



October 11, 2022

Little Hoover Commission  
925 L Street, Suite 805  
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Dear Distinguished Commissioners,

Thank you for giving me this opportunity to share my experiences and thoughts. My name is Elizabeth Barrios Gomez, and I am here before you as a passionate mother of a 15-year-old son with Down Syndrome. He teaches me every day to see the many possibilities. Oscar Antonio is not aware of what makes him different. We celebrate his happy, trusting and kind soul. He embraces life with enthusiasm and high expectations. He has high hopes and desires to live an inclusive and normal life as best possible. Unfortunately, that is not always the case with the current systems that are designed to support him. The unsettling reality is that Oscar Antonio is not alone.

I am here today to share my testimony as a mother, member of the community and as a co-founder and Director of the Integrated Community Collaborative (ICC). ICC is a Community Based Organization that is composed of Self-Advocates and Parents who on a peer-to-peer basis and a relationship-based outreach model help families engage and navigate the intellectual and developmental systems of support in California. The ICC Community Integradora outreach protocol was made possible from the POS disparity grants through the Department of Developmental Services that is designed to empower parents and self-advocates, engage, and elevate our voices and become part of the solution. We see this as a must to help the system we support.

The ICC has helped families in 18 of the 21 regional center catchment areas with primary focus in North Los Angeles County Regional Center within San Fernando and Antelope Valleys and Valley Mountain Regional Center within the Stockton area. ICC walks hand-in-hand with families and joins them in key regional center meetings, IPP's and through the fair hearing process as part of their circle of support. We inform, train and embrace the community we represent.

There is plenty of data and reports that confirm that if you are a person of color with an intellectual/developmental disability in California you are most likely to experience some form of discrimination, barrier and or roadblock when trying to access services. Most



specifically this is reflective of Latino families who at 42% are by far the largest group served by the regional center system. ICC strives to not only address the root of the barriers and roadblocks but continue to collaborate and try to be part of the solution in helping eradicate them.

We find that the system of service coordination has not evolved with the community it is tasked to serve. One of the biggest barriers encountered by the self-advocates and families we support is that the system is extremely challenging to navigate. It has become complex, frustrating and many find it over-reaching. It does not take into account our diversity, rich culture and family nuances. The regional center system is designed for individuals to adhere to their process in a more dictatorial and unbending fashion.

I would like to share the following true story as an example: A dear friend, Mother and fellow Advocate unexpectedly lost her beautiful 15-year-old son with Autism just several days ago. What I remember is the endless hours we spent in navigating the system for her son all of last year and facing the harsh barrier after barrier that included ridiculous request such as needing to provide detailed calendars as proof of what she did every day from morning to night, hour by hour including when she sleeps and when she wakes up. Detailing when she helped him every hour of the day. This was construed by the family as insensitive, an evasion of privacy and lack of respect. We are not sure if this is requirement is applied to everyone or just mainly the Latino families. This type of service coordination is not made public. Aside from the multitude of request for proof and documentation. she was also required to vilify her son to just prove that the services were needed. The family felt as if there was lack of respect and a blatant disregard for their privacy.

For Latino families we see that this is more of the norm within the system. In addition to overstepping the boundaries into family's private life, the family still had to provide all sorts of additional request medical reports, copies of IEP's reporting work hours of everyone in the house including other children. All ending in denial of services and eventually led to attending an overwhelming and intimidating informal meeting that resulted as a result of a hearing process required to get her son the much needed supports.

All these efforts and months later they overcame the odds and were finally awarded the services he had always qualified for. The family were celebrating and with high hopes and expectations were ready to move forward. Tragically that very same day her son passed away unexpectedly. He never had the opportunity to use the services they fought so hard for. How is it fair and just to expect a Mom to carry this type of burden. Mikey's mother



provided me with permission to share this story in the hopes that her son's experience can make a contribution in helping others like him by sharing his story to bring systemic change. The family will move forward as they have a daughter who is also served by the regional center system, but I would not be truthful if I didn't share that this process has taken a very heavy toll on them all. We grieve with her and must find the ability to make sure we do not see repeat what Mickey and his family went through. Every day is precious and every day that someone goes without the much-needed support is a day they can never recover.

Within our culture it is about relationships. It is about validation. It is about empathy. Trust and respect are two key and fundamental elements in service coordination. Yet, these are the two items most disregarded as we have experienced with many families. Things like having support staff enter a home and make culturally insensitive/offensive remarks or reporting families without basis that later have severe consequences for families that can even lead to separating children from their home, is something families experience.

When Families do question and stand up in advocating for their child, they are then perceived to be the problem family, adversarial and non-content. We have seen situations that when Families are placed onto this category, they are most likely to be retaliated against and the process becomes much more challenging. This is experienced across the state. There are some regional centers who are making great strides and progress where others by far are not. This is a fear that many families have and are very reserved and cautious when it comes to engaging with the regional centers.

Regional centers each vary in how they interpret policy and procedures. Interpretation of DDS Directives and established policies are all based on internal perspectives within the regional center. We have seen times where even within the same regional center the interpretation will vary by each department. Also, in many instances, we see that that the regional centers place focus on service coordination based on compliance instead of person-centered service coordination.

Most Parents are overwhelmed, confused by the process, and are trying to obtain the needed services for their child as quickly as possible. They will even sign documents that they have no idea what they are signing. In addition, the very service coordinator that they need to trust and build a rapport with is the one who can and will testify against them in a hearing and will use information obtained from those meetings and reports that were



perceived to be used for something else and confidential. This is when we see that the trust is completely broken beyond repair.

Following are some areas where key barriers exist:

- **Respite:** A law was passed in 2018 that lifted the respite cap; however, internal policies still establish a cap for the number of hours approved. Each regional center has a different measurement tool. Unfortunately, these tools do not capture the full scope of the need. For the most part the community reports that it measures physical disabilities and not the Developmental Disabilities that challenge most families. Therefore, limiting the number of hours.
- **Social Recreation & Camp:** The much-requested Social Rec and Camp services that have been restored are now showing the same problem. The internal policies continue to limit the proper implementation of this important service. Some Regional Centers internal policies make it difficult to approve and provide these services. The conflict we see is some are doing a good job and others are not offering this needed support.
- **Generic Resources Process:** Families are sent on their own to first apply for generic resources prior to being considered for some regional center services. This is a long and complex process that takes months at end and many families do not even know how to even apply for these services and some don't even qualify for them such as IHSS.
  - Once a family manages to obtain a denial from a generic service the regional center requires families to appeal the decision in which it leads to another lengthy and complex process.
  - Once you do receive the denial months later the regional center still requires your request to be reviewed and considered by an internal POS Committee whom you do not know, and they do not know you or your child. Because of this disconnect many families receive denials and a Notices of Action which now send them through an intimidating and overwhelming Fair Hearing process. By then, families report that most of them just give-up pursuing the much-needed services for their child.
- **Safety Net Services:** A family's worst fear is the safety of their loved one. Timely access is important. Safety net support is hard to access and understand. The lack of information and in many cases, families are told that there are no proper vendors or personnel to help in a timely manner.
- **Self Determination:** To transition to SDP many Latino families are experiencing delays that can take 6 months or more. In many cases the process and interactions with the regional center SDP teams are overwhelming. There is a very strong interest in migrating



to this new program to eradicate disparities but many families are frustrated and get discouraged and decide not to pursue it. The process needs to be more streamlined and consistent.

- We must make sure that existing barriers and roadblocks do not migrate to the new program as well as be diligent in assuring new ones do not present themselves.

I believe that there is a lack of accountability for service coordination and limited options for families. The regional center system has a deep-rooted culture and practices that have historically left the individual and community served out of the loop. One example is that you may require all regional center staff to take implicit bias training, but there is no follow-up to that training, its implementation or the impact that it has had. We find that in many cases it is not that the service coordinator is not knowledgeable or informed, but the disconnect tends to be within the implementation process or lack of because of little to no accountability.

I would like to share my opinion of the some types of systemic changes and solutions that are needed to ensure more equitable access to services are:

- Engage the community in a true and unbiased manner regardless of ethnicity or where you live.
- Simplify the process to access services in an equitable manner
- Reach decisions and provide services in a timely manner
- Establish accountability across every touchpoint that the individual served by the system receives
- More consistency in service coordination across the 21 regional centers
- Collaboration and Partnership. It is not us against them mindset but that we are working together
- Culturally appropriate request without humiliating the person for asking.
- Build the trust with the center by embracing the families and really listen
- Respect all families. Staff Speaking their language is not enough.
- Do not place the burden on families but engage in service coordination even when pursuing generic services.
- Hold regional centers accountable for retaliatory practices.

As a community we are grateful for the Lanterman Act and embrace the opportunity to help the system help our families. We want to be part of the solution and have a seat around the table. We are also grateful to DDS Director Bargmann and her staff for



providing Community Based Organizations like the ICC the opportunity to advocate and be part of the process and solution for systemic change with meaningful outcomes. We have been working closely with a couple of regional centers where we have seen significant progress and improvement. There is an answer and a solution but still a lot of work ahead of us that collectively and through a true collaborative effort individuals can be supported and in an equitable and meaningful way.

Our vision is to continue with our efforts to unite and elevate the voice of the community by having a strong presence of the ICC Community Integradoras in all of the 21 regional center catchment areas. There are many self-advocates and family members who are ready and willing to take an active and collaborative role in helping the system help us

Thank you again for the opportunity to share my views. I am happy to answer any questions you may have or expand on any of the points I made.

Sincerely,

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