



Good morning, Sen. Steinberg and Senate Select Committee Members. My name is Martha Matthews. I am the Directing Attorney of the Children's Rights Project of Public Counsel in Los Angeles.

Public Counsel has worked with hundreds with low-income, mostly Latino and African-American families in Los Angeles who are parents or caregivers of children with autism and other developmental disabilities. We have seen firsthand the barriers and inequities these families face. I want to tell you about one family whose story, sadly, is typical of our clients' experiences.

"Angelo"¹ is a 6 year old boy with autism. He babbles but cannot speak. He has no control over his bladder or bowel and must wear diapers; he is too big for ordinary diapers so his family must buy more expensive large pull-ups. He cannot bathe or dress himself. He only eats pureed or liquefied foods. He is severely hyperactive, and cannot focus even on something he enjoys for more than one minute. He has chronic insomnia, and will only sleep for 2-3 hours per night for weeks at a time. He cannot play or interact socially with others, and needs close supervision, due to his tantrums, self-harming behavior, and tendency to wander off.

Those of us here who are parents -- imagine the extreme challenges of caring for this child, even with all the education, connections, financial resources, family support and other advantages we enjoy. Now imagine what it is like for Angelo's parents. They only speak Spanish. His father is a laborer and his mother is a seamstress. They live in a poor neighborhood in South Central Los Angeles, and they do not have a car.

When this family came to Public Counsel for help, Angelo was not receiving *any* special education or Regional Center services, despite his eligibility for both programs. We found them a pro bono attorney who helped them get special education services.

For six months, our office tried to get Regional Center services for Angelo. Here are some of the barriers this family faced:

- When the family asked for in-home behavioral intervention services to help manage Angelo's behaviors, the Regional Center said his insomnia and feeding problems were medical and not developmental, and sent the family away to seek treatment from a doctor. (Regional Center offered no plan to address Angelo's other behavior problems, including tantrums, self-harming behavior, and tendency to wander off.) After trying medications, two doctors agreed that Angelo's insomnia and feeding problems had no medical cause and were due to his developmental disability.

Regional Center still refused to provide in-home behavioral intervention services. Instead, it sent the family a two-page, single-spaced letter in English, "explaining" the denial and offering the family weekly group classes in behavior management, saying they had to attend all the classes, try the

¹ We have changed the child's name to protect his and his family's privacy.

generic techniques taught in the classes, and then if this failed, ask Regional Center again to consider funding in-home services.

- When the family asked for help with the high cost of diapers for an older child, Regional Center said Medi-Cal should pay for them, and sent the family away to seek help from their Medi-Cal HMO. But the HMO did not cover this cost, so the family had to switch their health care plan to fee-for-service, which required them to obtain a signed medical exemption form from Angelo's doctor. Once the switch was finally made, the family had to find a provider who would submit a funding request to Medi-Cal for the pull-up diapers. This process took over three months, but Regional Center refused to help pay for the diapers in the interim.
- When the family asked for help with the cost of transportation to Angelo's multiple doctors' appointments, Regional Center refused to provide a bus pass and sent the family away to apply for City Ride. City Ride denied services because the family did not have documentation of Angelo's disability. When the family asked Regional Center for documentation, it told the family to go and get documentation from the Social Security Administration.

Even after 6 months of intensive advocacy, what were we able to get for Angelo's family from the Regional Center? A one-month supply of pull-up diapers; one month supply of bus tokens; and 10 behavior management classes.

This story illustrates the "Catch-22s," run-arounds, and outright denials that less-privileged families experience in seeking Regional Center services. Unlike the more affluent family featured in the Los Angeles Times story, Angelo's parents could not quit their jobs, hire a private attorney, search the internet, network with other parents, and basically make it their full-time occupation to get adequate Regional Center services for their child.

Even with our help, they ended up with far less from Regional Center than a white, middle-class child with the same disability might receive a few miles away in West Los Angeles. This is wrong.

We and Special Needs Network have submitted joint recommendations to change this tragic inequity, in which children and families already disadvantaged by race and poverty get the least help from the Regional Center service system.



Senate Select Committee on Autism & Related Disorders
Joint Recommendations
April 30, 2012

1. Regional Centers should be required to demonstrate compliance with the case finding provisions of the Lanterman Act by engaging in culturally and linguistically appropriate community-based outreach activities targeting populations that are underserved by that Regional Center and providing notification of availability of services in languages appropriate for those target populations in the service area.
2. Regional Centers should be required to provide eligible clients and families of eligible children with clear, accessible information about the range of services potentially available under the Lanterman Act which can meet client needs identified in the IPP process.
3. Regional Centers should be required to ensure that all written materials and correspondence are translated into languages which clients understand and interpreters are available during IPP and related meetings.
4. Regional Centers should be required to provide, in a publicly accessible format, reports of POS utilization and expenditure data by age, disability, and race/ethnicity on an annual basis. DDS should be required to provide monitoring and oversight of these reports and of Regional Centers' implementation of #1-3 above and other efforts to reduce racial and ethnic disparities in POS utilization and expenditures. The regional centers' outcome-based performance contracts should include a mandatory outcome which evaluates and addresses funding disparities based on race and ethnicity.
5. The Legislature should create a statewide commission to work with DDS in monitoring POS utilization and expenditure data and to determine effective solutions to reducing racial and ethnic disparities associated with POS utilization and expenditures by regional center. The Commission shall provide an annual report to the legislature on the extent of race/ethnic disparities in POS utilization and expenditures by regional center and specific efforts to reduce any such disparities.