



SPIN NEWS

Special Parents Information Network
Serving families of children with special needs

Volume 2 • Issue #3 • September 2002

Planning for the Future: Wills and Trusts

SPIN

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Your Family's Future

Basic Estate Planning For Children with Special Needs

By: Mitchell A. Jackman, Attorney At Law

Someone once told me, "If you really want to get back at your family, don't do anything." It has been my experience that most people want to take care of their families, they just do not take any steps towards planning for disability or death. There is a good reason. It is not easy to think or talk about these things.

It has been estimated that less than two percent of the population has a formal estate plan. However, there is never a bad time to get started on a plan for your family's future. This article is a basic introduction to estate planning for the family who has a child with special needs. Actually, good estate planning is not that much different for children with special needs than it is for any child.



The Basic Tools of An Estate Plan:

Every estate plan is like a fingerprint. No two plans are exactly alike. Most estate plans include some basic components. Here are a few of them to consider.

A Will is really nothing more than a set of instructions after someone has died. It does not serve any other purpose. Contrary to popular belief, a Will does not avoid court supervision of your financial assets if you become disabled or die. Wills have a very important role in the basic estate plan. It is a good starting point for most people. By themselves, Wills are truly not enough to get the job done.

Trusts are an arrangement for someone (a "Trustee") to hold and manage financial assets for another person (a "Beneficiary"). Trusts can be created within a Will. These are known as "Testamentary Trusts" because they only exist after someone has passed away. The more common type of trust is a "Living Trust." These trusts are created during a person's lifetime to avoid court supervision of a person's financial assets if they become disabled or meet with an untimely death. Living Trusts are different than a Will. They are a separate document and require a greater level of attention to planning and detail.

A Power of Attorney is designed to reduce the chances of court supervision of your financial affairs if you become disabled. They have no purpose after one's lifetime. Although these tools can be a very important part of a good estate plan, they are often viewed by financial institutions with a great deal of skepticism and can be a source of potential abuse. A good estate plan will include a carefully drafted power of attorney as a back up to a living trust.

Continued on page 4

Letter from the Director

Hello fellow travelers,
In our last issue, I wrote a "Letter from the Chair of the Board". I am now writing this as Executive Director. Wow! What a difference a few months makes! I am very happy to be SPIN's first director, and also feeling that there is so much to do to continue developing an organization that will be responsive to the special needs community. Pat Golditch, our new Chair of the Board and Jim Baker, our new Vice Chair, bring with them much expertise and experience with families and special education.

I am confident that they and the rest of the Board of Directors will continue to guide SPIN with great aplomb. We are all doing lots of thinking ahead to the future, collaborating with other organizations, and especially planning for services to the families in our network. We are open to suggestions and ideas! Which brings me to another kind of planning.....

Planning for the years ahead, when you and your family may not be around to care for your child, is a very difficult thing to do. It is difficult to even think about. But if you don't do it, who is going to? We cannot be assured that the government or local service agencies are going to have the resources in the years to come to provide even the basic needs of a person with disabilities, not to mention the extras that we may think of as necessary for a person to have a reasonably full life.

The article on "Basic Estate Planning" included in this issue is the first in a series of articles that will appear in this newsletter on "Planning for the Future". It is an introduction to will, trusts, and insurance. Please come to our **"Information Night" at Dominican Hospital on Oct. 28 at 7 PM** for a presentation on estate planning by the author, Mitchell Jackman, a local attorney. He will be allowing time for questions, so please bring them with you. Also, check out the list of websites in this newsletter that may be helpful as you search for more information.

It is with great pleasure that I announce to you that SPIN has opened an additional office in Watsonville. It is located at 294 Green Valley Rd., Ste 313, and provides desk space for myself and our new Administrative Assistant, Joan Norvelle. Please feel free to call us there at 722-2800.

A planning meeting with Florene Poyadue



Left to right: Florene, Sheryl Wobber, Debbie Wechsler, Mary Balzer and Pat Golditch

Joan Norvelle joined the SPIN staff in July, on a part-time basis, to provide much needed organizational and administrative assistance. She comes to us with a background in office administration and graphic design, and has been a professional dancer and textile artist as well. She also serves on the board of directors of the Arboretum at UCSC. She is extremely talented and we are thrilled to have her. Welcome Joan!

Some more great news! SPIN was selected as a United Way 2002 Community Hero for the Santa Cruz County Community Assessment Project, for its work to help parents in the community. Please join us at the **Public Celebration on Monday, November 18, 10-11:30 at West Marine Products Boathouse in Watsonville.**

A short update on the Family Empowerment Center on Disability: As of this writing, we are still recruiting for two half-time Parent Support Coordinators, for south Santa Cruz County and for San Benito County. We hope to fill the positions as soon as possible. As part of the FEC grant, we are conducting a "family needs assessment" that will be mailed to every family in both counties who has a child receiving special education services. Be looking for it in your mailbox around the end of September or early October. And be sure to mail it back, so that we know what you would like to see the FEC offer to you regarding support and information. We will then develop a training curriculum and community awareness and networking events. I attended a conference of the 12 FEC directors from around the state on Aug. 19, and am encouraged that the FEC consortium will be advocating for families who have

children with special needs at the state level with a concerted effort. I will keep you posted on developments!

Be sure to join us for an inspirational presentation on **Saturday, November 16th from 2:30-5:30pm** when **Florene Poyadue will speak about Accepting and Appreciating Your Child with Special Needs**. Florene is a wonderful speaker and very inspiring. Read more about Florene and her presentation in the following pages. Also mark your calendar for **October 20th – the SPIN Family Potluck** at the Harvey West Clubhouse in Santa Cruz. We will have a lot of fun eating and talking and there will be a surprise for the kids. See flier inside this issue.

And, if you missed our last three fundraisers, (The First Annual Quiz Nite, headed up by Sam Paior, the Human Race, coordinated by Franklin Orozco and the SPIN Volleyball Tournament, managed by Amanda Owens), come to the **SPIN Shadowbrook Fundraiser on December 17th**. Details on the postcard included with this newsletter. Hope to see you there!

Finally, we will publish our next newsletter in January, so I will take this opportunity to wish you joy and family harmony over the holidays!

Best regards,
Mary Balzer

Need Peer Support?

Please contact SPIN at 423-7713 if you would like to be matched with a parent of a child with a similar special need for sharing and support.

Teen Group for Special Needs Now Forming

If you would like to volunteer to help out with social activities for a teen group, or have a teenager who would benefit from being in a teen group, please contact Octavio Garcia at 831-466-0727 or via email: evansgarcia@earthlink.net

ADD/ADHD Support Group

Would you be interested in heading up a support & information group for parents who have children with ADD/ADHD or learning disabilities? Please call Sheryl Wobber at SPIN's Santa Cruz office at: 831-423-7713 for details.

Early Childhood Program

Special Parents Information Network's Early Childhood Program started in July 2001 through a grant from the Santa Cruz County Children and Families Commission. This was a first in many respects for SPIN. It allowed us to hire our first staff person, open our first office, support specialized parent support groups and create a resource guide.



Parent Support Coordinator,
Sheryl Wobber

The Early Childhood Program has allowed us to formalize our parent to parent support, offer more training and workshops for parents and professionals on a wide variety of topics and assist in distributing the SPIN newsletter. It has also given us greater visibility in the community and has opened doors to partnerships with local public agencies and non-profit organizations that had not been aware of SPIN.

We opened our first office at 1105 Water St. in Santa Cruz, in the WIC building. We were also fortunate in hiring Sheryl Wobber as our Parent Support coordinator. Sheryl was able to step in and start developing programs and procedures, and begin collaborating with other organizations.

Our Parent to Parent Support Program is continuing to evolve. We have key mentors to answer general support questions and to help the parent maneuver through the system to obtain services for their child. We continue to recruit volunteer support parents and parents who would like to be matched with a support parent.

We have been able to offer a variety of workshops and support groups. This year we have presented IEP trainings in English and Spanish, IFSP training in English and Spanish, Parents as Partners in Education panel discussion, a family Sunday Supper, the Father's Network Group started by Dave Kramer-Urner, a sign language class with the Down Syndrome Support Group, headed up by Sam Paior, IEP training with Special Connections, and Sibling Relationships in conjunction with Easter Seals.

Continued next page

Early Childhood Program (continued from page 3)

The biggest endeavor of the year was the resource guide. After many hours of research, interviews and editing, we have completed the resource guide for age 0 – 5 to help parents sort through the maze of agencies and services available to their children. The resource guide is unique in that it provides eligibility requirements and descriptions of services provided, and also includes a directory of local support groups and website resources. Please call Sheryl if you would like a copy.

SPIN's visibility in the community has been greatly enhanced by presentations to community programs such as Family Resource Centers, Field Public Health Nurses, and California Children's Services. We have received requests to partner with other agencies and organizations on workshops for parents in the future. In the spring, we received the Community Heroes Award presented by the Children and Families Commission for our work in strengthening families.

This year was one of capacity-building, learning more about what our families need, and building relationships with other organizations. We look forward to next year with a wider variety of workshops and a greater capacity for outreach in the community.

Please call Sheryl Wobber at 423-7713 or email swobber@spinsc.org if you would like more information.

A Very Special Thank You

To the following volunteers who have made huge contributions of their time and talents! We love them!!

- Mike Barr, owner of Process Science Industries in Watsonville, for his invaluable assistance in setting up and networking the computers at our new office.
- Mitchell Jackman, Attorney at Law, for writing an article for this issue, and speaking at our upcoming information night at Dominican Hospital on October 28th . Also for coordinating his men's group to help us with our first "Quiz Nite" fundraiser, including Bill Adams, Don Adams, Glenn P. Davis, Miles Dolinger, Tazio Fulmer, David Garibotti, Steve Goodman, Tim Scully.
- Michael Rosenberg, Marketing Consultant for Strategic 6, for his graphic layout expertise and many, many hours assisting Sheryl Wobber in the production of the Resource Guide.

Your Family's Future (continued from page 1)

The hardest topic for people to talk about is insurance. There is the added cost of insurance premiums, the risk of purchasing the wrong product from the wrong company and the need to deal with sales people. I cannot emphasize how important insurance can be for most parents of children with special needs. Nothing is more devastating than the loss of annual income from the disability or death of the bread winner in a family. For every bad insurance agent, there are an equal number of highly skilled and caring agents that can serve you and your family's needs. Some of these agents are parents of children with special needs themselves.

Special Needs Provisions:

In most cases, parents of children with special needs will want someone to manage their financial resources for their children if they become disabled or die. The high cost of long term medical treatment for individuals can easily deplete the average estate or trust if there is no income to replace those resources.

The two primary programs for public assistance to help pay for long term medical costs are MediCare and MediCal. MediCare is a federally funded program for certain qualified individuals with disabilities. MediCal is the primary source for the payment of medical costs for low income or indigent individuals. Both of these programs have very strict rules governing eligibility and payments.

Several decades ago, some courageous and thoughtful people started thinking of ways to preserve the family's assets without disqualifying the disabled child from public assistance for long term care. Several legal challenges and changes in law brought about the use of "Special Needs Trusts," a device designed to maximize the preservation of family assets and government assistance. These trusts can be found in Wills, living trusts and unique trusts designed for life insurance proceeds. There are strict limitations and restrictions associated with Special Needs Trusts but they are the most powerful planning tool available to parents and family members of individuals with special needs. Make sure your estate and tax professionals have specific training in these areas.

Continued next page

Guardianships and Limited Conservatorships:

Although good estate planning will reduce or eliminate the need for court supervision of your assets upon death or disability, there are a few legal procedures that are unavoidable. It is important as a parent of a child with special needs to be educated and prepared to deal with these issues.

Although you can avoid or reduce the chances of court supervision over your financial affairs, the State of California has a strict duty to watch over the personal guardian for your minor child. It is likely that no one will ever be as dedicated to your child as you. However, a Nomination of Guardian will reduce the chances of the wrong person being appointed to serve as a surrogate parent for your child.

When your child reaches adulthood, he or she may still need your assistance with every day tasks. California law does not allow a parent to continue making all decisions regarding all of their child's needs after the age of eighteen without court supervision. There is a legal process known as the limited conservatorship. The limited conservatorship encourages the parent to give their child the broadest possible independent lifestyle while allowing the parent to protect their disabled child in other ways. Be prepared for the day when your child reaches adulthood and know your limits as a parent.

Conclusion:

Parents of children with special needs have a commitment that usually goes beyond the level of most other parents. However, with some exceptions, they need the same estate tax planning tools used by everyone else. In many cases, the needs of their children will continue well into the child's adulthood and require a greater level of thought and detail. Do not assume that your situation is too simple or complex. Get help and get it from the people that are trained in all of these areas. Take action to planning for your family's future. Delays are more costly to the people that depend on you the most.

Mitchell A. Jackman is a Local Tax and Estate Planning Attorney in Santa Cruz County with a Practice Devoted to All Families Including Families of Children with Special Needs

Some beneficial websites about financial planning for the future that you may want to explore:

- www.disabilityresources.org
This is a comprehensive website with loads of information on every topic regarding disabilities - a must for parents as they plan for the future.
- www.thearc.org/faqs/trustqa/html
A very good article on future financial planning for children with mental disabilities. Also look at www.thearc.org/misc/futplan.html.
- www.medsupport.org
Contains a good, informative article on definitions of disability for estate planning.
- www.nichcy.org
This is the website of the National Information Center for Children and Youth with Disabilities. Chock-full of links and other resources for parents.
- www.eparent.com/lifeplanning
You must register to explore this site, but it is a treasure-trove of info on life planning with lots of articles that have appeared in Exceptional Parent magazine in recent years. Includes information on guardianship and the "letter of intent" in a will.

Another Special Thank You

To the following people who spoke about recreational opportunities for children with special needs at our Information Night at Dominican Hospital May 20th, 2002:

- Foster Anderson of Shared Adventures
- Suzanne Carlton of Therapeutic Equestrian Vaulting
- Ruth Gabrielle Fisher of The Dancenter of Capitola
- Liz Grumet of Special Olympics, Monterey Bay

Photographs Wanted

Send us a photo of your family to feature in our newsletter. Please send original photos with a stamped self-addressed envelope to:

Attn: SPIN Newsletter Editor
PO Box 2367, Santa Cruz, CA
95063-2367

Accepting and Appreciating Your Child with Special Needs

Presented by Florene Poyadue

Saturday, Nov. 16 • 2:30-5:30pm
United Way Conference Room
1220 41st Ave., Capitola

This heart warming presentation by Florene Poyadue will guide us through and beyond the turmoil of walking an unchosen path after we have received information that our child may have or has a special need.

She will introduce us to the fact that the loss/grief process with its five steps (denial, anger, bargaining, depression, and acceptance) is one step short of where we can arrive on this path. That sixth step she calls “appreciation—the all right stage.”

Reaching that sixth stage allows you to let go the chronic sorrow, let go that little nagging conflict between head and heart, and let go the blinders that prevent you from cherishing the unique individual entrusted to your family.

Come, and share a story of loving, a more accurate estimation of the quality and worth of our diversity, and a freeing moment about understanding our human worth. Appreciating our children more!

Refreshments will be provided, and a short video will be shown. Sorry, no childcare. RSVP 423-7713.



Florene Poyadue and her son Dean

Florene Stewart Poyadue, RN, BE, MA, MFCC

Florene is a former executive director, a family counselor, registered nurse, and mother of four children – one who has special needs.

She founded and for over 20 years was the CEO of Parents Helping Parents, Inc. a non-profit family resource center now recognized as a national model, and is, like SPIN, a Family Empowerment Center on Disability.

Parent leaders and professionals nationally and internationally have consulted with her about developing parent to parent programs.

With Kaiser Permanente as a partner, she created a consumer/provider partnership model for activating family-centeredness in managed health care.

This dynamic keynote speaker and consultant with over 25 years experience has also traveled throughout the USA, Canada, and Guam helping others solve problems and create service systems.

Santa Clara University awarded her a Ph.D. in community service, and the state of California named her a Woman of the Year 1991, only one among numerous awards she has received. Florene is the co-author of The Parent to Parent Handbook, Brookes Publishing Co., 2001.

Parenting Children With Autistic Spectrum Disorders

(Autism, Asperger's Syndrome, PDD)

10 Week Therapeutic Support Group forming this fall. Led by Glenn Saltz MD & Lisa de Faria LCSW
Call (831) 684-2281 for more information.

Call for Newsletter Articles and Information

If you are starting or have a support or playgroup and would like to get the word out, please send your info to SPIN Newsletter at the address on the front of the newsletter.

Thanks March-July Donors!

Carol & Bob Baker
James Baker, Jr.
Jim Baker
Marie Baltz
Andy Balzer
Bariteau's Linen Service
Bay Photo Lab
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Bookshop Santa Cruz
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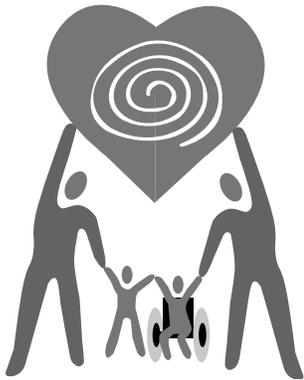
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Bill & Sheryl Wobber
Steven Young, Chiropractor

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Calendar of Events

October 5th, Saturday – Saturday Supper for Spanish-speaking Families – 4-7pm. La Manzana Center, Watsonville. SPIN welcomes our Spanish-speaking families to a supper to socialize and to get to know our staff and Board of Directors. Call Sheryl Wobber at 423-7713 for more information.

October 11th, Friday – Keeping Families Healthy: Sibling Relationships (Spanish) – 6:30-8:30pm, La Manzana Center, Watsonville. Speaker: Lupe Macias from Answers Benefiting Children. This workshop will help parents with issues concerning the non-disabled children in the family. Call Sheryl Wobber at 423-7713 for more information.

October 20th, Sunday – Family Potluck – 12:30-3:30. Come meet other families who have children with special needs. Bring something to grill for your family and a dish to share. Drinks, paper goods and utensils will be provided. Harvey West Park Clubhouse. Contact SPIN at 722-2800 for more information.

October 26th, Saturday – Down Syndrome Buddy Walk. Contact Stephanie Stewart at 338-4150 for more information.

October 28th, Monday – Planning for the Future: Wills and Trusts for your Child with Special Needs – 7-9pm. Speaker: Mitchell Jackman, Attorney at Law. Dominican Hospital, Rooms 2 and 3. Call SPIN at 722-2800 for more information.

Date TBA – Speech and Language Development Workshop – Call Sheryl Wobber at 423-7713 for more information.

November 16th, Saturday – Keeping Families Healthy: Accepting and Appreciating your Child with Special Needs – 2:30-5:30pm. Speaker: Florene Poyadue, former director of Parents Helping Parents. United Way Conference Room, 1220 41st Ave., Capitola. Call SPIN at 423-7713 for more information.

November 18th, Monday – United Way 2002 Community Hero Award Celebration – 10-11:30am. Please join us at this public celebration for SPIN and other recipients of the United Way 2002 Community Hero Award. West Marine Products Boathouse in Watsonville. Call SPIN at 722-2800 for more information.

December 17th, Tuesday – Shadowbrook/SPIN Fundraiser – Come join SPIN for a festive dinner at the beautiful Shadowbrook Restaurant in Capitola. Reservations for groups of 2-16 are available from 5:30-9:30pm, beginning November 17th, 2002. Call Shadowbrook (475-1511) early to reserve your table! Look for postcard in this issue.

4th Wednesday of every month is Autism Santa Cruz's meeting date. Call Terri Mykland at 831-457-1600 for more information.

1st Thursday of every month is the Facilitated Communication (FC) Support Group: 7-9pm. Get together with other parents and professionals. Call Lynn Bariteau for more information at 429-8914.

4th Sunday of every month is the Tourette Syndrome Support Group's meeting date (some holidays excluded). Meetings are 2-4pm at Dominican Hospital's education building. For more information, call Nancy at 425-3764 or Cindy at 426-5648.