

The CJD SO News

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"A Brighter Tomorrow"

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Plan Now, Rest Later

By Stephen A. Newbold, Attorney

Don't put off your financial and legal special needs planning. Waiting only makes hitting your goals harder to do. There are many different concerns that factor into legal and financial planning for your child with special needs. Each family's circumstances are unique but there are common issues we all need to address. The worst choice you can make is to do no planning at all. Let's look at some of the major questions you need to ask yourself. The sooner you get started, the better off your child will be.

1. Have you drafted a Letter of Intent? Excellent planning means we need to draft a Letter of Intent that sets out your vision for your child. It serves as comprehensive directions on how to best care for your child after you are gone or when you become unable to continue caring for your child. It puts into your own words your hopes, desires and goals for your child. These are the nitty gritty details about what you want for your child such as where will your child live, what kind of employment is desired, future education plans, religious preferences, medical issues, social desires and preferred habits of daily living. Drafting the Letter of Intent forces you to think hard about your child's future and lays the foundation for your planning so that when the time comes for your successor caregiver to take over, the transition is as smooth as possible for the caregiver and your child.

2. Do you have someone identified who is willing to be a successor caregiver or guardian for your child? We all know how tough it can be to raise a child with a disability. Think of the medical issues, school and work issues, the extra expenses, housing issues, the government programs, and the constant effort to integrate our kids into the social network of our community. *Cont...*

Continued from page 1...

We get so used to doing these things "day to day", but think of what we are asking someone else to undertake when we no longer are able to fulfill these duties. To someone on the outside looking in, especially someone with no experience raising a child with a disability, it must look overwhelming. Who in their right mind would sign up for this job? Fortunately, there are good people out there who are willing. But we owe it to them and our child to make the caregiver duties as easy to carry out as possible. The Letter of Intent described above is the first vital step to a smooth transition.

3. Have you provided financially for your child? You must determine how much money will be required to meet your child's future needs. We need to make sure that we are not imposing a financial burden on our chosen caregivers that forces them to shy away from undertaking the task. Their job will be tough enough already. Financial pressures may tip the scales to having them decline to undertake this mission. The earlier you start to plan for creating this fund for your child (and the caregiver), the easier it will be to achieve your desired results. This must be accomplished while still meeting your own goals for retirement and other financial goals such as an education for siblings.

4. Have you obtained the government benefits your child needs and is entitled to? In special needs planning, one of the goals is to maximize your child's eligibility for government benefits. Programs such as Medicaid, Medicare, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and a host of other programs may be available for your child. By using a combination of these programs with your own income or other resources, you can make it much easier to meet your goals for your child. Some of these programs have stringent eligibility rules you must be aware of to keep your child receiving these benefits.

5. Do you have your legal affairs in order? Do you have current Wills and a Special Needs Trust that work together to implement the vision you supplied in your Letter of Intent. The Special Needs Trust will hold the funds you have set aside for your child to fulfill your vision. It is specifically designed to make sure your child remains eligible for government programs while still providing money for those finer things in life you want for your child, such as a trip to Disney. Powers of Attorney for health and property are also needed. You also need to make sure you have proper beneficiary designations on your financial accounts so that your plan is put in place properly.

Does this all sound too complicated? It really isn't if you break it down step by step. We will be doing just that at a workshop I am conducting called "Plan Now, Rest Later" on April 15th from 6:30 to 8:00pm at Calvary United Methodist Church, 1700 N. Towanda Avenue, Normal, Illinois. Planning puts your mind at ease. Your child and your successor caregiver will thank you!

Conferences Families Might be Interested in...

Illinois Family leaders collaboration is presenting the 4th Annual Family Conference on Resources and Inspiration for Adult family Members and Caregivers of Children with disabilities Sat. May 1, 2010 in Springfield.

The Heart of Illinois Down Syndrome Association is presenting "Dwell In the Possibilities featuring Bridget Brown, self advocate and Nancy Brown, Project CHOICES Inclusion specialist. March 18th 6:30-9:00 in Morton Ill.

The Arc of Illinois presents the 60th Annual Convention in Lisle Ill. April 28 and 29th. Featured presenters are Stedman Graham, Valerie Paradiz and Al Condeluci.

The 2nd Annual Focus, Aim and Achieve Conference in Memphis April 17 2010.

Featured presenter will be Michael Remus a national consultant and author of several books on inclusion.

Hello CIDS0 Families!

Is Hannah Montana still popular at your house? Are the Jonas Brothers hot or not? Does anyone still like Tiger Woods? Are you humming the "High School Musical" soundtrack in your sleep? Is talk of Apolo Ohno consuming your dinner table? Are the kids trying to land the hurricane in the backyard just like Jeret Petersen?

We (really Marc Trembley) is putting together a list of people and places to contact for various items to be used for the Buddy Walk raffle and CIDS0 Gala auction. This is where we need help. Please talk with the people in your life and find out who is hip, happenin', totally awesome, cool, phat, bad, rockin', da bomb, and whatever ever else term currently describes the popular people. Maybe a singer or group, actor or actress, movie or TV show, author, athlete, team or local celebrity.

You have the easy part, just send me the names. Marc has volunteered for the hard part, tracking down an address and soliciting a donation.

While it may seem early, we are already starting to make plans for the CIDS0 Gala and Buddy Walk and need to start soliciting donations. The silent auction at the Gala and the raffle at the Buddy Walk are great fundraisers for CIDS0. As Illinois continues to cut back it's budget, now is the time CIDS0's funds are being requested more and more. Your help is greatly appreciated in this matter. Besides, if you leave it to me we will have a signed 8x10 of Rick Springfield..... oh wait, I still have that from college!

Thanks much! Dawn Mattia CIDS0 Buddy Walk



Event focused on changing the culture of hiring adults with Autism Spectrum Disorder and Down syndrome.

Autism Spectrum Disorder affects 1 in 110 people according to the Centers for Disease Control. Down syndrome occurs in one out of 800 births. With the proper supports, people with Autism and Down syndrome can lead full and meaningful lives.

The Central Illinois Down Syndrome Organization and the Autism Society of McLean County are hosting an employment summit. It is crucial for people with disabilities to have opportunities to develop the skills they will need in school, college and the work force.

This summit will introduce local employers to opportunities to provide employment to adults with Down Syndrome or Autism. We will also share ways to help prepare young adults for the workforce through job sharing, mock interviews, internships etc. Lastly, we will invite keynote speakers and experienced business leaders to our summit to share their best practices for working with the disabled. We are very excited to partner with local agencies including:

MARC First, United Cerebral Palsy, Easter Seals, Department of Human Services, The Baby Fold, Hammit School, District 87, and Unit 5.

What: Disability Employment Summit

Where: LOCATION, Bloomington, IL

When: October xx, 2010

Times: Registration: 8:00 a.m.

Presentations: 9:00 a.m.

Lunch provided.

Contact Information: d.warner@autismmclean.org or register online at: www.autismmclean.org

CIDSO Brochure

We are needing to redo our CIDSO brochure. Families are invited to submit pictures of family members with Down syndrome for consideration. A limit of one or two photo's maximum per family can be sent to Brenda electronically at jekkel1@msn.com by March 31. Please make sure pictures are good quality and can be clearly reproduced. Any pictures submitted that can not be clearly reproduced will not be considered for the brochure.



News from NDSS

The College of Charleston will launch the Realizing Educational and Career Hopes (REACH) program in Fall, 2010, an inclusive program designed to provide postsecondary education opportunities for students with intellectual disabilities. The College Transition Connection (CTC) is funding the development of this innovative model program, with financial support from the State of South Carolina. CTC Chair Donald Bailey announced that the grant will total \$155,000 over three years and that it is the fourth project to be funded in South Carolina. The National Down Syndrome Society (NDSS) is providing technical assistance and grant administration.

Charleston Mayor Joseph P. Riley, Jr. joined College of Charleston President P. George Benson and Board Chair Marie Land, State Superintendent of Education Jim Rex, State Representative Harry B. "Chip" Limehouse, III, Charleston County School District Superintendent Dr. Nancy J. McGinley, College of Charleston faculty, CTC board members, NDSS representatives, and prospective students with disabilities and their parents when the program was announced today at an event on the College of Charleston campus.

The four-year inclusive program is designed to provide students with mild to moderate intellectual disabilities the opportunity to participate in the academic, residential, social and professional experiences offered by the College, with appropriate support for success. REACH students will participate in regular classes and a career development program and will receive a certificate upon program completion.

"The College of Charleston's leadership in developing innovative, inclusive postsecondary education opportunities, coupled with financial support from the College Transition Connection and the State of South Carolina, will result in long-term benefits for students with and without disabilities and will serve to transform the education and employment of students with intellectual disabilities within a state that is developing a comprehensive system of such opportunities," said Stephanie Smith Lee, NDSS Senior Policy Advisor.

A small number of students will be admitted for the pilot starting Fall semester, 2010, with additional students accepted each Fall thereafter. REACH will be co-lead by Dr. Cindi May, Associate Professor of Psychology, and Dr. Fran Welch, Dean of the School of Education, Health, and Human Performance. A director will be appointed to administer the program.

The College of Charleston REACH program is supported by a partnership between CTC, NDSS, and the Center for Disability Resources at the University of South Carolina. For more information visit: <http://blogs.cofc.edu/life/>

White House Apology

White House Chief of Staff Rahm Emanuel apologized to a group of disability advocates for using the word "retarded" and said he would pledge to help end use of the word. Emanuel met with leaders from Special Olympics, The Arc of the United States and the American Association of People with Disabilities as well as two self-advocates and a parent advocate at the White House.

The meeting came more than a week after The Wall Street Journal quoted Emanuel using the phrase "f-ing retarded." "He sincerely apologized for his mistake and the pain it caused in our community," the advocates said in a joint statement following their meeting with Emanuel. "This is another small step on the road to a country that accepts the gifts of all."

Last week, Emanuel called Special Olympics CEO Tim Shriver to apologize for the comment. But the private apology was considered inadequate by many in the disability community.

The issue erupted, however, when former vice presidential candidate Sarah Palin wrote about Emanuel's use of the "slur" on her Facebook page and called for him to be fired. In addition to the apology, Emanuel said he would take the Special Olympics pledge to end use of the r-word. The pledge is part of the organization's "Spread the Word to End the Word" campaign. Furthermore, Emanuel said the administration would review proposed federal legislation that would replace references to "mental retardation" with the term "intellectual disability" throughout federal law.

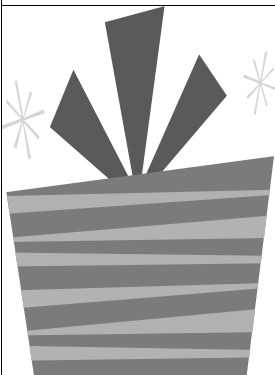
Mark the Date

March 15th: *Deadline for grant requests.*

March 18th: *HOIDSA Conference.*

April 28th & 29th: *ARC of Illinois 60th annual convention.*

Gifts and Memorials



CIDSO would like to thank the following organizations and individuals for their generous contributions.

*Clara Fry * Illinois Agricultural Auditing Association

*State Farm *Erna Harms

*John Hinrichs *The Center for Orthopedic Medicine

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with your health care professional.