem is not that the CMI number does not match the listed terminal bucket label (see the table on page 5 that you refer to), the problems are listed below. The issues are in which branch goes to the specific labeled bucket. There are mislabeled branches and buckets that are switched in location. Some of the lines are also labeled incorrectly. This should come out in the upcoming evaluation.

The information below was presented to the Governor's DD Advisory Committee meeting on Sept 9, 2026 by Dr. Tori Sorensen, BS, PT, DPT, CEAS and Carol Salber, MS, LIMHP. Nebraska's algorithm is on the left and the research article algorithm is on the right.

Nebraska's Case Mix Index

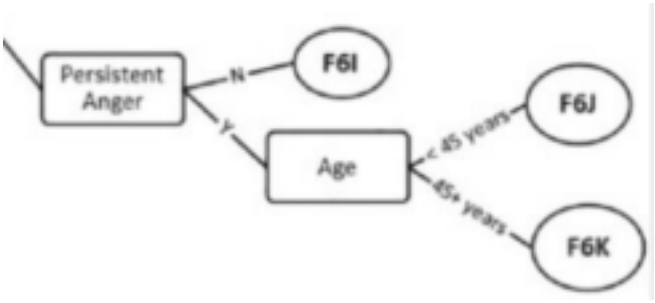


https://dhhs.ne.gov/DD%20Documents/interRAI%20Case%20Mix%20Groups.pdf

InterRAI Case Mix Index Research

Fries BE, James ML, Martin L, Head MJ, Park PS. A Case-Mix System for Adults with Developmental Disabilities. Health Serv Insights. 2019 Jun 25; https://pmc.ncbi.nlm.nih.gov/articles/PMC6593926/

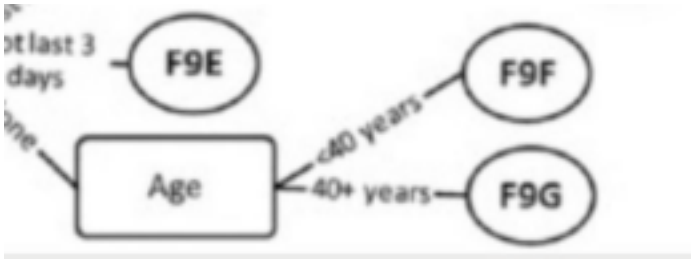
F6 Branch Error-has 3 errors of unknown significance



F9 Branch Error-causes a funding problem

Functional Hierarchy 9-11 → Left Home → no → Outburst of Anger → none → Age

Wasteful Wayne-<40 years old, (F9G in Nebraska) ends up getting High funding even though that is not supported by the research that Nebraska DHHS has said is reliable and valid; this is a WASTE of $67,942.67 FOR EACH INDIVIDUAL
Wanting Wanda->40 years old, (F9F in Nebraska) ends up getting Intermediate funding instead of High funding, losing $67,942.67 of funding that the research says she





needs for her care

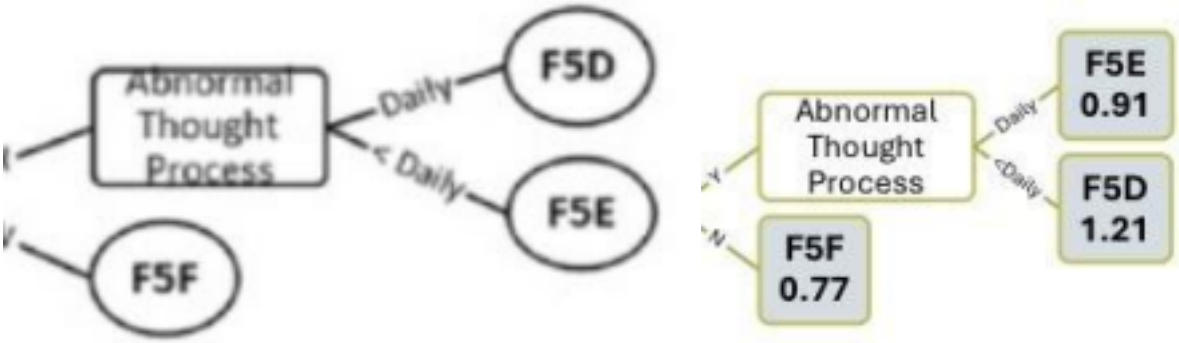
F5 Branch Error-causes an eligibility problem

Functional Hierarchy 5 → Physically Abusive → no → Communicates Verbally → yes → Irritability → yes → Abnormal Thought Process

* Eligibility information determined according to FOIA request, as DHHS has not been transparent about the methods to determine funding (as best as we can determine)

Homeless Heather (F5E in Nebraska) does not have the Informal Support Available domain triggered and could lose continuous residential habilitation and/or be placed in DDAD (day supports waiver) instead of CDD (comprehensive waiver)

Lottery Larry (F5D in Nebraska) triggers the Informal Support Available domain inaccurately and could be given extra waiver services that they do not qualify for according to DHHS Nebraska



4.5 Documentation Access Constraints

On August 28, 2026, the subcommittee requested copies of the current Nebraska InterRAI Manuals for adults and children. On September 4, BAC Leadership responded: *"Due to copyright issues and a limited number of InterRAI manuals that the state owns, we are unable to share a copy of the manual with the subcommittee."* While the committee subsequently acquired a copy through private sources, these restrictions severely restricted the subcommittee's capacity to evaluate internal consistency within the InterRAI and CMI frameworks.

Evaluating the systemic impact of InterRAI remains challenging due to internal administrative inconsistencies and the application of population-wide CMI averages to dissimilar groups.

Furthermore, the committee holds significant concerns regarding reported statistics on InterRAI's impact. Data currently presented reflects informal state reviews conducted outside the standard appeals framework. While the committee acknowledges state attempts to prevent harm, evidence indicates that current InterRAI and CMI applications pose ongoing risks across both DD and A&D waivers.

Discrepancies/inconsistencies between Nebraska's interRAI manuals and the original interRAI manuals compromise both the scientific standardization and the statistical validity of the system.

Nebraska DHHS modified the algorithm rules, made critical errors in inputting the data tables, and programmed the flowcharts in a way that actively deflates individual care scores.

5. Recommendations

1. **Competitive Request for Proposals (RFP):** The committee strongly supports the Nebraska Department of Health and Human Services (DHHS) decision to issue a formal RFP selecting an independent firm to evaluate the state's utilization of the InterRAI assessment tool for Developmental Disability (DD) Waivers. Transitioning away from a sole-source contract via an open, transparent review will help to restore stakeholder and legislative confidence.

2. **Implementation of a Hold-Harmless Period:** The committee recommends an immediate, temporary hold-harmless period to protect the health and safety of each participant.

3. **Stakeholder Involvement in the RFP/Evaluation Process:** In light of concerns expressed by families and advocates within the DD community, the BAC InterRAI Subcommittee recommends incorporating informed stakeholders into this process to ensure maximum transparency and maintain the highest standards of evaluation. The subcommittee nominates the following individuals to participate in the RFP process, the
independent evaluation of the assessment tool, and its subsequent implementation: Tori Sorensen, Adrienne Downs, Kathy Rohloff, and Curt Safranek.

4. **Adverse Decision Exception Process:** The BAC InterRAI Subcommittee recommends establishing an adverse decision exception process to collect data and provide appropriate timely relief on funding and/or specific waiver decisions to maintain health and safety on an individual participant basis. This would be an interim solution for

participants to have immediate relief while district court cases are processed and the independent review is completed. We believe this is essential as there is imminent risk to human life with the current system that individual agencies cannot rectify due to individual needs vs budgetary limitations from DHHS. Crucially, this exception process should incorporate external oversight by community members with clinical expertise, operating independently of DHHS.