



# REALITY CHECK

Contact: Judy Mark, President, 310-621-2045  
judymark@dvunited.org      disabilityvoicesunited.org

## Efforts to Reduce and Eliminate Disparities from the Self-Advocate & Family Perspectives Provided to the Senate Budget Subcommittee #3, Health & Human Services March 15, 2018

### Executive Summary

---

In response to a scathing 2013 *Los Angeles Times* article on racial and ethnic disparities in services for individuals with autism, the California legislature directed the state's regional centers to publicly report the amount of money spent on services. The results showed system-wide dramatic disparities with Latinos, blacks, and Asians generally receiving between half to two-thirds as much as whites. Regional Centers were also instructed to make changes to reduce these inequities.

Shining a light on the disparities should have caused the regional centers to improve, but, over five years, the data showed that no progress had been made and, in some cases, the disparities worsened. So, in 2015 and 2016, the Legislature went a step further and provided \$11 million a year for programs and strategies to reduce disparities. Regional Centers and community-based organizations are utilizing the funds to add staff, develop cultural competency and person-centered thinking trainings, translate materials, develop outreach programs, train parents, offer parent-to-parent assistance, and more.

Yet all of these measures may be efforts around the margins. The grants have not targeted proportionately regional centers with the largest populations with disparities. They have not utilized decades of evidence on how to reduce health disparities. They have not tied funds to actual reductions in disparities. They have not substantially included the community in their equity grant planning and implementation. They are not requiring rigorous evaluation of their programs. They have not required regional centers to provide easy-to-understand information on services or disparities.

Our member families and self-advocates tell us they believe that the underlying root causes of these disparities are a culture of "no" at the regional centers that often includes hiding information about available services, little accountability, intimidation and fear of retaliation, and insufficient ability for those affected to have a voice. **As long as these root causes are not addressed, the problem will continue.**

This report recommends the following steps in order to improve and eventually eradicate disparities:

1. Erase the "culture of NO" and replace with true whole-person case management. Require more DDS oversight over regional centers' treatment of individuals and families to ensure respect.
2. Require more rigorous, evidence-based, data driven processes for funding grants by targeting grants in areas with the greatest levels of disparities; require accountability for the funds to ensure they went directly into projects that will reduce disparities.
3. Restore funding for social/recreational programs. Monitor the implementation of the lifting of the respite cap to ensure families are receiving an increase when needed.
4. Require true and deep community involvement by establishing permanent regional center board committees on ensuring equity and evaluating and reporting on how and to what extent community involvement influenced the provision, implementation, and evaluation of grants.
5. Require reporting in accessible plain language to improve transparency.
6. Consider disparities in the context of the future of our service system, including ensuring that the self-determination program individual budgets allow adjustments for disparities, and moving toward outcomes-based and satisfaction-based incentives for providers.



# ***REALITY CHECK***

Contact: Judy Mark, President, 310-621-2045  
judymark@dvunited.org

## **Efforts to Reduce and Eliminate Disparities from the Self-Advocate & Family Perspectives Provided to the Senate Budget Subcommittee #3, Health & Human Services March 15, 2018**

*This report and recommendations were researched and written by Dr. Alicia Bazzano (parent, San Diego), Fernando and Elizabeth Gomez (parents, Los Angeles), and Judy Mark (parent, Los Angeles), all volunteers with Disability Voices United, a statewide advocacy organization directed by and for individuals with developmental disabilities and their families. We advocate for: choice and control over our lives; meaningful outcomes that matter to us; and, systems that are equitable and accountable to us.*

### **Introduction: Decades of Disparity Unnoticed**

---

In 2011, the *Los Angeles Times*' article, "Warrior parents fare best in securing autism services," reported that Latino and African-American children with autism received much less funding for regional center services than white children. At the time, the state Department of Developmental Services (DDS) spent a statewide average of \$11,723 per autistic child on whites, compared with \$11,063 on Asians, \$7,634 on Latinos and \$6,593 on blacks. The uproar created by the article underscored the opacity of the system to outsiders. The families within the developmental disabilities system had been living the harsh reality while going unnoticed for decades.

Regional Centers had actually known about these disparities in services since at least 1991, when a study showed the systematic differences in payment not only for those with autism but for children and adults with all of the developmental disabilities in the system (autism, intellectual disability, cerebral palsy, epilepsy, Down syndrome and others). Some of the regional centers acknowledged the issue and had tried strategies to change them. Others called them "variations." Even in the *LA Times* article, one regional center's conclusion was that the problems stemmed from the inherent differences in the cultures of the communities and the lack of providers, without acknowledging the role the regional centers might play in creating the disparities.

Parents, on the other hand, used the article to spur protest and demanded that the California state legislature take action to force the developmental disabilities system and regional centers to address these inequities. A year later, the California State Senate created a task force and eventually required DDS and the regional centers to report to the public on the amount of purchase of services (POS) for every person in the system by race/ethnicity, language and age. The legislature then required regional centers to "undertake certain activities to identify significant disparities and barriers to equitable access to services and supports, and to develop recommendations and plans to reduce existing disparities." The legislators believed that shining a light on the disparities and requiring transparency would force the system and regional centers into making significant improvements.

As expected, the initial data that began to be released in 2013 showed profound disparities. In **every single regional center** throughout the state, **Latinos were receiving 30-50% less** service expenditures than whites. In most regional centers, **African-Americans were receiving about 30% less** in expenditures. **Asians** were generally **receiving from 10-50% less** in expenditures.

As time went on, it became clear that just making this issue transparent would not be enough. Every year, the regional centers made public the data that showed widespread ethnic disparities and laid out a plan to fix the problem. This data was presented at public forums, often poorly attended, and placed on their websites, usually under difficult-to-find headings such as “Transparency” and “POS Data.” And, five years later, despite a great deal of attention, the disparities have not improved. In fact, **they have worsened**. In Fiscal Year 2016-2017, the level of inequity remains stunning. While every regional center faces this issue, some areas are experiencing crisis levels of disproportionality.

### **Disparities at a Glance**

**Latinos** are 67% of the population served and receive per consumer expenditures of **\$6,760 compared to \$38,271 for whites and \$19,001 for African-Americans**

*South Central Los Angeles Regional Center*

**Latinos** are 71% of the population, yet they received **34% of what whites receive**

*East Los Angeles Regional Center*

**Asians receive only 45%** of what whites receive

*Golden Gate Regional Center*

White children, age 3-21, have expenditures of \$9,320 while **Latino children have \$5,786**

*Regional Center of Orange County*

**20.7 % of Asian adults and 21.7% of Latino adults receive no services**, compared to 14.5% of whites

*Harbor Regional Center*

White adults living at home get \$16,295 per consumer while similar **Latinos get only \$12,110**

*Regional Center of Orange County*

White adults using supported or independent living services receive \$31,844 versus similar **Latinos who receive only \$18,748**

*San Diego Regional Center*

English-speaking consumers receive \$25,201 in services while **Spanish speakers receive \$16,472**

*Westside Regional Center*

The “Other/Multi-Race” population comprises a significant 18% of consumers who **only receive a quarter of the services that whites get**

*Inland Regional Center*

### **Disparities Aren’t Just Numbers, They’re People**

Sometimes it is easy to get caught up in the data. But we must constantly remind ourselves that underlying the racial and ethnic disparity statistics are real children and adults with developmental disabilities. They all have families who are struggling, not only to find appropriate education and services for the child with disabilities, but they may also be facing poverty, immigration issues, language barriers, caring for other children or family members, or disabilities or illness themselves.

## Roberto's Story

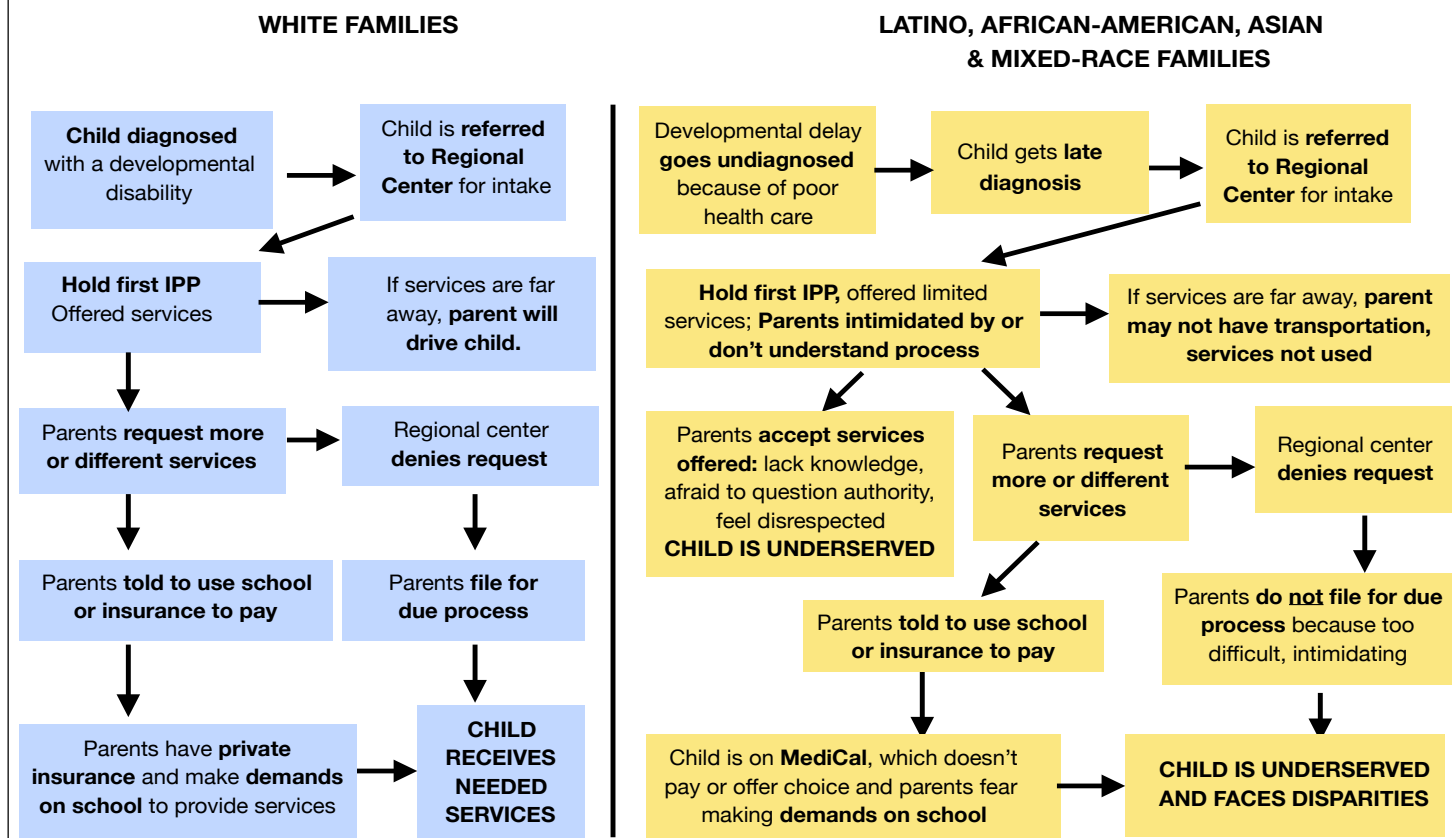
Roberto, 23, has received very few services from South Central Regional Center even though he has autism, is non-verbal, and can be self-injurious and aggressive at times. When Roberto was required to exit the school, none of the day programs the regional center offered would accept him. He stayed home for nine months while his mom called and emailed over 25 times and begged even the top executives to call her back. Finally, when Roberto's mom showed up to a town hall meeting at South Central regional center and told her story publicly, Roberto was offered a program that was more appropriate. She asked, "Why did it take showing up at a public forum to get services that Roberto is entitled to?"

## Jared's Story

Jared is a client of Harbor Regional Center and was born with a rare developmental disability called Dandy-Walker syndrome, which affects his brain and causes intellectual disabilities, severe autism, partial blindness, hearing loss, and motor difficulties. Jared had received very few regional center services over his life, despite his intense needs and his mother's consistent requests for help. Jared developed severe behavioral challenges and bites himself regularly because he has no way to communicate. He was eligible for regional center funded behavior therapy and his mother desperately requested direct intervention for him for five years through over 100 emails and phone calls. Jared was finally approved, then the regional center said it was difficult to find a provider that had availability.

Many parents of children facing disparities express common experiences. Often their child is diagnosed late because their Medi-Cal provider didn't pick up the delays. Then they are intimidated by the regional center intake process and their first IPP. They accept whatever services are offered and feel uncomfortable asking for more. As their child gets older and the parents gain more experience, they may ask for more, but often get turned away. If they persist in their requests, many tell us they gain a "reputation" as a "difficult parent."

## Many Families' Perspective on Disparities



## **The True Cause of Disparities: A Culture of “No” at Regional Centers**

Latino, African American, Asian, and multi-race families face multiple barriers to receiving services. We believe the greatest root cause of the disparities is the culture of “no” that families experience when trying to get services. Parents tell us that instead of it being their ethnic culture, it is **the culture of regional centers** that keep their children from getting the services they need. They say they feel the Regional Center culture is often an “**us versus them**” mentality, in which the “them” are the very families the regional centers are supposed to be serving.

Many in the underserved communities report feeling **intimidated** by the regional center system and staff. They tell us, “We are parents who are devastated by the diagnosis of our child. But the regional center knows that some of us are low-income, don’t speak English well, and lack formal education. And then we face people with college degrees who are experts, and they use their position against us.” We also hear that parents, even those with education and who speak English, are sometimes **afraid of speaking up** in fear of **retaliation against their child**.

While many regional center staff are caring and work very hard for their clients, too many parents report that they are treated in a condescending or **disrespectful** way. One parent told us that the psychologist who came to evaluate her son to determine a diagnosis took only 15 minutes with him, and at one point during that time, posted something on her Facebook page. Another parent said her service coordinator told her that he “can’t trust parents because many parents lie.”

Most commonly we hear that **parents don’t know what services are offered** by their regional centers. They feel grateful when their service coordinator gives them a small amount of services for their children. But, as parent Abner Antunez said at the Senate Human Services hearing on disparities in 2017, “It’s like we are starving and they give us a little piece of candy and we think we are being helped. But we haven’t been given the whole menu. We don’t know what else there could be. We have to find out about things ourselves. Nothing is provided unless we ask. Even then it is a battle.” Regional Centers are required to provide a list of vendored service providers on their websites, but our analysis shows that these lists are often difficult to find, completely disorganized, and littered with inaccuracies. For example, some regional center websites have vendor lists that include agencies that are out of business and individual providers who are deceased. The service coordinators become gatekeepers since they have built relationships with preferred vendors and the information on services that the service coordinators give families is the only information that families get.

In addition, sometimes families report that there are **language barriers**. We have heard stories of parents needing to bring friends or family to meetings to interpret for them. Many parents don’t understand that they have a right to an interpreter and to have all important materials, such as the IPP, translated. Many regional centers believe that having translation is an unfunded mandate and **will not provide translation** unless specifically requested by an individual family.

The 2009 funding cuts that eliminated social/recreational programs and put a cap on respite have also contributed to disparities. Many Latino and African-American families relied on these services, such as swimming, horseback riding, and summer camp – all programs that low income families can’t afford on their own. But last year, the legislature lifted the cap on respite specifically to target those affected by disparities. We are concerned, based on reports from families, that access to additional respite remains difficult and that caps basically still exist – in practice if not in words in their service standards. Since **regional centers do not regularly track and make public funding of a specific service by race/ethnicity**, it is very unclear if families are benefitting from increased respite at every regional center.

We also hear consistently that a common tactic at regional centers is to **not respond to families' requests**. "Mostly, they don't call us back or return our emails. Or they say they are 'working on it.' We don't usually get denied a service. And if we finally do get denied, the regional centers know that we can't afford to go to due process or understand what that means."

Ultimately, parents report that they are incredibly frustrated with having to fight for services for their child. They experience a **"culture of no"** where they feel that often what they ask for is ultimately turned down. Some parents, who are most often white, educated, and with financial means, will go through due process to appeal for services. But for families from non-white ethnic groups, with a culture that doesn't question those with power, the answer "no" is final. Though families are told of their rights to appeal (in legalese), these families are not able to fill out the confusing paperwork and are not supported in the intimidating process in front of a judge. The result of these **barriers to due process** are that those who have the means, education, and ability to hire a lawyer (typically white families) are those who are able to fight to obtain services. **The Regional Centers should not have to be a place where families need to fight for services to which they are entitled, and those without the means, language, or knowledge to appeal are left out.**

### **Finding Alternative Reasons for Disparities Is Not Going to Reduce Them**

Instead of recognizing that regional center culture is a significant contributor to disparities, many regional centers have stated that reasons for disparities include demographic, community cultural differences, and lack of providers. Some argue that a major demographic reason for the disparities is because Latino consumers are more likely to be younger—specifically children. The Regional Center system spends less on children who are usually served by the school districts. However, in every regional center, **Latino children still have lower purchase of service amounts than white children.**

Regional centers have also contended that a cause of the disparities is because Latino and African-American adult consumers tend to live at home with their parents far longer than whites, who often live in group residences or in their own place with support. Because living away from your parents allows you to receive funding for a costly group home or supported living services, whites will have more services purchased. Yet, **when you compare "apples to apples," and look at adults who live at home, Latinos and African-Americans still face a disparity.**

Furthermore, Latino families should not be punished for keeping their children at home with their families. Many of these adults need high levels of support, which are often not funded by regional centers, and families go without the help they need. Restricting intensive support services only to adults who move away from their families discriminates against Latinos who want to keep their son or daughter close.

Regional Centers also blame the lack of providers who speak other languages or work in underserved communities. But we need to recognize that some regional centers have vendor policies that create this shortage. Regional Centers often utilize arcane, convoluted, and inconsistent vendoring processes that take months or years. For example, requiring previous experience specifically in the developmental disabilities system automatically eliminates providers who may have broad experience with disabilities and a specific ethnic community but have never been a vendor. These requirements also create an isolated system in which people with developmental disabilities can only be served separately from the community.

Regional Centers also make the claim that non-white families are receiving more generic resources—those provided by other agencies and schools—than white families, which makes up for the difference in funding. However, **neither DDS nor Regional Centers track provision of services by any other agencies.** This creates an information vacuum in which no coordination with these services can occur. Instead of Regional Centers providing true case management services, they coordinate only among their own vendors.

As we've heard from parents, ***"The word 'no' is the same in Spanish and English."*** Ultimately, regional centers should be saying "yes" to equity, "yes" to families, and **provide true case management**. That means a "no" turns into, "Yes, we will help you get you the services you need. We may not be able to pay for all of it with regional center funds, but we will help you navigate other systems to be sure your family member's and your whole family's needs are being met."

## **Investment in Reducing Disparities**

---

In 2016, the legislature recognized that more needs to be done and prioritized the issue of disparities through a special allocation. They directed \$11 million "to assist regional centers in the implementation of strategies to reduce POS disparities. Regional centers are required to meet with their communities to discuss proposed strategies to address disparities in the POS data." DDS received proposals from all of the regional centers and made decisions on their grants at the end of 2016.

This fiscal year, the legislature renewed their commitment and allocated another \$11 million. But this time, the legislature wisely decided to allow community-based organizations (CBO), which includes grassroots family groups, to apply for the majority of the grants, with the remainder going to the regional centers. DDS gave out 35 grants to CBOs totaling approximately \$7.3 million.

After reviewing the process for distributing grants and the projects and staff that were funded, Disability Voices United provides these suggestions:

### **Community/Stakeholder input and involvement must run deep and be meaningful**

The legislature required that regional centers engage their community stakeholders in the process of devising strategies to remediate disparities and report to DDS on their course of action. Yet few regional centers have gone further than a yearly stakeholder meeting in which the directors provide statistics in confusing PowerPoint presentations. And no boards of directors have established ongoing committees chaired by parents and self-advocates from underserved communities to explore barriers and ensure regular community input. DDS does not directly monitor the depth of community participation and dialogue. They don't ask whether underserved families that have little interaction with the regional center were contacted and included. It is also uncertain whether any community feedback was meaningfully utilized in developing the regional center's strategies or whether staff already had their plans laid out.

### **Parents assisting parents is the best approach but groups need independence**

The grants provided to regional centers and CBOs cover a wide range of projects, some of which could have a clear impact on disparities. In particular, we believe the projects that place parents as leaders in providing outreach, training, and guidance to other parents have a greater chance of assisting underserved consumers in receiving needed services. Parents assisting other parents in accessing services for their child, often called Promotoras or navigators, is an approach that most regional centers, or CBOs in their area, will use. We are concerned, however, about how these projects get implemented. First, it is critical that these parent leaders have a level of independence from the regional centers in order to recognize barriers and address them. Second, these leaders must take data on the interventions they are using and their results in order to assess whether they worked in getting services for underserved consumers.

### **Funds should be based on level of disparity and size of population**

The funds were not allocated based on numbers of underserved community members. We note that some regional centers with significant numbers of underserved families have obtained less funding than might be needed to develop strategies to reduce disparities. For example, San Diego Regional Center, with a very large Latino population experiencing significant disparities, applied for a relatively small amount of funding. None of their projects include parent-to-parent navigation assistance, and there are no CBOs funded to work in that catchment area.

### **Regional centers received funds for translation and interpretation they are already required to do**

Many regional centers requested funds to translate materials, provide interpreters, and hire bilingual staff. We know that language access is critically important and we believe that regional centers need to follow the laws that already exist requiring regional centers to translate critical documents and provide interpreters at meetings. But our surveys of families show that these concerns are overshadowed by the way parents feel they are treated by regional center staff, regardless of the language spoken. In fact, some parents report that they have been treated more poorly by staff of their own race. Furthermore, language access is already required by state law. While some regional centers have claimed this requirement is an unfunded mandate, we argue that it is a matter of priority and that regional centers use government funds for many things they aren't required to do.

### **Projects need to directly reduce disparities**

It is also critical to explore how the disparity funds will directly reduce disparities. Some of the funded projects may have great value, as long as they are connected clearly to getting underserved consumers the services they need. For example, DDS funded seven regional centers to provide person-centered thinking training for staff and vendors. We know this training is very important for staff to serve all consumers, particularly with the coming federal rule changes. But since these trainings are funded entirely by disparity funds, we need to ensure that the trainers are experts in the issues surrounding disparity and clearly link the training to creating equity for underserved consumers.

### **Funds are allocated to projects without evidence-based practices in reducing disparities**

We are concerned that the state has invested \$22 million in projects to reduce disparities, but we honestly have no idea whether these strategies will work. DDS and Regional Centers have not required their grant recipients to understand and follow evidence-based practices in improving disparities. Decades of work in significantly reducing health disparities could be utilized in developmental disabilities and yet none of this information is provided to grantees or regional centers. In addition, DDS is not requiring an independent analysis of the projects to ensure they are reducing disparities.

### **Community-Based Organizations are not necessarily the voice of community**

We are encouraged with the direction of moving toward funding CBOs to work toward solutions to disparities. We believe that those organizations, if they truly represent the community, will have a good chance of gaining the trust of parents and creating a bridge with the regional centers. But they must be encouraged to partner with the underserved families in developing solutions instead of coming in assuming they already have all of the answers. Moreover, DDS's efforts to include small, unaffiliated parent-led groups is appreciated, but the reality made it very difficult. The small groups were required to associate themselves with a fiscal agent, University Center for Excellence, or other organization, which created barriers and loss of control. These organizations that received grants not only need to be the voice of the community, they need to help the community be their own voice.

### **Disparity managers must break down barriers and not create new ones**

With the new disparity funds, almost all of the regional centers hired staff to manage their efforts to reduce disparities. It is important to monitor the work of these managers to ensure that they are directly impacting disparities. Because they work for the regional centers, the community needs to know that the disparity managers' loyalties, which may naturally lie with their employers, will not create a conflict that prevents them from honestly recognizing barriers that may exist within their own organizations. We must also ensure that they are meaningfully engaging underserved consumers, parents, and communities as opposed to creating more obstacles.

### **Data on Disparity Funding is Obscured**

In reviewing the funded projects, we observed DDS posted the regional center proposals that were funded, but these numbers don't match the actual grants provided. Thus, it remains unclear exactly how some of the \$22 million of taxpayer money is being spent.



## **Assessing Whether the Grants Have Reduced Disparities**

---

DDS is creating a draft set of measures to assess whether the disparity funds have moved toward a more equitable system. We support a set of measures such as this as long as they are moving quickly toward a true reduction in disparities. These measures also need to have as a goal the elimination of disparities completely, not just a reduction. These measures should also be developed at the regional center level, and even the individual service coordinator level, and set goals for each center with different targets, based on the disparities in that community. Overall, we are concerned that it will be difficult to truly assess whether the disparity funds will reduce, and eventually eliminate, disparities in the long-term for the following reasons:

### **Evaluation efforts are unclear and project funds are not linked directly to reducing disparities**

All evaluations required by DDS are internal evaluations and are not subject to any standardized quality metrics. They are not required to have formalized evaluations of their processes and outcomes. Furthermore, grant recipients are not required to rigorously evaluate and report family experiences with the intervention in the context of disparities. No outside or external evaluation is required. Most importantly, grant funds do not need to be linked directly to increases in POS funding for individual clients or as a whole. In other words, the goals and objectives of the projects do not have to be measurable directly in terms of POS improvements.

### **Accessing Information on Disparities on Regional Center Websites**

While regional centers meet their statutory requirements to post their POS data on their website, it is often buried in a place that is very hard to find – usually under “Transparency” or “Governance.” Moreover, the information is not provided in plain language and is very difficult to understand for many self-advocates and families. The data is aggregated and in tables and none of the data tables are searchable. DDS does not freely allow data queries so that services can be searched by race/ethnicity, regional center, location, etc.

In another example, the “Other Ethnicity or Race/Multi-Cultural” field comprises 12% of those individuals served statewide, and they face the same significant disparities. It is unclear, however, which race/ethnicities are included in this category. This is unusual in comparison with other state and federal agencies’ requirements for reporting and makes it very difficult to interpret what is happening and how to improve disparities for these individuals.

### **Data should be compared to ethnic population in catchment area**

Regional centers do not answer what percentage of people with developmental disabilities living in their catchment area they serve. Assessment measures should include attempts to gauge how many individuals are left out of the system entirely with the goal of targeting outreach to those communities.

## **Recommendations: Getting to a Culture of “YES!”**

---

Ultimately, we need to ask whether, with all of the efforts, publicity, and \$22 million, we have gotten to the roots of the barriers to an equitable system. If we don't address the root causes of the disparities, any progress we make could be erased over time. With that in mind, we urge the legislature to consider the following recommendations:

- 1. Erase the “culture of NO” and replace with true whole-person case management**, including
  - a. more DDS oversight and accountability over regional centers treatment of individuals and families
  - b. DDS creation of an office dedicated to eliminating disparities, sharing best practices, development of plain language information, and ombudsman with phone number/email for concerned families
  - c. a statewide ongoing survey on satisfaction and perceived treatment, focusing on equity and disparity (well beyond the NCI survey), reported annually to be disseminated widely;
  - d. a statewide policy that any client or family contact (phone, email, etc.) should be returned respectfully within 48 hours, with the ability for family to report concerns
  - e. independent mediators provided for parents who express concerns about intimidation or fear of retaliation from their regional centers
  - f. new hire and yearly mandatory trainings on serving families with dignity, compassion, and respect as equals
  - g. encourage hiring of diverse senior management at regional centers
  - h. true whole-person case management to be conducted and documented in the IPP, including the quantity, frequency, contact information and cost of any generic services recommended or provided beyond regional center vendored services
- 2. Require more data reporting and more public access to data to improve transparency**
  - a. Make more freely accessible the POS data in usable form with clear data in which each variable is searchable. Tables should be made with each data point by race/ethnicity or region. Similarly, POS data should be made available so that each service can be searched by race/ethnicity, regional center, location, etc.
  - b. DDS should clarify their “other/multi-cultural” race/ethnicity data field and conform it with other federal and state requirements for race/ethnicity data.
  - c. Regional Centers should be required to analyze their “reach” and determine what percentage of each race/ethnicity is being captured by the regional centers and what portion is not being served
  - d. DDS and Regional Centers should be required to make more clear and accessible to clients and families each of the services provided, an active list of agencies currently providing those services, and geo-mapping of services by address.
  - e. Require data on regional centers websites to be found easily under titles that are descriptive with information written in plain language.
- 3. Require more rigorous, evidence-based, data driven processes for funding grants while also ensuring inclusion of grassroots groups with connections deep into the community**
  - a. DDS should target grants to regional center catchment areas and ethnic groups that are experiencing the greatest levels of disparities proportionately. DDS should monitor and disseminate the results of efforts in proportion to the population.
  - b. The legislature should require accountability for the funds spent to ensure they went directly into projects that will reduce disparities. Regional centers and CBOs should quantify how many families and consumers were assisted with getting services and the amount of those services.
  - c. DDS should provide information on evidence-based practices and require utilization of those practices as a condition of grants to regional centers and CBOs.

- d. At the same time, special consideration should be given to grassroots, unaffiliated, parent-led groups who have a reach deep into the community.
  - e. Independent (third party) evaluation research must be conducted into whether the current projects are actually working and future projects must be tied to outcomes of reduction in disparities and outcomes of improvements to individual's lives.
4. **Eliminate additional barriers by dropping legislative restrictions on funding**
- a. The legislature should restore funding for social/recreational programs that was cut almost a decade ago. Funding for these services will help reduce disparities and are critical for better outcomes for consumers.
  - b. The legislature and DDS should monitor whether regional centers are providing more respite hours to families since the cap was lifted on January 1, 2018.
5. **Require deep community involvement and leadership of families and self-advocates**
- a. Community engagement should not be a once-a-year exercise but an ongoing practice. Regional centers should be required to establish ongoing relationships with family and consumer-led groups
  - b. Regional centers should be required to establish permanent board committees on ensuring equity, with the goals of developing and monitoring their center's efforts and projects, ensuring the voice of the community is heard, and seeking to overcome barriers for the long-term.
  - c. DDS should be required to evaluate and report on how and to what extent community involvement influenced the provision, implementation, and evaluation of grants.
6. **Consider disparities in the context of the future of developmental disabilities system**
- a. As the Self-Determination Program (SDP) moves closer to implementation this year, it is important that this new option doesn't perpetuate disparities. Since SDP participants' budgets are developed based on previous spending, unless adjustments are made, Latinos, African-Americans, and Asians will continue to be underserved.
  - b. DDS and regional centers need to ensure that Latino, African-American, and Asians families, particularly those who speak languages other than English, are provided timely information and training about the new federal Home and Community-Based Services (HCBS) rules, requiring regional center-funded services to be delivered in inclusive settings. Unless special attention is paid to these communities, they may be faced with additional disparities with no compliant services available.
  - c. The system should move toward an outcomes-based rather than fee-for-service based funding model. Regional Centers and vendored agencies should ultimately be paid based on the outcomes they achieve with clients and the clients' satisfaction, rather than the hours reported as spent with clients. This method of funding would ultimately provide better accountability to all of the families served.



**For more information on Disability Voices United, go to:**  
**[www.disabilityvoicesunited.org](http://www.disabilityvoicesunited.org)**  
**530-JOIN-DVU**