

A Place Where No One Is Alone

Agency offers support and more for families who need it most

When parents first learn that their child has a disability or special health care need, they are plunged into a frightening new reality of testing, diagnosis and treatment. They may feel afraid for their child, uncertain where to go for information, and very alone.

The staff of nonprofit Support for Families of Children with Disabilities is all too familiar with this situation. Many of them are parents of children with disabilities or special health care needs, and they too have spent sleepless nights worrying about their children and how to find proper care and services for them.

Support for Families began as a support group formed by two parents in 1982, and has blossomed into an extensive organization providing approximately 600 families each year with information, education and parent-to-parent support. The Human Services Agency underwrites the organization's phone line, support groups and trainings.

"We exist to help families minimize the impact of disabilities and special health care needs," said Executive Director Juno Duenas. "When they're informed and educated about how the system works, and what their child's particular situation is, they're better able to get the services that will help that child become as independent as possible. There are a lot of opportunities for these children, no matter how severely disabled they are. Unfortunately, because systems are so complicated children may lose out on opportunities that would help them become contributing members of society."

Unlike many of the other systems and organizations which serve this population,

Support for Families is completely parent-focused in its structure and services. "A lot of families get bounced around from one system to another," said Duenas, "but here there's no eligibility requirement, no time frame. They can just call us or drop in. If what they need doesn't exist, we'll make networking opportunities to create it."

Parents come to Support for Families for a range of conditions, from asthma to autism, Down Syndrome to cerebral

palsy. Some don't yet have a diagnosis for their child's behavior or medical status. They find a wealth of information and support, no matter what their situation is, and a warm welcome from their first call or visit.

"All of our community resource parents who staff the phone line have children with disabilities or special health care needs," said Nina Boyle, the agency's Family Resource Center Program Manager. "They can help callers in English, Spanish, Cantonese or Mandarin. From the beginning, we try to build relationships with the parents. They may call us with just one question, but we encourage them to tell us their story so we can figure out how to support them. The community resource parent will call them back in a week to see how they're doing. Some families stay in touch with us for many years."

Staff can provide crucial information for parents trying to navigate the world of services outside the agency. But Support for Families also offers an enormous array of in-house services as well. There is a huge list of support groups, including those that focus on a particular age range or disability, or others which are for families whose children are recently diagnosed, or who are transitioning to adulthood. "These parents are fabulous resources for one another as they learn to navigate the system," said Boyle. "We represent a small percentage of the population, so creating opportunities for shared experiences is really important."

Volunteer parent-to-parent mentors provide crucial emotional and technical support. The agency's resource library is



Nina Boyle and the Support for Families resource library.

These parents are fabulous resources for one another.

Nina Boyle, Family Resource Center Program Manager, Support for Families

stocked with books, videos and audio tapes in multiple languages, from reference materials to children's books that depict people with disabilities. The library is available to both families and professionals looking for more information. And Support for Families also hosts monthly workshops on topics including Individualized Education Plans, Social Security Disability Insurance, transitioning into the adult system, and assistive technology. These workshops are hosted in multiple languages for small groups, so everyone's questions can be answered. Much larger periodic workshops open to both families and professionals such as case managers and social workers are held on topics such as emergency preparedness.

And then there's fun. Every quarter the agency hosts a special event so families can just get together and enjoy themselves. "We have a winter ice skating party where we take over the Yerba Buena Gardens ice skating rink," said Boyle. "We had 400 people this past winter, with wheelchairs and walkers and parents who'd never skated all on the ice together."

But perhaps the most crucial service Support for Families offers is the peer-to-peer mentoring program. Parents of children with disabilities and special health care needs volunteer to attend extensive training sessions and serve as mentors. Laurie Strawn, who first came to Support for Families seeking help for her daughter, has been a parent mentor for three years.

"I get calls from parents who want to talk to another parent one-on-one to get support, information, resources and a shoulder to cry on," said Strawn. "Support for Families matches us up with parents whom they think would really be appropriate for us to talk to. It gives me a chance to give back some of the feeling of connection and support which I've been given through this agency. And it's an honor to have someone who is going through the biggest adventure of their life be so forthcoming and open about their experience with me. It's a human con-

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Laurie Strawn, Volunteer Peer Mentor

nection that is so important, and I'm so pleased to be able to help them feel like they're not alone."

Strawn is a strong believer in the importance of information and resources to help families cope. "I've always been someone who wants to be educated when I'm in a difficult situation," she said. "I go brain forward. It's overwhelming to find out your child has a disability. You already have these enormous emotions of protection and love for your child, and an all-consuming interest, and then when there's an issue that somehow poses a threat to them, you're stunned. I love that in the support groups, you're accepted for however you are. If you're feeling good and optimistic, or you're feeling low and raw, or anything in between, it doesn't matter. No one has the energy to put up any walls. They can just be who they are, and be in love with their child. It's almost spiritual. You'll never meet more amazing human beings than these parents."

Strawn first approached Support for Families when her daughter was diagnosed as having had a prenatal stroke. "We mentioned to the pediatrician at Julia's three-month well-baby visit that she only used her left side," she said. "He wanted us to see a neurologist. Eventually we found out she'd had a serious stroke before she was born."

Julia's stroke means that she's considered to have a mild form of cerebral palsy. Her condition has responded well to various types of physical therapy, especially because her brain injury occurred when



Laurie Strawn and her daughter Julia.

she was very young. Glasses correct her vision, and an orthotic device helps her walk well. Like most little girls her age, Julia is looking forward to going to mainstream kindergarten in the fall. "We're thrilled that she's only mildly affected," said Strawn. "She's a very adorable, verbal five year old, and she can attend school with only some minimal accommodations."

From Strawn's perspective, one of the biggest strengths of Support for Families is the agency's approach. "They have this amazing attitude that I encounter every time I talk with them," she said. "Their attitude is 'absolutely yes, we can help you.' Even if they don't have the exact answer or support group at their fingertips, they're excited that you're calling. Some of the parents who come in have been through real battles for their children, and they're in a very sensitive, difficult space. And here they encounter an organization whose whole bent is 'yes, you have reason for hope here. We're glad you called. We can help.'"