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September 10, 2024

Governor Gavin Newsom  
1021 O Street, Suite 9000  
Sacramento, CA 95814

**RE: AB 1147 (Addis), as amended August 22, 2024 – Issues and Concerns**

Honorable Governor Newsom:

The Association of Regional Center Agencies (ARCA) represents the network of 21 community-based non-profit regional centers that coordinate services for, and advocate on behalf of, approximately 450,000 Californians with developmental disabilities. On behalf of ARCA, I wish to share our issues and concerns regarding AB 1147 (Addis), that deserve attention and appropriate resolution.

This bill would subject regional centers to the California Public Records Act (PRA) starting January 1, 2026. ARCA and its member regional centers have and continue to support increased transparency into regional centers' decision-making processes but do not believe the PRA is the appropriate avenue for achieving this goal considering the following:

- Implementation costs associated with this new mandate, which ARCA estimates at \$9.9M per year for regional centers;
- The complexity of balancing privacy with public information in Medicaid-funded services; and,
- Avenues already available for accessing granular and systemic information.

For the above reasons, ARCA opposes this new mandate.

ARCA conservatively estimated this will cost regional centers nearly \$10M per year for the regional center system statewide to hire the necessary new, specialized staff. The Administration's overall cost estimate for implementation of this provision was substantially higher. In addition to potentially significant legal fees arising from disputes about whether requested information is subject to PRA, ARCA's estimated costs include the following staffing for each regional center: 1) Public Information Officer (CEA III); 2) Legal Analyst; 3) Technical Data Staff; and, 4) Administrative Assistant. The calculation of regional center costs to respond to PRA requests is not tied to the volume of requests anticipated, but rather, the new positions that must be created and filled with entirely new types of staff, to be able to respond at all. The sponsors have said these costs could be offset by charging to produce records, but that is inadequate given statute does not allow agencies to recover payment for staff time for compiling records and fundamentally unfair to those without means.

Those served by regional centers and their families have guaranteed access to their own records upon request. Critical information about the types, volume, and cost of services provided each year and documentation regarding future goals and services are provided automatically to each individual and

those supporting them. Regional centers also maintain large volumes of information about individuals from other sources, such as other social services agencies, schools, and doctors.

It should be noted that complying with PRA requests has an added challenge, in that the majority of non-aggregated regional center data contains protected health information covered by the Health Insurance Portability and Accountability Act (HIPAA) or Welfare and Institutions Code (WIC) §4514. Due to the extreme sensitivity of developmental services records, WIC §4514 extends protections that exceed federal HIPAA standards. It is common for many types of records to refer to multiple individuals. ARCA has heard directly from families their wariness about others having access to information specific to their loved one. This is a theme that has been echoed during broader public conversations about California’s developmental services system. Regional center staff do not have the necessary expertise in data de-identification standards and techniques to prevent the unintentional release of personal information through missed redactions or other errors.

Unlike most private entities, information about regional center operations, purchases, and those served is provided on a regular basis to a state department, including daily information about individuals they support. Due to its extensive audits and ongoing communications with regional centers, the Department of Developmental Services (DDS) has comprehensive information about regional centers’ operations. DDS is already subject to the PRA and has the infrastructure in place to respond to hundreds of PRA requests annually. It also posts vast amounts of information on its own website.

Additionally, regional centers are required by multiple parts of state law, state regulation, and contract with DDS to make the following information, data, and policies freely and readily available on their websites:

<b>Subject</b>	<b>Collecting Statute*</b>	<b>Reporting Statute*</b>	<b>Required per RC Contract</b>
Appeals	WIC §4704.6	WIC §4704.6	No
Audits	WIC §4639(a)	WIC §4629.5 (b)(1)	RC Contract Article I, Section 19 b. 1)
Bi-Annual Fiscal Audits	WIC §4629.5 (b)(2)	WIC §4629.5 (b)(2)	RC Contract Article I, Section 19 b. 2)
Board Meeting Agendas and Approved Minutes	WIC §4629.5 (b)(7)	WIC §4629.5 (b)(7)	RC Contract Article I, Section 19 b. 7)
Board Member Rosters	Recommended, not Required	Recommended, not Required	No
Community Resource Development Plan - Approved Proposals	WIC §4679 (d)	WIC §4679 (e)	No
Community Resource Development Plan - Priorities for Community Discussion	WIC §4679 (c)	WIC §4679 (c)	No
Conflict of Interest Policy - Board Approved	WIC §4626.5	WIC §4626.5	No
Conflict of Interest Reporting	Title 17 §54533 (f)	Title 17 §54533 (f)	No

Statements			
Contract Awards	WIC §4629.5 (b)(4)	WIC §4629.5 (b)(4)	RC Contract Article I, Section 19 b. 4)
DDS Dashboard – Quality Assessments	WIC §4572	WIC §4572	No
HCBS Final Rule	WIC §4519.2 (b)(1)	WIC §4519.2 (b)(1)	No
HCBS Waiver Program Review	Multiple Statutes	WIC §4629.5 (b)(10)	RC Contract Article I, Section 19 b. 10)
List of Services	WIC §4629.5(d)	WIC §4629.5 (b)(14)	RC Contract Article I, Section 19 b. 13)
Managerial Salaries, Wages and Benefits	WIC §4629.5 (b)(15)	WIC §4629.5 (b)(15)	RC Contract Article I, Section 19 b. 14)
NCI Quality Assessments - Data Reports	WIC §4571 (h)(2)	WIC §4629.5 (b)(16)	RC Contract Article I, Section 19 b. 15)
NCI Quality Assessments - Meeting Notice	WIC §4571 (h)(1)	WIC §4571 (h)(1)	RC Contract Article I, Section 19 b. 15)
NCI Quality Assessments - Report to DDS	WIC §4571 (h)(3)	WIC §4571(h)(3)(B)(i)	No
Performance Contract - New Year	WIC §4629	WIC §4629.5 (b)(9)	RC Contract Article I, Section 19 b. 9)
Performance Contract - Year End	WIC §4629	WIC §4629.5 (b)(9)	RC Contract Article I, Section 19 b. 9)
Performance Contract - Year End Meeting Notice	WIC §4629 (f)(1)	WIC §4629 (f)(1)	No
POS Policies	WIC §4629.5 (b)(5)	WIC §4629.5 (b)(5)	RC Contract Article I, Section 19 b. 5)
Protection and Advocacy Agency	WIC §4519.2 (e)	WIC §4519.2 (e)	No
Purchase of Service Data Collection - Data	WIC §4519.5 (a) and (b)	WIC §4519.5 (c)	RC Contract Article I, Section 19 b. 17) and Article VII, Section 6
Purchase of Service Data Collection - Meeting Notices	WIC §4519.5 (e)	WIC §4519.5 (e)	No

All regional centers now have a uniform button on the home page of their websites that takes visitors directly to this information.

If there is specific information not yet publicly available that would be helpful for transparency and decision-making, ARCA is willing to explore alternative means to fill the identified gap. For instance, given the sponsors' expressed interest in ensuring public access to greater details about how service delivery decisions are made, ARCA proposed in its August 22, 2023 letter on this bill an expansion of WIC §4629.5(b)(5) that would require regional centers to post on their websites "purchase of service policies and any other policies, guidelines, or regional center-developed assessment tools used to determine the service needs of a consumer." This would be a cost-effective and equitable way to achieve this worthy

outcome. Additionally, ARCA proposed a guarantee of individual access to their own records within 15 business days, which again, could be achieved without an additional appropriation.

We deeply appreciate the Administration's commitment to improving the lives of Californians with developmental disabilities and their families. This is particularly evident in the Master Plan for Developmental Services process, which is currently tackling questions about those systemic reforms, both big and small, that would improve services for those served by regional centers and their families. We look forward to continuing to work with you, your staff, the Legislature, and countless stakeholders to support the thoughtful evolution of California's developmental services system.

If you have any questions regarding our position, please do not hesitate to contact me directly at [awestling@arcnet.org](mailto:awestling@arcnet.org) or (916) 877-4148.

Sincerely,

/s/Amy Westling  
Executive Director

Cc: Assemblymember Dawn Addis  
Julianne Cravotto, Legislative Director, Office of Assemblymember Addis  
Angela Pontes, Chief Deputy Legislative Secretary, Governor's Office  
Mark Ghaly, Secretary, Health and Human Services Agency  
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