

# Engaging Underserved Communities to Address Chronic Inequities in Accessing DD Services in California Related to Race, Ethnicity, and Language



Roxanna Topete, J.D. Equity & Diversity Fellow 2017-2018

## The Issue

For over 20 years in the state of California, there have been Purchase of Service (POS) disparities affecting multiple communities of color. POS disparities occur when members of certain racial, ethnic, linguistically diverse communities are not receiving POS dollar amounts as comparable to white clients with the same needs, leading to inequities for these communities.

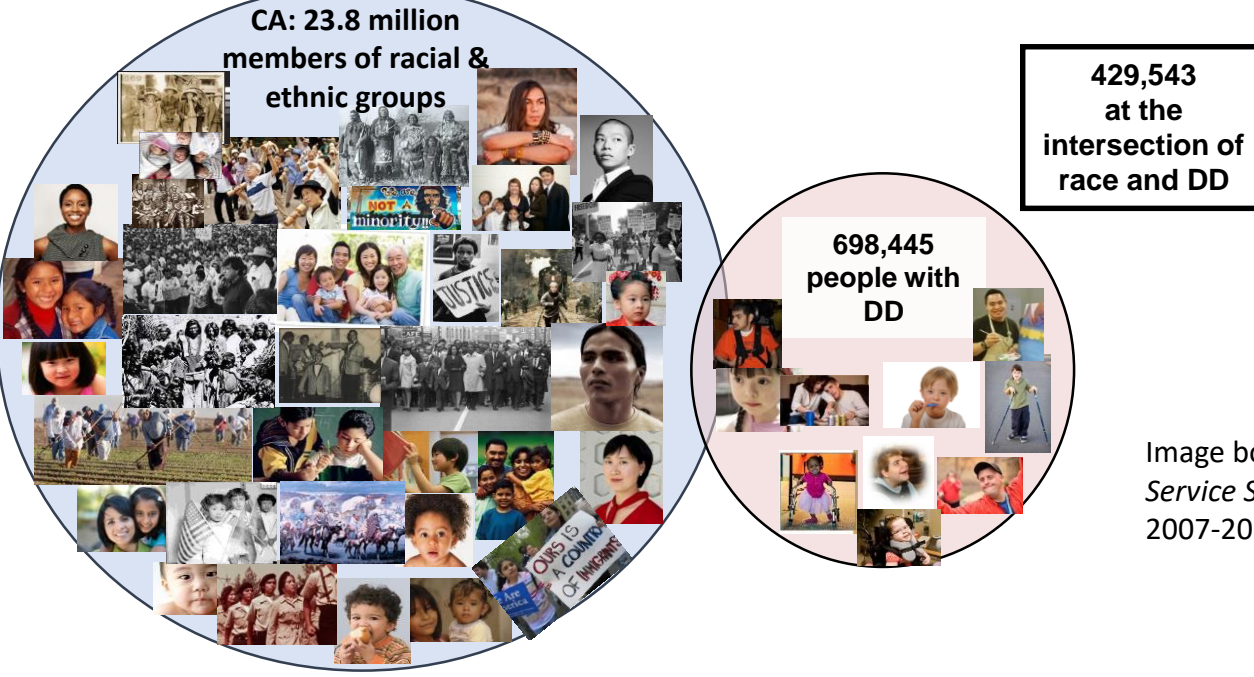


Image borrowed from a presentation "An Orientation to the DD Service System" to CA-LEND students by B. Wheeler, USC UCEDD, 2007-2017.

## Regional Centers

California currently has 21 Regional Centers (RC) that were established after the Lanterman Developmental Disabilities Act (entitlement legislation) passed in 1969, making RCs centralized points of contact for persons with developmental disabilities (DD) and their families.



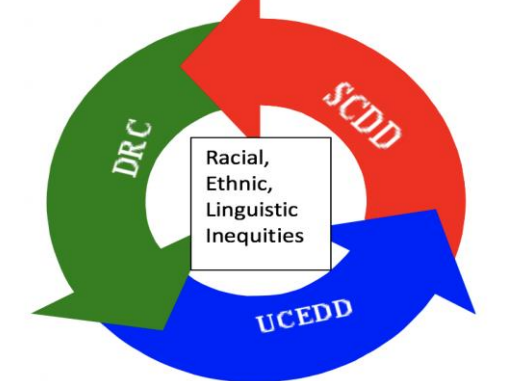
The current budget is 4.5 billion dollars to provide services for Developmental Disabilities (DD) in California alone.

If a consumer of a RC has a need for a particular service identified in their Individual Program Plan (IPP), the RC must first attempt to fund it through a generic funding source (e.g. Medicare).

If there is not a generic funding source available, a part of RC budgets includes funds to pay for needed services for consumers, called POS dollars.

## The Solution

The Developmental Disabilities Assistance & Bill of Rights Act (DD Act) authorizes and funds 3 agencies (University Centers for Excellence in DD (UCEDD), Protection and Advocacy Agencies (P & A's) and the State Council on DD (SCDD)) in every state to utilize different methods and to work together to address issues and barriers facing individuals with I/DD who are underserved by the system.



Borrowed from a presentation "An Orientation to the DD Service System" to CA-LEND students by B. Wheeler, USC UCEDD, 2007-2017. Figure represents the power of each partner working individually and together to create the synergy solution.

The CA DD Network Partners working on this issue include the University of Southern California (USC) UCEDD, Disability Rights California (DRC), and the SCDD

## Disability Rights California



Image borrowed from <https://www.disabilityrightscalifornia.org/public-policy>. I worked with Attorney Evelyn Abouhassan, 3<sup>rd</sup> person on the right.

DRC is the designated P&A in California. DRC's method for change is to advocate, educate, investigate, and litigate to advance the rights, dignity, equal opportunities and choices for all people with disabilities.

### \*DRC's Passage of WIC § 4519.5 Trailer Bill Language (TBL)

With respect to addressing POS disparities, DRC was critical to the success of creating a pathway for change by successfully passing WIC § 4519.5 TBL. The new TBL required that the California Department of Developmental Services (DDS) and RCs work together to annually publish data on their websites relating to POS dollars authorized, expended, and utilized by client age, type of disability, and race, ethnicity, language, and to convene a public meeting within 90 days of these postings to discuss the data. Once this was passed, the other DD Network Partners (USC UCEDD and SCDD) jumped in.



UCEDDs are based at Universities and their method for change is through training, community services, research and evaluation, and policy development. The USC UCEDD specializes in addressing racial, ethnic, and linguistic disparities for persons with I/DD.

### USC UCEDD's Information Dissemination and Capacity Building

In response to complaints from parents of color groups sharing that they could not understand the data posted on RC websites (see Table 1), the USC UCEDD converted the RC posted data into figures and charts (see figs. 2 & 3) which could be more easily understood by parents. Additionally, the USC UCEDD collaborated with parents of color groups in LA County (Fiesta Educativa, Inc. (FEI) and the Chinese Parents Association for the Disabled (CPAD)) to prepare parents to testify at the yearly POS public hearings.

### Community Services/Technical Assistance

In 2017, because of limited funding, a decision was made with the SCDD, to train the managers and staff of the 12 Regional Offices of SCDD to replicate the methodology used by USC UCEDD. Additionally, the USC UCEDD with partners FEI and CPAD, provided training on "Outreach to Underserved Communities" to the staff of the 21 Clients' Rights Advocacy offices and to the Outreach Units of DRC.

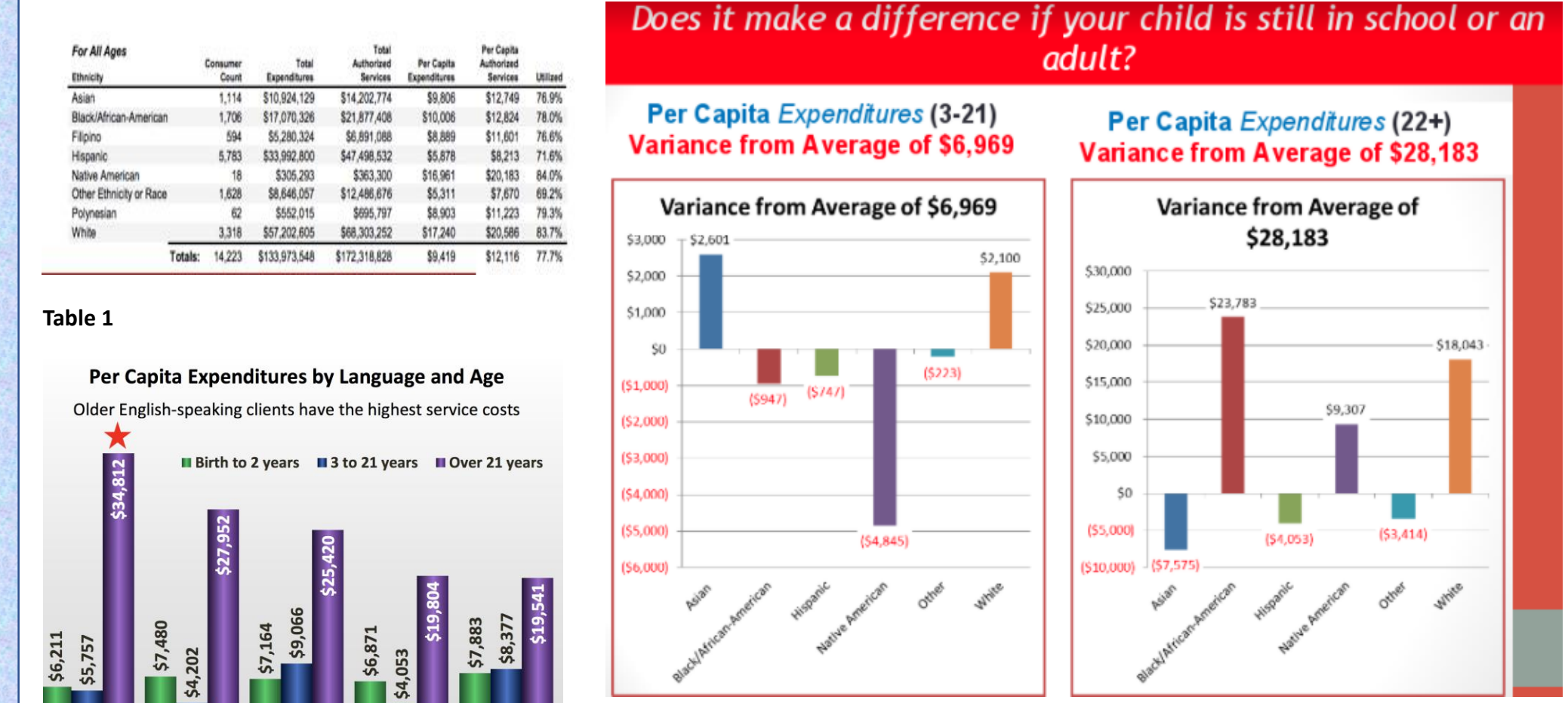


Fig. 2 From ppt presentation entitled "Training for SCDD Regional Managers on Educating Minority Communities about POS Disparities in Regional Centers and assisting them to participate in Public Hearings" by B. Wheeler, I. Diaz, F. Goldfarb, USC UCEDD, 1/16/17.

### Fig. 2 Explained

- White families get significantly more purchase of service dollars than the average dollars spent on all RC clients.
- Disparities between white and ethnic groups varies depending on whether the child is still in school or out of school.
- For Adults 22 and older, White clients get **\$18,403 MORE** and Black clients get **\$23,783 MORE**, and Native American clients get **\$9,307 MORE** than the average.
- In contrast Asian clients get **\$7,575 LESS** than the average, Hispanic clients get **\$4,053 LESS** than the average. Said another way, the Average per capita expenditure for White clients is **\$46,226/yr** and the Average per capita expenditure for Asians is **\$20,608/yr** and **\$24,130/yr** for Hispanics for this particular RC.
- Not shown here is the additional disparity associated with speaking other languages, for those whose primary language is Spanish, and Southeast Asian (Vietnamese).

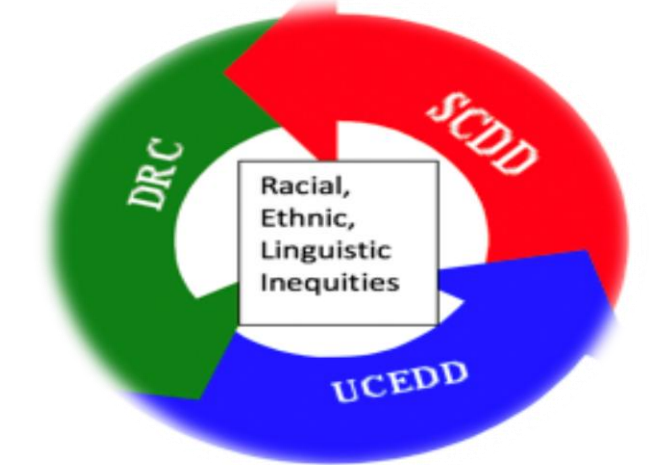


SCDD is established by both federal (the DD Assistance and Bill of Rights Act) and state law (the Lanterman Act) as an independent state agency to ensure that Californians with DD and their families receive the services and supports they need. SCDD does this through promoting advocacy, capacity building, and systemic change in CA through a governor-appointed State Council and through 12 Regional Offices.

### Converting Data into Charts

SCDD's role is critical to the long-term sustainability of this effort because of its presence throughout the state, providing access to clients served by all 21 RCs. Now it is up to SCDD to continue using the methodology used by USC UCEDD.

**When the DD Network Partners collaborate in responding to a single problem, i.e. POS Disparities, this creates a powerful synergy that could not be achieved as individual agencies.**



## Much More Than A Fellowship

This fellowship gave me a tremendous amount of opportunities to actively engage with my surrounding communities including:



- Working with attorney Evelyn Abouhassan on updating bill letters: Support for AB 2331 Medical Redetermination Developmental Disability, Opposition for SB 1011 Proceeding to Establish Limited Conservatorship, and Support for SB 354 Special Education IEP Translation Services.

Attending a Developmental Disabilities (DD) Budget hearing in Sacramento and giving my first public comment at a state hearing.



- Attending the California Medical Association 44<sup>th</sup> Annual Legislative Advocacy Day, April 17<sup>th</sup>-18<sup>th</sup>, where I spoke to Senator Anthony Portantino on the importance of passing AB 1894: College Student Hunger Relief Act.



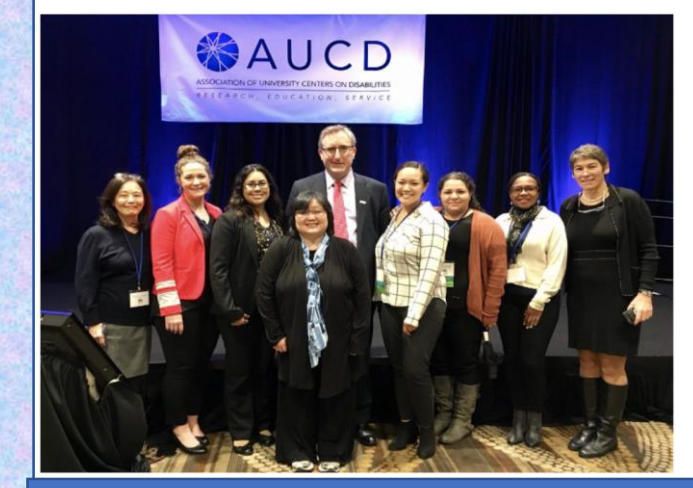
- Worked as a Quality Assessment Project Interviewer for the State Council on Developmental Disabilities which allowed me to interview 38 adults with mild to severe Intellectual/ Developmental Disabilities.
- Successfully completing CA-LEND training.



## Special Thanks

Special thanks to my supervisor, Dr. Barbara Wheeler, who has invested her time, energy, and resources to educate me in this field.

Special thanks to the USC UCEDD-CA Lend Training Team for their awesome commitment to teach and mentor us from a variety of professions towards a common cause.



Special thanks to AUCD for granting me a scholarship to be here again and Christina Liao for connecting me to some really great people and resources.

## Acknowledgments

This project was funded by a grant to the USC UCEDD at Children's Hospital grant #90DDTI0003-01-00 DHHS, Administration on Community Living, UCEDD Education, Research, and Service National Training Initiatives, Diversity Fellowship and Partnership planning.

