



EXCEPTIONAL TIMES

FALL NEWSLETTER 2007

*The mission of
Exceptional
Parents
Unlimited
is to strengthen
and empower
children and
families facing
extraordinary
medical,
developmental
and parenting
challenges.*

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- EPU Is On-line

A Family's Journey Haley's Story

Jon and Cara Lacey were living the American Dream with great careers and two beautiful daughters, Emily and Ciara. Cara had a difficult second pregnancy which caused concern when they got the news she was expecting again. The grim reports of differing possibilities exhausted the couple. Because of their beliefs they made the decision to stop testing and wait for the arrival of this new addition to their family. When Haley was born seven weeks premature to their joy, she appeared to be fine.

Like so many families who come through our doors, the journey begins with a mother noticing there isn't something quite right with her child. Cara kept mentioning to the pediatrician that Haley wasn't developing like her other children. There was a wait and see approach taken by the doctor believing children develop at different speeds. By six months Haley was unable to hold herself up, she wasn't smiling and seemed to be disconnected. All the tests seemed to be fine, but the Lacey's were convinced Haley was not fine. They were given a referral to CVRC where it was confirmed Haley was not on track and there was cause for concern, but no clear diagnosis. The Lacey's were referred to EPU to begin the process of working with the challenges they did know.

Cara said about her journey here that, "The staff researched materials for me and was with me every step of the way. I would have been completely lost without this place. The support



and genuine love for every child that comes through that door baffles me. I know they have many people they are working with, but you feel like they are just there for you." Haley was immediately placed with an early interventionist, a physical therapist, occupational therapist and Cara had support groups where she met with other parents. There were many painful sessions of therapy with Haley because she had multiple sensory issues which made it unbearable to put her feet on the ground. Through perseverance of the team and dedication of a loving hands-on family, there was noticeable progress.

At 10 months the Lacey's met with a geneticist who said there were clear signs of autism, but wasn't convinced that was the only issue. She did further blood tests which revealed the diagnosis of Fragile X, a genetic condition which presents with symptoms of autism, developmental delays, feeding issues and later a seizure disorder. Haley had been a mystery because Fragile X is usually seen in boys. With a diagnosis now in hand EPU staff became their resource for Fragile X doing research to build a future plan! "We came here 4 days a week for all the different services which created an issue for Haley's sister Ciara, only a year ahead of Haley. EPU was a great place for Ciara she had a sense of normalcy because she was able to be in toddler group and have the pre-school experience she was not able to have because of

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Heart to Heart



This morning I walked out of my office into the hallway and was greeted by 2 1/2 year old Campbell who was curiously and proudly exploring the hallways with the assistance of her very tiny walker and little pink glasses. I leaned down to talk to her, and she came toward me with arms held out in a way that let me know she wanted a hug. What joy I felt as I took her into my arms and felt her nuzzle into my shoulder. Every now and again, experiences like this remind me of just why EPU exists.

So often when we meet families, they are frightened as they and their children face uncertain futures by less than hopeful information filled with predictions of what their children won't be able to do. Yet, once within the care of EPU's diverse and caring staff, each child is allowed to write his or her own story. We often comment that our little ones don't read the books - they write their own!

Our work here at EPU centers on our children and their families and the uniqueness that each brings to life. With a wide array of services and programs which have merged multiple funding sources, families can receive what they need and we can keep the challenges of funding our services behind the scenes. One of our important goals is to keep the complexities and frustrations of the service delivery system as invisible as possible so that parents can concentrate on the important asks of nurturing their children and meeting each child's unique needs.

It is through the help and dedication of our friends in the community that EPU is able to serve so many children and families with comprehensive services. I hope you will take the opportunity of coming by for a visit so you too can experience the joy in the smiles of our children and the gratitude of their parents.

Marion Karian
Executive Director

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Ambassadors For Children

"Ambassadors for Children" are individuals who share a commitment and provide a voice to those in our community who are interested in improving the lives of vulnerable children and families with special needs. If you would like to learn more about EPU and how you can become an Ambassador for Children, please join us for an informational luncheon and tour on October 16, 2007 at 11:30 a.m.

For reservations, please call Rita Easley at 229-2000, ext. 150.

Dreams come one size too big . . . so you can grow into them.

- 1976** Marion Karian, RN, started the first parent support group at Valley Medical Center.
- 1979** The first parent was hired to work part-time in the program.
- 1980** The first early intervention staff was hired. This included a full time Nurse, Social Worker, Parent and Community worker, and part time Pediatrician; Occupational Therapist; Physical Therapist and Speech Therapist.
- 1991** EPU became incorporated as an independent private non-profit corporation. The Infant Family Program consisted of 17 employees; Family Resource Center had about 8.5 employees.
- 1992** A new program was created, the Learning About Parenting Program (LAP) consisting of three new employees.
- 1998** LAP expanded; adding yet 10 new positions. These positions consisted of Home Visitors; an RN; Social Worker (Team leader); Child Development Specialist; Program Manager and Program Assistant.
- 2001** Play-N-Grow was formalized. This program consisted of a Program Manager, Developmental Assistants, Program Assistants and a Transportation Coordinator.
- 2003** A new program opened - Child Development Services. This program consisted of two Pediatricians; a Program Manager; Nurse Practitioner; Receptionist and Program Assistant.
- 2005** Assessment Center opened its doors; with a total of 17 new employees.

With a total of 105 employees and 5 programs in 2007, we remain committed to strengthening and empowering children and families facing extraordinary medical, developmental and parenting challenges. We continue to do so keeping cultural diversity and competence a priority.

Meet our staff...

We currently have: 8 Psychologists and 1 Pediatrician
4 Registered Nurses, 2 Occupational Therapists,
4 Speech Pathologists and 1 CPA
13 employees have Masters Degrees (12%)
36 employees have Bachelors Degrees (34%)
44 employees are bilingual (41%)
62 employees are bicultural (57%)
29 employees have children or someone closely related to them with a disability.

My, How we've grown!

Assessment Center For Children (ACC)

The Assessment Center for Children provides assessments of children birth to five years of age. Parents, pediatricians, childcare providers and others who have multiple concerns about a child's learning, development, behavior or socialization may refer to the center. Assessments are conducted by a team of professionals from many disciplines and multiple agencies including the family.

Professionals include:

Developmental pediatrician, occupational and speech therapists nurses, infant and child mental health clinicians, and psychologists.



Family Resource Center (FRC)

The Family Resource Center is the umbrella for programs for parents of children of all ages with disabilities and other special needs. Each member of the Family Resource Department has a child or a close family member with a special need.

- Parent to Parent Support Groups
- Parenting Classes
- Individualized Education Plan trainings and clinics
- Individualized Family Service Plan trainings and clinics
- Assistance in advocating for services
- Resource information, coordination and referral
- Services provided in English, Spanish and Hmong

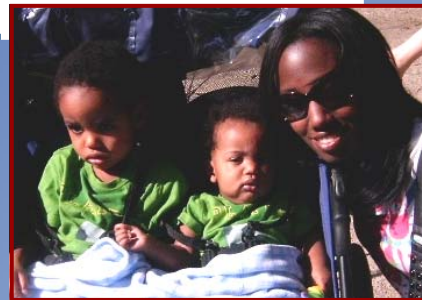


One Call For Kids

"One Call for Kids" is the number to dial for finding help when there are concerns about children 0-5 years of age. One call opens many doors. The system of services is large and complex and "One Call for Kids" will assure there is no wrong door to access services throughout the community.

559/225.1102

- Child centered and family focused
- "Plan of Care" development
- Interpreting and transportation available as needed
- Support for families both prior to and following the assessment
- Assurance of a warm hand-off to community based providers and services



Learning About Parenting (LAP)

The LAP program serves families whose Children are birth to five years of age. The Program focuses on families in which parents are overburdened with life challenges that impact their ability to be effective parents to their children. The LAP program provides home visitation, center based classes, support groups, and interactive play groups. The LAP staff works to assure that families are nurtured and children are safe.

- Home visitation
- Anger management
- Family advocacy
- Life skills classes
- Smoking Cessation
- Health education classes
- Infant-family mental health services
- Parent support groups
- Rural outreach
- Substance Abuse Support and Education



Infant Family Program (IFP)

The Infant Family Program helps infants and toddlers get off to a good start. This program serves infants from birth to three years of age whose development is delayed, who have a diagnosed condition that is known to cause developmental delays, or who have serious medical conditions or risk factors which may affect their development. The Infant Family Program is a place where infants and parents can learn together. Children participating in this program must qualify through Central Valley Regional Center.

- Center based intervention services
- Service coordination
- Home visitation
- Transportation
- Rural outreach
- Parent support groups
- Family mental health
- Individualized Family Service Planning
- Child centered and family focused services
- "Play and Grow" groups for infants and toddlers
- Services available in English, Spanish and Hmong



Ask Dr. Dana

One of the biggest issues I work with as a psychologist is sleep deprivation; a condition that causes poor attention, poor memory, irritability, moodiness, angry outbursts, and hyperactivity. Sleep deprivation is so common in kids (and adults) that I routinely ask about sleep habits in my first meeting with parents. The best bedtime for toddlers and preschoolers is between 7:30 and 8:30 p.m. How do you know if your child is getting enough sleep?



Ask yourself these questions:

- Does my child fall asleep in the car almost every drive?
- Do I have to wake my child up almost every morning?
- Does my child seem overtired, cranky, irritable, aggressive, over-emotional, hyperactive, or have trouble thinking during the day?
- Does my child sometimes "crash" much earlier than their usual bed-time, or does my child sometimes sleep in late?

If you answered yes to any of these questions, your child may be sleep deprived. So, what can you do?

First, make sure bedtime is a calm and pleasant time. Do not engage your child in any rough housing or active play before bed. Second, turn off the TV. one hour before bedtime. Third, create a routine bath, pajamas, snack, brush teeth, bedtime story, cuddle and tuck in. Fourth, dim the lights: use a small nightlight or, if your child demands more light, place a blue or green light bulb in a small lamp. Finally, if your child has a hard time falling asleep use white noise (run a fan, play a relaxation CD of the ocean or rain, or use a white noise maker). What if your child's bedtime is much later than the 7:30 to 8:30 recommended time? Work your child's bedtime back by 15 minute intervals every few nights. For example, if your child falls asleep at 10 p.m., put him/her to bed at 9:45 p.m. for three nights, then 9:30 p.m. for three nights, then 9:15 p.m., etc... You'll know when your child is getting enough sleep when he/she is getting up on his/her own and staying alert and happy throughout the day. Good luck.

Aloha,

Dr. Dana

Haley's Story *Continued from page 1*

Haley's schedule. My kids grew up here. There is such support and care for the entire family. The team got Haley walking and touching things so much so that I couldn't stand it on the days I wasn't here." This inspired the Lacey's to enclose their patio and build a room for Haley right at home. Through the Physical and Occupational therapist team's instructions and care, they now had a space where therapy was continued at home. Haley is now four and can run, has simple and improving language and loves her moments at the water park with the family floating down the lazy river.

This has been a huge transition and lifestyle change for the Lacey's.

Cara went from corporate Recruiter to grieving parent to mom on a mission. She believes the love and care they received at EPU, inspired and empowered her to use her voice to give back. She has spoken before congress with the Fragile X Foundation and has become an advocate in our community on behalf of children like Haley and with our Family Faculty. Life is not easy for any family who has a child with special needs, but it doesn't have to become insurmountable when there is an open door with loving arms waiting on the other side. Exceptional Parents Unlimited is not just a name it's a statement of the heart.



How much sleep does a kid really need?

Here's a handy dandy chart:

Age	Hours of
0 to	Up to 18 hours
2 to	14 to 15 hours
12 m	14 hours
18	14 hours
2 yrs	13 hours
3 yrs	12 hours
4 yrs	11.5 hours
5 yrs	11 hours (no nap)



exceptional parents unlimited, inc.
4440 North First Street
Fresno, California 93726

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Exceptional Parents Unlimited is Online

Our site is updated regularly in both English and Spanish and offers parents many helpful tools to help support and assist you in navigating your child's future.

- EPU service information
- Disability specific fact sheets
- Thought provoking articles
- Calendar of events
- Contact information for EPU and staff
- IEP information and how to schedule a one on one clinic
- IFSP information
- Information on Parent Groups
- Link to Tumble Books free on-line reading program
- Podcasts: Interviews with parents and professionals
- Personal stories
- Cataloged EPU newsletters
- Links to topical web sites
- Parent resources
- About our on-site Resource Library



*Getting off
on a
good start.*

Find all this and more at:
www.exceptionalparents.org