

## Senator Champions Services for Families and Kids with Special Needs

Republican [Senator Tony Strickland](#) (19<sup>th</sup> District) visited with families, Social Service Providers and Therapists in the community on Tuesday, October 13, 2009, to hear about the direct effects the CA State Budget cuts have had on people with developmental disabilities. In late August, the Senator signed on as a co-author of [AB 1260](#) aimed at amending some of the recent reductions made to Respite Care.

His first stop of the day was to [Channel Islands Social Services](#), a family run organization based in Camarillo that provides In-Home Respite Care to hundreds of Ventura County families. CISS serves families with children and adult relatives who have developmental disabilities such as Autism, Down Syndrome, Cerebral Palsy, Mental Retardation, Epilepsy and other special needs. When a child is diagnosed with a developmental disability, the child then qualifies for life-long Regional Center funded services such as Respite Care designed to give parents a break from the demands of daily caregiving. At [Tri-Counties Regional Center](#) (TCRC), most families qualify for 8 - 25 hours/mo of In-Home Respite Care.

Senator Strickland was visibly moved after listening to the very personal experiences of five local families who are raising children with special needs and how much Respite Care has meant to them. The del Aguila family have three boys under the age of 10 who have varying forms of Autism. Joined by her husband Fidel, Griselda del Aguila voiced the struggles of many families who are doing their best to raise their children in this very difficult economy and in a society that is not understanding about Autism. "I am confident that the State of California will not give up on these children," she said in a prepared letter read to the Senator. "Respite has been an extremely valuable form of assistance for my family. Without the support of my Respite Caregivers through Channel Islands Social Services, my family would be unable to live a 'normal' life."



With her seven year old son playing next to her, Renee Ballard, parent and [Ventura County Autism Society](#) Vice-President, discussed how beneficial Respite has been over the years to allow her and her husband some time together. She reviewed the recent findings published in the journal [Pediatrics](#) showing a marked increase in the prevalence of Autism in children age 3 – 17. "It used to be 1 in 150 children had Autism, but this study now shows Autism occurs 1 in 91 births or about 1% of U.S. kids." Since Autism affects boys three times greater than girls, the study shows that Autism now occurs in 1 out of 58 boys. Senator Strickland expressed concern and questioned this steep rise. Ms. Ballard shared that the exact cause is still unknown, with varying professional and parental opinions, and that Autism continues to be studied. The Senator was presented with a copy of the recent study and with an Autism Awareness pin he proudly wore on his lapel.

Andrea Boles choked back tears expressing her daily joys and struggles just to keep her daughter Madison, who will soon be eight years old, living at home and going to school. She shared how difficult it is as a single mother to raise three children and how the recent cuts to Respite and to the [In-Home Supportive Services](#) (IHSS) program will be devastating to her family. Mady has a rare diagnosis of [Rett Syndrome](#) and uncontrolled seizures. Andrea shared that the Pleasant Valley School District has not been able to support her in a classroom for over a month due to her care needs. Her respite hours were recently cut by TCRC and she plans to appeal. "Nobody has a clue what it's like to raise a child with intensive needs – they even told me that I should put her in a group home. Don't they realize that would cost the state even more money and would not provide the best care for her!" exclaimed Andrea sitting with her long-time Respite Caregiver, Gina Cantrell.



"The State has chosen to make short-term cuts affecting many essential services that are going to cost much more in the long-term," stated Lori Boehm, parent, [Special Needs Advocate](#) and long-time associate of the Strickland family. Lori helped to organize the day's tour and the Senator thanked her for keeping him informed over the years on issues affecting the special needs community.



"My husband Tim and I started this agency to help families support their children to stay living at home and every child deserves a healthy family," stated Sharon Francis, CEO of Channel Islands Social Services. "It was very frustrating to find out on July 28<sup>th</sup> when the State budget passed that service reductions were made retroactive to July 1<sup>st</sup> after we had already provided hundreds of hours of service in good faith. Families are now limited in the number of respite hours they can receive each quarter and as of October, the State will no longer fund most Respite Care for kids under age 3. Our agency supports AB 1260 and Senator Strickland's bipartisan efforts to get this Urgency bill passed. We also hope that the State reverses the cuts to Regional Center operations since the Service Coordinator caseloads are now over 100, which makes it nearly impossible for them to get to know each person's needs."

Commenting later by email, Mike Huckins, President of the [California Respite Association](#), stated "The recent legislation was rushed and families and caregivers are suffering the effects. The budget trailer bill language placed arbitrary caps on the amount of support that families can receive. The budget cuts were aimed at saving \$5.2M from respite services, but our members have demonstrated that the impact will be closer to \$50M or about 15% of the overall state respite allocation. This is on top of the 3% cut that respite agencies have already received earlier this year. The CA Respite Association supports AB 1260, which proposes to achieve the targeted savings by removing this cap and replacing it with a 2% reduction in the amount of authorized respite services. In so doing, the burden of the cuts will be shared by everyone equally, and not just by those most in need." (To learn more about this and other bills, go to [www.leginfo.ca.gov](http://www.leginfo.ca.gov) and type in the bill number to view content and status.)

Channel Islands Social Services had to lay off one Administrative staff due to budget cuts and the agency is very worried about the effects of additional cuts on families, Respite Caregivers, and the agency's ability to continue to recruit, retain and adequately pay staff. "Respite care is vital in strengthening families. It is so hard for any parent to take time out for themselves and their spouse, but it is especially difficult when you have a child who has special needs," said Ms. Francis. "Families deserve caring, qualified, well-trained people helping them and we have been very fortunate to be invited into the private homes of families to help provide some needed relief over the past 5 years."



After autographing some basketballs he gave to the kids, Senator Strickland traveled to Newbury Park to tour "The Center", where an array of therapeutic services such as Speech, Occupational, and Physical Therapy are provided to children and adults. He had the opportunity to meet the staff of [Communication Matters](#), and was particularly intrigued by the gym where [Therapy in Action](#) provides Occupational Therapy. Two moms proudly shared the success stories of their toddlers who participate in speech and occupational therapy at the Center. They acknowledged that their participation in the Early Intervention pilot program run by the non-profit Center for the Whole Child, privately funded for the first year by donations, was at the core of their success. Unfortunately, the outstanding program which all had hoped would be funded through Early Start has been forced to close.

All present expressed disappointment over the drastic cuts to the State's [Early Start](#) program, which serves children under the age of three years. The changes include the elimination of services to children who are at high risk for developmental delay and the re-structuring of criteria which determines if a young child is eligible for services. Mindy Newhouse, Speech-Language Pathologist and Co-Founder of Communication Matters and Center for the Whole Child, discussed the effects of the recent cuts. "A child must now demonstrate severe delays to qualify for early intervention services from regional center, yet the burden is placed on the family who must first determine if their medical insurance will cover the needed services," Ms. Newhouse stated. "Unfortunately, the medical insurance maze is quite difficult for both families and providers, and creates yet another barrier to service." She explained to the Senator that there are few providers who understand insurance, fewer 'preferred providers', and the medical insurance system is resistant to cover 'delays'. Additionally, families must pay deductibles and co-pays for the services which many cannot afford.



At each visit, Senator Strickland expressed his appreciation to the families and providers and stated that he intends to continue to push AB 1260 forward. The bill has bipartisan support and it has been stalled in Sacramento now for a month, despite it having Urgency Status. He conveyed that as a husband and father, he knows how stressful and rewarding parenting can be, even for families who have children without special needs and he is dedicated to helping in whatever way he can. Local families will be holding him accountable to his future votes, especially now that he is better informed of the issues.

Photo Captions:

1. Fidel and Griselda del Aguila, parents of three boys who have Autism and receive Respite Care through Channel Islands Social Services, speak to Senator Tony Strickland
2. Renee Ballard's seven year old son plays as his mother speaks to the Senator about the rise in Autism diagnoses in the U.S. and the benefits of Respite Care for families
3. Senator Tony Strickland pausing to take a photo with Andrea Boles and her seven year old daughter Madison with their long-time Respite Caregiver Gina Cantrell
4. Sharon Francis, CEO of Channel Islands Social Services, speaks to the Senator and group of parents about the devastating effects of the recent State Budget Cuts.
5. Senator Tony Strickland, L.A. Lightning Basketball player, autographs balls to give to the kids at Channel Islands Social Services
6. Senator Tony Strickland visiting with Chris Burkholder, The Center Clinic Coordinator, and Mindy Newhouse, Speech-Language Pathologist and Director of Communication Matters