



ASSOCIATION OF REGIONAL CENTER AGENCIES
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April 25, 2012

The Honorable Darrell Steinberg, Chair
Senate Select Committee on Autism & Related Disorders
State Capitol
Room 205
Sacramento, CA 95814-4900

RE: ARCA Testimony before the Senate Select Committee on Autism & Related Disorders : Ensuring Fair & Equal Access to Regional Center Services for Autism Spectrum Disorders (ASD)

Dear Senator Steinberg:

California's twenty-one nonprofit regional centers carry out a variety of services for approximately 250,000 Californians with developmental disabilities including intake, assessment, case management, and resource development. The Association of Regional Center Agencies (ARCA) represents the statewide network of regional centers.

In December 2011 the Los Angeles Times published a series of articles written by Alan Zarembo that examined autism rates and public spending on the disorder in California. In one article in the series entitled "Warrior Parents Fare Best in Securing Autism Services"¹ Zarembo summarizes disparities within the educational and regional center systems largely along ethnic lines. As he notes, however, "It might be tempting to blame such disparities on prejudice, but the explanation is more complicated." ARCA agrees with this statement.

Defining the Problem:

Zarembo points to statistics that are reflective of a long-standing concern regarding equal access to publicly funded services in the health and human services field. This issue is neither new nor unique to the regional center system.

Racial and ethnic disparities are present in a variety of publicly funded services. Zarembo's article also points to disparities in service levels to pupils diagnosed with autism within Los Angeles Unified School District, noting distinctions along ethnic and socioeconomic class lines. A study by the California

¹ Alan Zarembo, "Warrior Parents Fare Best in Securing Autism Services," Los Angeles Times 12 Dec. 2011, 17 April 2012 < <http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory>>.

Department of Mental Health² notes that foreign-born Latinos receive minimally adequate treatment at less than half the statewide average rate. An article in the Journal of the National Medical Association³ notes that “the real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in the developing and implementing of strategies to reduce and eliminate them.” The same is true for services in most health and human service delivery systems.

Regional centers have been grappling with the issue of service level disparity in purchased services for more than twenty years. In that time, it has become apparent that the issue is not based in racial or ethnic prejudice, but rather is more a product of the relatively high correlation between minority status, socioeconomic class, language barriers and education levels. A study in 2002⁴ found negligible differences in regional center service delivery levels by ethnicity when accounting for age, client characteristics and residential setting. This sentiment was echoed in a report from the Department of Developmental Services (DDS) to the Legislature in 2003⁵. On the other hand, several analyses of the issue have pointed to challenges associated with poverty as well as limited English proficiency and literacy as larger determinants of access to services. An ARCA issue paper from 1990 notes, “Poverty creates the need for the family to concentrate its available energy on sheer survival and meeting its basic needs for food and shelter before giving attention to secondary issues such as developmental disabilities.”⁶

Regional centers require active participation on the part of families with minor children in order to provide services. The ability of families in lower socioeconomic positions to meet this obligation is limited by several factors. They oftentimes rely on public transportation which is inconvenient and may be cost-prohibitive. They may live in areas which vendors are unwilling to serve, either rural or inner-city. They may move more frequently, which challenges service continuity. They may work in low-wage or agricultural jobs which make taking time off of work to access services nearly impossible. Language and literacy challenges may also exacerbate the problem. Each of these barriers is more pronounced in the provision of intensive services to young children with autism. The time, focus and follow-through required from parents in order to see optimal benefits as well as to meet new legislative mandates related to parent-training and participation may be insurmountable barriers for many.

The Shift of the System:

Regional centers were developed as social work agencies not only to provide an alternative to institutional care for people with developmental disabilities but also to provide support and resource linkages for clients and their families. Over time, as California sought federal financial participation for

² California, UC Davis Center for Reducing Health Disparities, Community- Defined Solutions for Latino Mental Health Care Disparities (Sacramento, 2012) 4.

³ Alan Nelson, “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,” Journal of the National Medical Association Aug. 2002: 666-668.

⁴ California, Department of Developmental Services, A Statewide Descriptive Statistical Analysis of Variation in Purchase of Services Categories for 1995-1996 and 1999-2000: Volume 1(Sacramento, 2002) 1.

⁵ California, Department of Developmental Services, Purchase of Services Study II: Report #1: Modeling the Variation in Per Capita Purchase of Services Across Regional Centers (Sacramento 2003) xi.

⁶ Focus Issue: Ethnic Issues (Association of Regional Center Agencies, 1990) 2.

its community based services, the role of the case manager grew to include increasing levels of paperwork to meet federal standards. As regional center operations budgets have stagnated and shrunk in response to state budget constrictions, changes in service delivery have resulted. Regional center case management staff is now juggling higher caseloads than before, resulting in less time for social work intervention.

Some have suggested that the implementation of a form of self-directed services would help to alleviate the service disparity by providing a pre-determined dollar amount for the provision of services to each client. This is an overly-simplistic response to a complex problem that likely stems more from a lack of comprehension and other access barriers than from a lack of available public funding. One study recently showed that it took an average of 2.6 teaching sessions for patients to learn complex medical information⁷. Services and supports to address a child with autism are intricate and require a great deal of time-intensive explanation.

Unlike other publicly funded agencies, the provision of support, guidance and advocacy by regional center staff is in itself a valuable service to clients and their families. For this reason it is not unusual for many families to have no purchase of service dollars expended on them but choose to remain connected to the regional center system. In a 2004 report DDS notes that "it is clear that the Hispanic families in this sample desired more interaction with their service coordinators"⁸ and that "...concerns might readily be dealt with by increasing the use of bilingual service coordinators who spend additional time assessing family needs and prioritizing their concerns"⁹. Regional centers have implemented a variety of mechanisms to try to bridge the gap in services, ranging from multicultural family support groups to bilingual case management provided by either regional center staff or contract staff from social service agencies that are well-established in underserved communities. Bilingual case management, while effective, is more time intensive due to translation and interpretation issues across settings. In order to recruit and retain bilingual case management staff, many regional centers pay a salary differential to bilingual staff, a cost which is not reimbursed by DDS when regional center operations budgets are calculated. In lean economic times, it is difficult for regional centers to allocate the necessary staff resources to break down these barriers.

Recommendations:

Regional centers adhere to the philosophy that services, particularly those for young children with autism, can be transformational in the lives of our clients and their families. Due to a variety of factors, the current model of intensive autism treatment services that are typically provided in the family home, require high levels of parental participation and are oftentimes inaccessible to families with limited incomes who are disproportionately minorities. ARCA suggests the following strategies as an initial response to addressing barriers to service delivery:

⁷ Kevin B. O'Reilly, "The ABC's of Health Literacy," American Medical News 19 March 2012, 3 April 2012 <<http://www.ama-assn.org/amednews/2012/03/19/prsa0319.htm>>.

⁸ California, Department of Developmental Services, Purchase of Services Study II: Report #2: Determination of Service Variation Across Regional Centers: Implications for Clients and Policy (Sacramento 2004) 8.

⁹ Department of Developmental Services, Purchase of Services Study II: Report #2 11.

- There is a need for research of alternative models of autism treatment for young children that can be provided effectively with fewer demands on parental time. This would alleviate the “all or nothing” access to necessary services.
- A study by the U.S. Department of Education published in 2006 illustrated that only 12% of adults are able to read and comprehend complex medical information¹⁰. This is particularly true for individuals with disabilities and individuals with low education levels or who are not proficient in English. The case manager is in an ideal position to promote greater “health literacy” related to a child’s disability and available services. Additional funding for staff is needed to allow for caseload reduction to permit sufficient time for this intervention to take place.
- The Department of Mental Health awarded grants in 2009 to study disparities in service utilization in their system and to propose methods to reduce those¹¹. ARCA proposes that DDS engage in a similar process with an eye towards making services more accessible to a wider range of individuals.
- Central Valley Regional Center is the recipient of two grants. The first is a Mental Health Services Act grant administered by DDS. The second grant is from First Five, Fresno County. Both grants were funded for the purpose of training representatives of education, social service, and private providers who come in contact with families whose children may be at risk and/or are diagnosed with a developmental disability. The focus of the training is to utilize the “infant mental health model” of providing support to families. If this proves successful in reducing barriers to services for children, funds should be made available to allow other regional centers to replicate this project.
- Regional center clients who are recent immigrants would benefit from greater case management time to assist in navigating available systems. One regional center recently noted that as Latino families grow comfortable with case management staff their reluctance to request needed services drops away. ARCA proposes funding a pilot project to serve some of these clients on smaller distinct caseloads to study whether service utilization increases for this population.

ARCA would like to thank the Senate Select Committee on Autism for convening a hearing on such an important issue for the children of California and for allowing the opportunity to submit written comment on this topic. California remains the only state in the nation with a service entitlement for all

¹⁰ United States, U.S. Department of Education, The Health Literacy of America’s Adults (Jessup: US Department of Education ED Pubs, 2006) 40.

¹¹ California, Department of Mental Health, California Reducing Disparities Project (Sacramento: 2010) 17 April 2012 < http://www.dmh.ca.gov/Multicultural_Services/docs/CRDP_FactSheet_Final_February2010.pdf>.

residents with a developmental disability. It is imperative that we work to find solutions to make these services more readily accessible to all young children with autism that we serve.

Sincerely,

A handwritten signature in black ink, appearing to read 'Eileen Richey', written in a cursive style.

Eileen Richey
Executive Director

Cc: Senate Select Committee on Autism & Related Disorders
Louis A. Vismara, M.D., Chief Consultant