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Independence • Inclusion • Empowerment

Re: Special Board Meeting – July 13, 2026
Subject: NCI 2023–2024 Reports

Date: July 16, 2026

To Whom it may concern,

This letter is submitted in reference to the Special Board Meeting held on July 13, 2026, during which the Board reviewed findings from the National Core Indicators (NCI) 2023–2024 reports, including the Adult Family Survey (AFS), Child Family Survey (CFS), and Family/Guardian Survey (FGS).

The NCI survey is a voluntary national initiative used by state developmental disability agencies to assess system performance and outcomes for individuals with intellectual and developmental disabilities (I/DD). It serves as a critical tool for evaluating the quality of services, identifying disparities, and informing strategic planning efforts.

The NCI FY 2023–2024 presentation on July 13, 2026, provided an overview of three primary surveys used to collect data, the AFS, the CFS, and the FGS, and included an opportunity for public input to gather feedback, perspectives, and concerns from participants regarding the findings.

The State Council on Developmental Disabilities was not present at the meeting. No public input was received.

Caregivers have reported to IRC that the NCI AFS, CFS, and FGS are lengthy and often feel repetitive, covering similar topics multiple times, which can contribute to survey fatigue. Many also report that some questions are unclear or too technical, making them difficult to interpret, particularly for families with limited English proficiency. Caregivers have also expressed concern that completing the survey does not always lead to visible or immediate improvements, which can reduce motivation to participate. These concerns are important to consider, especially given that participation is voluntary and results may not fully represent the experiences of all families.

The presentation identified several IRC specific findings, including significant concerns related to ongoing challenges in language access and communication, particularly as they

relate to the survey process and engagement with the Deaf and Hard-of-Hearing (DHH) community served by IRC. Notably, the data reflected extremely low reporting of American Sign Language (ASL) use among survey respondents. This finding raises concerns that current NCI outreach strategies and survey methodologies may not effectively capture the experiences of DHH individuals. As a result, the data may lack reliability and inclusiveness, limiting its usefulness for equitable planning, policy development, and service improvement efforts.

These concerns are not new and reflect a persistent, multi-year pattern identified in prior NCI public input reports and listening sessions. In the FY 2020–2021 public input report, IRC explicitly noted that no clients who use ASL or identify as DHH were included in the survey sample, and that culturally competent ASL outreach materials were lacking, resulting in limited engagement from the DHH community. Similarly, in the 2019–2020 Family/Guardian Survey public input report, IRC again identified a lack of culturally appropriate marketing and outreach to the DHH population, as well as broader underrepresentation of low-frequency language groups in survey participation.

More recently, the FY 2021–2022 listening session and public input report reaffirmed these concerns, noting that DHH individuals did not participate in the survey process and may be effectively excluded due to ASL barriers. The report further highlighted that ASL was not included in survey marketing materials, limiting accessibility for individuals who rely on a visual language without written or spoken components. Additional barriers included lack of awareness of the survey within the Deaf community, inaccessible outreach strategies, and insufficient use of ASL interpretation or culturally appropriate communication formats.

Collectively, these findings demonstrate that the current concerns regarding DHH representation in the 2023–2024 NCI data reflect a longstanding and systemic issue. Despite ongoing recognition of these barriers, DHH individuals, particularly ASL users, continue to be underrepresented in NCI survey data. This persistent gap is especially concerning within the IRC catchment area, which encompasses Riverside and San Bernardino counties, regions known to have a significant and diverse DHH population.

The discrepancy between the known presence of DHH individuals in the IRC community and their limited representation in survey findings suggests that current outreach, accessibility, and data collection methods are not adequately reaching or engaging this population. As a result, the data may not fully capture the lived experiences, needs, and service barriers faced by DHH individuals served by IRC.

This ongoing underrepresentation underscores the urgent need for the State Council on Developmental Disabilities (SCDD) to implement targeted and sustained improvements in

outreach strategies, survey accessibility, including ASL-inclusive methodologies, and culturally and linguistically appropriate engagement practices. Strengthening these efforts is essential to ensuring the equitable inclusion of the DHH community in future assessments, planning processes, and system improvements, particularly within the IRC service region.

Another significant issue highlighted in the Child Family Survey is the low response rate at IRC, approximately 7%, despite the region serving one of the largest populations in the state. This low level of participation creates a substantial risk that key populations, including non-English-speaking families, rural communities, DHH individuals, and other underserved groups, are underrepresented. As a result, the data may not fully reflect the diversity and complexity of IRC's service population, potentially affecting the accuracy of decision-making and quality improvement initiatives.

Geographic disparities also contribute to inequities in service delivery. Approximately 11% of IRC's population resides in rural areas, presenting unique challenges such as longer wait times, fewer provider options, transportation barriers, and difficulty accessing respite and specialized services. These barriers further affect emergency preparedness and overall service access, particularly in regions prone to wildfires, power outages, and other environmental risks.

Communication challenges between families and case managers were also identified as an ongoing concern. Families report difficulty reaching case managers and concerns regarding coordination among service providers. These issues are often compounded by language diversity, geographic factors, and increased demand for responsive communication during crises or emergencies. Such barriers may negatively impact service planning, responsiveness to changing needs, and overall satisfaction with services.

Emergency preparedness continues to be identified as an area of concern, despite IRC's significant investment in disaster preparedness training and outreach over the past five years, suggesting that additional strategies may be needed to ensure effective reach and impact across all populations served.

Families report needing additional support in planning for emergencies, with IRC facing heightened risks due to its geographic conditions. This is particularly critical for families who are non-English speaking, living in rural or high-risk areas, or supporting individuals with complex medical conditions, as these groups are disproportionately affected during emergencies.

Workforce shortages and service gaps were also highlighted as major barriers to effective service delivery. These challenges include a shortage of qualified providers, limited

availability of bilingual and culturally competent staff, and delays in accessing essential services such as applied behavior analysis (ABA), respite care, and behavioral supports. These workforce limitations disproportionately impact underserved communities within IRC's service area.

Despite these challenges, the presentation also identified areas of strength. IRC demonstrates strong residential stability, with approximately 68% of individuals living in the same placement for over five years, slightly above the statewide average. This reflects consistency in housing support for individuals receiving services. However, the data also indicate areas for improvement, including expanding independent living opportunities, enhancing access to community-based support, and addressing disparities in service delivery.

The presentation concluded by outlining IRC's 2026–2031 Strategic Framework, which prioritizes communication reform, equitable access, workforce development, vendor network stabilization, and trust-building with the community. These priorities are intended to reduce disparities, strengthen system capacity, and improve outcomes for the individuals and families served.

These strategic priorities provide a critical framework for addressing the concerns identified in the NCI findings. The focus on communication reform is directly aligned with addressing language access barriers and improving consistency in information sharing. Expanding multilingual communication systems, including ASL accessibility, standardizing interpreter services, and improving translated materials will be essential to ensure that all individuals and families can fully participate in services.

Similarly, the emphasis on equitable access addresses disparities affecting rural communities, underserved populations, and underrepresented groups. Increasing outreach, improving survey participation, and ensuring accessibility regardless of geography or language will enhance both service delivery and data accuracy. Workforce development efforts further support this work by addressing shortages of bilingual, culturally competent, and ASL-fluent staff, while improving coordination and reducing service delays.

The strategic priority of vendor network stabilization directly responds to service gaps, particularly in rural and underserved areas, by expanding provider availability, increasing access to specialized services, and reducing wait times. Additionally, the focus on trust-building and community engagement is essential to improving participation and representation, strengthening relationships with underserved communities, and ensuring services are responsive to community needs.

In summary, IRC's strategic priorities establish a comprehensive approach to addressing systemic issues identified in the NCI data, including language access barriers, DHH underrepresentation, workforce limitations, and geographic disparities. With intentional and measurable implementation, these efforts provide an opportunity to improve equity, strengthen service delivery, and enhance trust and outcomes for all individuals and families served.

Sincerely,

Lavinia Johnson

Lavinia Johnson, Executive Director

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