Activists criticize state over unequal autism aid; Advocates testify that families with fewest resources get the least help for their children.

BYLINE: Alan Zarembo

California lawmakers and advocates for children with autism assailed the state Department of Developmental Services during a hearing Monday over the deep racial and ethnic disparities in how it spends money on the disorder.

"Families that are already the most disadvantaged get the least," Martha Matthews, an attorney for the advocacy group Public Counsel, told a panel of legislators in Sacramento. "This is exactly the opposite of what it should be."

State Senate leader Darrell Steinberg (D-Sacramento), who heads a committee on autism, called for legislation to provide greater accountability in the $4-billion-a-year entitlement program for people with developmental disabilities. Autism now accounts for about a quarter of the 252,000 people in the state system and 45% of all new disability cases it accepts. Budgets have not kept pace.

Steinberg ordered the hearing in response to articles in The Times documenting how obtaining help for an autistic child can require waging battle against the gatekeepers of state services. Parents with the time and resources to fight receive much more, resulting in enormous racial and socioeconomic disparities.

It is not uncommon for autistic children from affluent families to receive 25 hours a week of one-on-one behavioral therapy. On the other hand, advocates said, poorer parents aren't necessarily even told what public services are available.

Matthews recounted the case of a severely autistic 6-year-old boy whose parents, a laborer and a seamstress who speak only Spanish, asked for individual behavioral therapy. The request was denied, despite a doctor's insistence that it was necessary. Instead, the state provided a month's supply of diapers, bus passes and 10 group classes in behavior management.

"This is such a hellish nightmare," state Sen. Mark Leno (D-San Francisco) responded.

In its December series, The Times found that for autistic children ages 3 to 6 -- a critical period for treating the disorder -- the Developmental Services department spent an average of $11,723 per child on whites in 2010, compared with $11,063 on Asians, $7,634 on Latinos and $6,593 on blacks.

"Black and brown children are discriminated against," testified Areva Martin, a Los Angeles lawyer who runs the Special Needs Network, which advocates for poor minority children.
"Parents should not be expected to sell their homes, quit their jobs and relocate to access services."

State money for the developmentally disabled flows to service providers through 21 nonprofit regional centers, which decide whether a child has a qualifying condition and what services to provide. Services are free for life, regardless of a family's means. In principle -- but not in practice -- everybody has the same opportunity for help. Regional center officials testified the state budget crisis has worsened long-standing inequities.

Harried case workers have less time to find "creative solutions," said George Stevens, head of the North Los Angeles County Regional Center. The process used to award services is "slowly crashing down on clients it was intended to serve," he said.

Dexter Henderson, head of the South Central Los Angeles Regional Center, said many families in his largely impoverished area did not aggressively pursue services and the regional center "has zero dollars to advertise."

In 2010, the center spent an average of $1,991 on each autistic child age 3 to 6 -- the lowest in the state. The center in Orange County had the highest average spending, at $18,356 per child.

Terri Delgadillo, head of the state Developmental Services department, testified that regional center budgets eventually will be set so that similar amounts of funding are available for clients with similar needs.

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