

**San Andreas Regional Center Legislative Breakfast
April 23, 2010, Seascape Golf Club**

Presentation by Sabrina Manno,
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My name is Sabrina Manno and I'm both a parent of a child with a developmental disability, and a provider of programs and services for children with disabilities in Monterey County.

As a parent, I can share with you the challenges of raising a child with severe special needs and how parents are doing their part to ensure the best possible future for their child.

Like most parents of children with developmental disabilities, after learning my child's diagnosis, I quickly assumed the role of part-teacher, part-therapist, part-pediatrician, part-psychologist, full-time advocate, and professional stain remover. My family has expanded to include a vast team of professionals with new and evolving titles and credentials who ebb and flow through our lives year after year. Diagnosed with an Autism Spectrum Disorder, mental retardation and global developmental delays, my son, Marcus, also suffers from severe gastrointestinal problems, has a history of self-injurious behavior, and is non-verbal.

To-date, Marcus has been seen by 6 neurologists, 3 psychologists, 2 gastroenterologists, a craniofacial specialist, a pain management specialist, and a multitude of pediatricians. He's worked with physical, occupational, speech, and behavioral therapists, plus dozens of teachers and instructional aides. He's had 2 brain MRI's, 2 EEG's, 2 endoscopies, a colonoscopy, 2 hospitalizations for gastrointestinal complications, major dental work under sedation, and countless blood draws. He's worn a cranial helmet and ankle braces, and has taken over 30 different medications and supplements.

Marcus is only 6 years old.

As you can imagine, all of these doctors, therapists and procedures have come at a price. Private insurance coverage is limited. Check the Autism box on any medical billing form and you're guaranteed little-to-no cost coverage. Some professional's fees range from \$100 to \$500 per hour – many don't bill insurance directly and most require payment up front, leaving parents to battle out reimbursement appeals with insurance companies. In six years time, my family has incurred over \$40,000 in expenses from our son's medical bills and we are *still* without a concrete diagnosis for his severe gastrointestinal issues.

In addition to being a costly journey, having a child with a developmental disability has had a profound impact on my family. It has impacted my marriage, sibling relationships, parent/child relationships and relationships with friends and family. Thus far, my husband and I have escaped the 85% divorce rate for parents of children with Autism, but we are far from unscathed by the tremendous pressures of parenting our son. My eldest daughter, Madeleine, Marcus' twin sister, suffers from a kind of post-traumatic stress disorder after being exposed to Marcus' 2-year binge of screaming, head-hitting and aggressive behavior – peaking at over 400 head hits per day and culminating in smashing his head through a plate glass window. My youngest daughter, Gabrielle, arrived after most of Marcus' severe

behavior had subsided, yet emerged as the occasional victim of a biting or scratching incident. Though supportive from a distance, family and friends on the East Coast don't understand why we resist traveling to visit them. While local friends, mostly comprised of other special needs families, *do* understand – Marcus' difficulty with changes in routine, and unfamiliar people and places prevent us from taking long trips... or any trips at all.

As a parent, I can tell you that I worry about what the future holds for my son. Just the other day, my daughter, Madeleine, asked me "Mommy, will Marcus have Autism when he turns 7?" I answer, "Yes, Madeleine, just like some people have red hair, or blue eyes, or only one leg, Marcus will always have Autism." "But Mommy," she continues, "who will take care of Marcus when you and Daddy are grandmas and grandpas?" (meaning when we're old) I told her "Don't worry, Madeleine, we'll find someone to take good care of Marcus." She worries and I worry. Still nonverbal and with a projected adult cognitive age of 5 years old, I worry about what kind of life Marcus will have after I'm gone. Will he be happy? Will he be treated with kindness and compassion? I worry because I know that *he* will know the difference.

Amidst a sea of worries, costs, emotional trauma and frustration, Early Start services provided through San Andreas Regional Center offered us a lifeboat. At just 14 months of age, Marcus began an early intervention program that provided a jump start to learning and dramatically increased his gross motor skills, enabling him to participate in age-appropriate physical activities. Equally as important, Early Start services provided our family with a critical lifeline of support, information and training, helping us to cope with Marcus' disability and learn new ways to build our family around him. With Early Start services now at great risk of disappearing – despite overwhelming evidence to support early intervention – what lifeboat will newly diagnosed families cling to?

My story is not uncommon – circumstances may vary, but the impact is universal to each family. I tell you my story not to gain your sympathy, but to let you know that parents are doing their part to support their child while shouldering the tremendous pressures and demands of raising a child with a developmental disability. They understand well and accept their responsibility whole-heartedly, but would be lost or (worse yet) *fail* without the network of supportive programs and services provided through San Andreas Regional Center.

That is what I can tell you as a parent.

As a provider, I can tell you that developing and operating programs for persons with developmental disabilities is no easy task. Maintaining quality, meeting requirements, hiring experienced staff, and sustaining programs requires great tenacity. All the while, gaps are widening in the continuum of services. Already gone are recreational programs that provided socialization and integration opportunities – the last essential step toward community inclusion. Raise your hand if you ever participated in a recreational or extracurricular activity, sport, camp or class when you were growing up? Shockingly, 75% of participants in our Special Kids Crusade Adaptive Skills Program have *never* participated in a single extracurricular activity or recreational experience and another 19% have only participated in wholly adaptive programs. How can inclusion occur if those community integration opportunities don't exist?

As a provider, I also worry about the future of programs and services for *all* persons with developmental disabilities. Legislation, rights and responsibilities for these individuals have only developed within my lifetime. The deinstitutionalization of persons with developmental disabilities occurred as recently as the 1980's, when recommendations for community-based services provided the rationale for public funding, agency development, and programs and services designed to return individuals to a home environment. Imagine if 40 years ago, your parent's only choice was to place you in an institution with no educational provision, no chance at community integration, and no more than orderly services for your basic care and feeding? We as providers, agencies, and legislators have a responsibility to maintain the network of community-based programs and services that families have come to rely on.

With additional cuts to programs and services being considered, there are decision makers who are asking themselves, "What difference will these cuts make?" and "Will they even know the difference?" As a parent *and* a provider, I'm here to tell you that they *will* know the difference. Families will be stressed to the breaking point, and children who once had opportunities to become contributing members of their community will concede to lifelong segregation. Once enacted, it will be difficult to undo the damage of these decisions. Do not allow us to move backwards in time. Do not cut Early Start and close the front door to programs and services. Do not sink the only life boat families cling to. When we've come so far, let us not fail families now.

Thank you.