

**OUR MISSION**

The Arc of Spokane Advocacy & Family Support Team provides information, education, resources, support, and advocacy to people with developmental disabilities and their families. Our goal is to help people become more informed and to empower people to become better equipped to access the services and supports they need. We promote independence and choice and respect the values and perspectives of families. We strive to be responsive to the needs of families and provide the understanding and support that families need.

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**Estate Planning to Provide for People with  
Developmental Disabilities**

By: Jessica C. Allen, J.D., LL.M.

For all families, it is important to have estate-planning documents in place in order to ensure that loved ones are adequately provided for. This is especially true when a family has a child with a developmental disability because parents want (and need) to know how to provide for their child when they are no longer around. Without appropriate planning, an outright inheritance to a child with a developmental disability can result in the child losing eligibility for means-tested government benefits (i.e., Supplemental Security Income ("SSI") and Medicaid).

**Enter the Special Needs Trust!** The Special Needs Trust can be created in the parents' Wills, which then allows the child with a disability to receive an inheritance from the parent without disqualifying the child from means-tested benefits. In order to preserve eligibility, it is important that the assets in the Special Needs Trust are used to supplement, but not supplant, means-tested government benefits. A Special Needs Trust is distinguished from other trusts because it is supplemental rather than supportive.

For example, Mom and Dad have 3 adult children: Alice, Brian, and Carl. Alice and Brian are independent and doing well. Carl has a developmental disability and is living at home with Mom and Dad. Carl will never be able to live independently; he will need a home, support system, and income for the rest of his life.

Mom and Dad wish to leave their estate equally to their three children; however, they do not want to jeopardize Carl's means-tested government benefits. Mom and Dad create a Special Needs Trust under their respective Wills. Therefore, 1/3 of their estate will pass to Alice outright, 1/3 of their estate will pass to Brian outright, and the remaining 1/3 will pass to Carl's Special Needs Trust for the benefit of Carl.

Mom and Dad will name a Trustee (who cannot be Carl) to monitor the trust assets. The Trustee will decide when to distribute from the Trust for Carl's benefit. The assets in the Trust can be used to provide for items and services that contribute to the happiness and comfort of Carl (i.e., visits to relatives, special transportation, companions, and personal items). This will provide an increased standard of living for Carl without jeopardizing his means-tested benefits.

**Is a Special Needs Trust the only way to go?** As an alternative to a Special Needs Trust, Mom and Dad could disinherit Carl. They would give Carl's inheritance to Alice with the informal understanding that Alice will take care of Carl. The concern with this approach is that if something unexpected happens to Alice (i.e., Alice dies, Alice is divorced, Alice is sued), Carl may not be provided for. Therefore, the beauty of the Special Needs Trust is that it can preserve eligibility for SSI and Medicaid for the individual with disabilities. The Special Needs Trust does not rely on the ability or the moral

*(Continued on page 2)*

## Lance's Notes

### Update from Deanna:

Lance has been in Olympia most of February, working with our legislators to save the services our children or family members with developmental disability need. The budget deficit our state faces is now 2.9 billion dollars. Cuts will need to be made, and new avenues of revenue have to be examined.

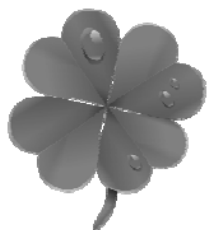
Your family may be affected by some of these changes. You can have an impact on what our legislature chooses to do. To find out how these changes please refer to the packet of information you received in the mail last week.

We as the advocates for those with developmental disabilities, whether a parent or family member, a self-advocate or a care provider need to make sure our voice is heard. If you want to know what the potential changes may be, go to the SCPC website, at [www.spokaneparentcoalition.org](http://www.spokaneparentcoalition.org), and click on budget comparison.

From Deanna for;



## Look for our survey in next month's newsletter!



*(Continued from page 1) Family Planning*

commitments of others to be successful.

Estate planning is necessary for all families to ensure that the Grantor's assets will go to his/her intended beneficiaries. In general, a basic estate plan should have a (1) Will; (2) Durable Power of Attorney for Property Management; (3) Durable Power of Attorney for Health Care; and (4) Health Care Directive. In addition, for a family with a special needs child, a Special Needs Trust should be discussed with an estate planning attorney.

Jessica Allen is a Washington estate planning attorney at Paine Hamblen, LLP. She can be contacted at (509) 455-6000 or [jessica.allen@painehamblen.com](mailto:jessica.allen@painehamblen.com).

P.S. Another option would be the Life Opportunities Trust. Please see page 4 for information about an upcoming Trust workshop in Spokane, or visit the DDD website at <http://www.ddlot.org/>.

[www.arc-spokane.org](http://www.arc-spokane.org)

### Our Readers

#### **Advocacy & Family Support**

is produced monthly and provides information to parents, grandparents, guardians, other family members, professionals and other adults who have a person with special needs in their life. We encourage you to copy and share this information. Please credit *The Arc of Spokane Advocacy & Family Support* and, where possible, the author.

### Submissions

Please send submissions for our next issue by March 20 to:

Deanna Noland  
The Arc of Spokane  
127 W. Boone Ave.  
Spokane, WA 99201  
(509) 328-6326  
[dnoland@arc-spokane.org](mailto:dnoland@arc-spokane.org)

### Mailing List

If you would like to be added, or removed from our mailing list, please call Deanna Noland at (509) 328- 6326.

### E-mail List

To receive this newsletter in PDF format via email, visit [www.arc-spokane.org/maillinglist.htm](http://www.arc-spokane.org/maillinglist.htm) and click on the link for **Advocacy & Family Support**. At that location you may also subscribe to lists for Local Events, Statewide Events, Legislative Advocacy and The ArcLite newsletter.

### Disclaimer

The inclusion of any article or resource in this newsletter does not imply endorsement.

Contents are intended for informational purposes only.



**PARENT to PARENT**

## Cathie's Notes

March brings St. Patrick's Day celebrations and thoughts of shamrocks and the legend about pots of gold. For the fifty-seven or so families that have obtained new houses since we began HomeOwnership Opportunities they certainly feel they hit the jackpot when they purchased their new home.

For some families it was a long road to success that began well before our program met them. Life happens and sometimes it smacks you with bad events as well as good ones! So for some families they had to learn how to make better choices when making financial decisions because in order to be eligible for a home loan, families can't have collections pending. Checking annually on what is being reported to the credit bureaus is important to each of us. Credit Bureaus may be getting information that is totally incorrect which may damage your credit score. Many motivated families have worked very hard to clear up misinformation on credit reports and forgotten debt to be able to purchase homes using the support of our program. Home Ownership Opportunities is here to help you with that process too.

HomeOwnership Opportunities is pleased to announce that we have received 2010 funding from the Washington Housing Trust Fund for down payment assistance for an additional 13 families. We are in the process of contract signing for these funds and want to identify families who may not know about our program. Families who have been thinking about homeownership but haven't been in contact with us should call to schedule an intake appointment. The down payment assistance has requirements that must be met that we will be happy to explain to families interested in exploring the possibility of purchasing a home.

HomeOwnership Opportunities has scheduled first time homebuyer classes in April and May. We are taking reservations for those classes now. This is an excellent way for families thinking about homeownership to become better informed about the process and community supports that are available to make their goal a reality. You can register to attend a class by calling Cathie or Helen at 328-6326.

Two last reminders this month, Spring is a good time to change the batteries in your smoke detectors if you haven't done it in some time. And changing your furnace filter to one that is a HEPA model which will screen out more allergy molecules will help your Spring be more symptom free.

Happy Spring to all of you!

*Cathie & Helen*

## How to Tell the Difference between a U.S. Census worker and a Con artist?

HomeOwnership Opportunities



A U.S. Census worker who knocks on your door will have:

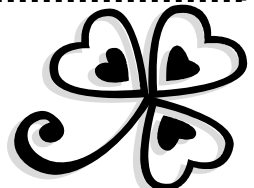
1. a badge, 2. a handheld device, 3. a Census Bureau canvas bag, and 4. a confidentiality notice.

## How to be Safe during the Census:

- Ask to see their identification and their badge before answering their questions.
- Never invite anyone you don't know into your home. You can speak to them at the doorway.
- Do not give your Social Security number, credit card or banking information to anyone, **even if they claim they need it for the U.S. Census.** The Census Bureau will **NOT** ask for Social Security, bank account, or credit card numbers, nor will employees solicit donations. **Any one asking for that information is NOT with the Census Bureau.**

Census workers may contact you by telephone, mail or in person at home. However, the Census Bureau **will not** contact you by Email, so be on the lookout for Email scams impersonating the Census. **Never click on a link or open any attachments** in an Email that are supposedly from the U.S. Census Bureau.

**REMEMBER, YOU REALLY ONLY NEED TO TELL THEM HOW MANY PEOPLE LIVE AT YOUR ADDRESS. YOU DON'T HAVE TO ANSWER ANYTHING AT ALL ABOUT YOUR FINANCIAL SITUATION.** The Census Bureau might ask for basic salary range but not specifics about your bank account. It is your choice to answer or not even the salary range questions.



**Helen Black**

Now that spring is quickly approaching and most of us and our children more than likely have a bad case of spring fever. Not to worry as there are many activities for our children to participate in.



If your child would like to play baseball there are some options in the Spokane area. Little League Challenger Division is a great way to get that baseball player on the baseball field. For more information contact Heather Sutherland by email: [hsutherland@comcast.net](mailto:hsutherland@comcast.net) or 747-0508/ 879-8888. There is also the Bambino Program which is also a baseball division under Babe Ruth for children with Disabilities. For more information contact Leslie Sigrah by email: [bambinoball-mom1@yahoo.com](mailto:bambinoball-mom1@yahoo.com) or 263-0088. Both programs are available to children ages 5-18 years of age with any type of Disability.

There are many day-camps or overnight camps available to children as well as young adults in the Spokane area. Spokane Parks and Recreation have a list of camps and schedules available. There are recreational guides with these camps listed in them, a guide may be obtained by contacting the Parks and Recreation department at 625-6200 or you may contact me as I have a limited supply. It is highly recommended families seeking camps inquire and register early as spaces are limited and fill up quickly.

Summer time is a great time to just meet in the beautiful parks we in Spokane are lucky to have. During summer 2009 there were a few of us who would meet in a park so parents could visit while our children played. If there is enough of an interest expressed to have a social time in a park again, I will be more than happy to schedule this time. Send me an email or a phone call to let me know if you are interested in having a meet in the park again.

*Helen*

## Washington State Life Opportunities Trust

**March 24, 2010      Airport Ramada, Spokane**

Trust Holder Session: 5:30 to 7:00 PM  
Informational Session: 7:30 to 9:00 PM

Sound financial planning is vital for families with children with developmental disabilities. And, the State of Washington made it easier when it established the Developmental Disabilities Endowment Trust Fund in 1999. Now called the Life Opportunities Trust, this public-private partnership creates a stable resource to enhance the quality of life for people with developmental disabilities.

The Life Opportunities Trust is an easy and effective way for you and your family to prepare for the future...and life's unexpected expenses.

Trust Holder sessions for those who already have a Trust. Information Session for those who do not have a trust but are interested in learning more.

## Thousands entitled to Earned Income Tax Credit payment could miss out

*Free tax help for low to moderate-income taxpayers available by dialing 211*

**Olympia, WA** – The state is urging you to apply for your share of millions in Earned Income Tax Credit money available to eligible families and individuals from the Internal Revenue Service (IRS). **Today** is National "Earned Income Tax Credit Day," designated to help raise awareness of this federal program that goes unused by about 20 to 25 percent of qualified workers who are entitled to receive a check for up to \$5,657. Based on these estimates, as much as \$140 to \$174 million could go unclaimed by Washington residents eligible for the credit.

"You work hard and you earn every dollar," said Gov. Chris Gregoire. "Taking advantage of the tax credit is the right thing to do for yourself and your family."

Thousands of working families and individuals in Washington each year fails to apply for the credit, missing out on their share of the money. Seniors, individuals with low incomes, and non-English speaking tax payers account for much of the unclaimed credits because they do not realize that they are eligible for it. Last year, 380,000 people applied for the credit, bringing about \$696 million into the state's economy.

The Washington State Department of Commerce has teamed up with the IRS, AARP Tax Aide, Community Action agencies, United Way agencies, banks and credit unions across the state to remind eligible taxpayers that they must file a 2009 federal income tax return to receive the Earned Income Tax Credit – **even if they owe no tax**. Communities throughout Washington are taking part in the national Earned Income Tax Credit Day on Friday to promote the tax credit.

Groups promoting the Earned Income Tax Credit (EITC) have a simple message: It's your money. Come get it. Any individual or couple who worked in 2009 should file for the EITC. The amount of the tax credit depends on family size and gross income. The American Recovery and Reinvestment Act (ARRA) also provides a temporary increase in EITC for taxpayers with three or more qualifying children.

Following are eligibility requirements:

- With three or more qualifying children, income less than \$43,279 or \$48,279 if married filing jointly. Maximum refund: \$5,657
- With two qualifying children, income less than \$40,295 or \$45,295 if married filing jointly. Maximum refund: \$5,028
- With one qualifying child, income less than \$35,463 or \$40,463 married filing jointly. Maximum refund: \$3,043.
- With no children, income less than \$13,440 or \$18,440 married filing jointly. Maximum refund: \$457.

Free tax preparation services are available to low and moderate-income families now through April 15. A directory of site locations throughout the state is available by dialing 2-1-1, Washington's Information Network. Ask for "free tax preparation" and operators will provide free tax site locations and hours in your area.

Parenting never ends. Sons and daughters do grow up, but they are always your children. One of the most difficult aspects of being a parent is dealing with the hardships and tragedies that inevitably occur in children's lives. Afterwards parents often feel responsible for what happened; they may question their judgment about decisions that seemed to be good at the time. Frequently, these feelings of regret last for years after an event has taken place.

This is especially true if the "bad thing" is of a sexual nature – rape or sexual abuse. Should the child have a disability, the parental burden can be even greater, magnifying a parent's sense of guilt.

Support groups are an excellent place for people to process and come to terms with such feelings. However, parents of children with disabilities may feel that parents of nondisabled children do not really understand their situation. For example; having a disability, (especially an intellectual disability) changes the perception sexual abuse. Often, it is marginalized and not identified as abuse by people in positions of authority like the police or facility staff.

To address the needs of parents of children with disabilities, the Partnership is beginning a parent's support group specifically for the parents of survivors of sexual trauma. It will be an opportunity for parents to come together for mutual support and understanding. The Parent support meetings begin in March. If you are interested, please give me a call, I can be reached at [tfears@arc-spokane.org](mailto:tfears@arc-spokane.org) or 328-6324.

Stay Safe,



## Washington Bus Summer Fellowship

The Washington Bus Summer Fellowship channels a cadre of capable, passionate young people into public life in Washington state.

The Washington Bus Summer Fellowship is a ten-week political boot camp in Seattle. Fellows spend the summer learning state-of-the-art campaign management, grassroots organizing, public policy formulation, and leadership skills. Alums are prepared to take leadership positions in campaigns and political movements.

What is the need? Young people in Washington state are left out of the political process. Washington has 147 state legislators, but just 16 are under 40. The voice missing in Olympia is that of a younger generation.

The Washington Bus Summer Fellowship takes young people who see the need for change, equips them with the best political tools available, and injects them directly into the political arena.

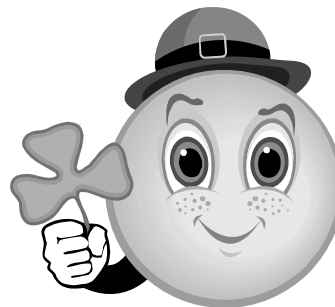
You can apply online ([www.washingtonbus.org](http://www.washingtonbus.org)). **Early Decision:** April 5th. Mailed applications must be postmarked by April 5th, 2010; emailed applications must be submitted by 11pm PST, April 5th. **Final Deadline:** May 14th.

## Date Night

### March 26th

**An Opportunity for your son or daughter with a developmental disability to meet new people while learning person safety and social skills.**

**Must** pre-register with Theresa @ 328-6326  
**Sponsored by the Partnership**



## SSA Expands Compassionate Allowance Conditions

The Social Security Administration (SSA) has announced that it is adding 38 more conditions to its list of Compassionate Allowances. The new conditions range from adult brain disorders to rare diseases that primarily affect children. Compassionate Allowances are a way of quickly identifying diseases and other medical conditions that clearly qualify for Social Security and Supplemental Security Income disability benefits. It allows the agency to electronically target and make speedy decisions for the most obviously disabled individuals. You can find more information by visiting at: [http://www.disability.gov/benefits/news/26\\_events](http://www.disability.gov/benefits/news/26_events).

### New Compassionate Allowance Conditions (effective March 1, 2010)

- |  |  |
|--|--|
| 1 Alstrom Syndrome   | 2 Amegakaryocytic Thrombocytopenia               |
| 3 Ataxia Spinocerebellar                                   | 4 Ataxia Telangiectasia                          |
| 5 Batten Disease   | 6 Bilateral Retinoblastoma                       |
| 7 Cri du Chat Syndrome                                     | 8 Degos Disease                                  |
| 9 Early-Onset Alzheimer's Disease                          | 10 Edwards Syndrome                              |
| 11 Fibrodysplasia Ossificans Progressiva                   | 12 Fukuyama Congenital Muscular Dystrophy        |
| 13 Glutaric Acidemia Type II                               |  |
| 14 Hemophagocytic Lymphohistiocytosis (HLH), Familial Type |  |
| 15 Hurler Syndrome, Type IH                                |  |
| 16 Hunter Syndrome, Type II                                | 17 Idiopathic Pulmonary Fibrosis                 |
| 18 Junctional Epidermolysis Bullosa, Lethal Type           | 19 Late Infantile Neuronal Ceroid Lipofuscinoses |
| 20 Leigh's Disease   | 21 Maple Syrup Urine Disease                     |
| 22 Merosin Deficient Congenital Muscular Dystrophy         | 23 Mixed Dementia                                |
| 24 Mucosal Malignant Melanoma                              | 25 Neonatal Adrenoleukodystrophy                 |
| 26 Neuronal Ceroid Lipofuscinoses, Infantile Type          | 27 Niemann-Pick Type C                           |
| 28 Patau Syndrome  | 29 Primary Progressive Aphasia                   |
| 30 Progressive Multifocal Leukoencephalopathy              | 31 Sanfilippo Syndrome                           |
| 32 Subacute Sclerosis Panencephalitis                      | 33 Tay Sachs Disease                             |
| 34 Thanatophoric Dysplasia, Type 1                         | 35 Ullrich Congenital Muscular Dystrophy         |
| 36 Walker Warburg Syndrome                                 | 37 Wolman Disease                                |
| 38 Zellweger Syndrome                                      |  |

### **FAMILY SUPPORT** **360 ONE-STOP CENTER**

The Arc of Spokane, in partnership with the Arc of King County, has been awarded a five year grant to provide services to families caring for children or adults with developmental disabilities.

We will be serving un-served or underserved families in rural, Latino, Russian and Native American communities. Program will start soon.

If you would like more information please contact Rosslyn Bethmann @509-328-6326.



"Blue Waxers" Cross Country Ski Team from the Spokane Parks Therapeutic Recreation Department completed the Langlauf 10 K race on Mount Spokane held Feb 14, 2010. The five team members posed prior to the race along with their coaches.

# MONTHLY SUPPORT GROUPS & MEETINGS



**Autism Society Of Washington**, Spokane Chapter, For more information e-mail; [Spokane@autismofwa.org](mailto:Spokane@autismofwa.org)  
**MOCHA Group**, Wed March 10 (7:30 pm); Forza Coffee House, 2829 E 29<sup>th</sup> Street Contact: [jennyheals1@yahoo.com](mailto:jennyheals1@yahoo.com)  
**MONTHLY FAMILY SUPPORT MEETING**, No March Meeting  
**TEEN/ YOUNG ADULT SOCIAL GROUP AND ADULTS SOCIAL GROUPS**, Sunday March 21 (1-3pm); Service Station Coffee House; 9317 N. Nevada [spokane@autismsocietyofwa.org](mailto:spokane@autismsocietyofwa.org)  
**ADULTS WITH ASPERGER'S GROUP**; A group activity is planned each month, [spokane@autismsocietyofwa.org](mailto:spokane@autismsocietyofwa.org)  
**EARLY INTERVENTION**; Contact Kristy Wessels at [kristywessels@comcast.net](mailto:kristywessels@comcast.net) for on-line support  
**April Awareness Event**; Autism Speaker's Forum, Fri April 30<sup>th</sup> (5-9 pm), "Treating Autism as a Neuro-Inflammatory Disease, not a Mental Disorder", Dr. Goldberg, FAAP UCLA Medical School. Dr. James Woods, UW Toxicology Department

**Brain Injury Groups**—Spokane; 2nd Wednesdays; 7:PM to 9:PM St Luke's Rehab, room 200 [www.tbiwa.org](http://www.tbiwa.org)  
**North Idaho**—3rd Saturdays 1to 3 pm; Kootenai Medical Center - room KMC3  
**TBI Survivors Network** (Advisory Board Development Meetings) 4th Wednesday of each month  
Contact Craig [imaginationman@comcast.net](mailto:imaginationman@comcast.net) or <http://tbisurvivorsnetwork.ning.com/> call Craig Sicilia at 509-218-7982

**Down Syndrome Family Network**; Saturday Breakfast; 2<sup>nd</sup> Saturday of every other month. (February, April, June, August, October and December) 9:00 am at Jenny's Café (9425 E Sprague, Spokane Valley) Carolyn at [theothercarolyn@yahoo.com](mailto:theothercarolyn@yahoo.com) Carolee Spradley, (509) 499-8792

**Epilepsy Foundation Northwest Spokane** 3rd Wednesday of each month from 6:30-8p.m. @ 928 W. Spofford, Ryan Oelrich, (509)325-1128 [roelrich@epilepsynw.org](mailto:roelrich@epilepsynw.org)

**FISH: Families in Support of Hearing** Next meeting No Information received ; Contact Kim Schafer 509-863-7097 [kim@spokanehopeschool.org](mailto:kim@spokanehopeschool.org)

**People First of Spokane** - (Lilac Chapter); 2nd and 4th Tuesdays 1:PM - 2:30:PM Down Town Public Library, lower conf. room  
**People First of Spokane Valley** 2nd and 4th Tuesdays 6:30:PM to 8:PM; 511 North Argonne (Ambitions auditorium)  
[www.peoplefirstsv.com](http://www.peoplefirstsv.com)

**Lean On Me** support group for caretakers and parents of the Developmentally Disabled. 3rd Wednesday of each month at the Whitworth Chapel (on campus) at 7:00pm, contact: Greg Siverly at 326-6716.

**Parent to Parent Support Group**; 1st Thursday of every month, 10:30—11:30 Open to any parent or Guardian who has a child with special needs..The Arc of Spokane, 127 W. Boone Helen Black – 328-6326 or Email: [hblack@arc-spokane.org](mailto:hblack@arc-spokane.org)

**Senior Families**. March 16th, 3rd Tuesday of the month; 11:30—1:00 pm; **Tomie Zuchetto, The Hospice of Spokane; Grief and Dying**. The Arc/IERR Building, 116 W. Indiana Ave. Deanna Noland, (509) 328-6326

**Spina Bifida Association of Washington State** Call for meeting time and location. Call Ed Kennedy, 326-6355, ext. 103

**Spokane Fathers Network; Thursday**, 3rd Saturday of each month; 7 pm: For fathers of children with special needs. Call Gregg Osborne, (509) 768-1383

## QUICK-LOOK CALENDAR 2010

### March 2010

- 3 & 4 National Campaign Against the "R" Word
- 16 Arc's Annual meeting @ Red Lion Inn at the Park
- 20 Family Support Conference @ SCC in the Lair
- 24 Life Opportunities Trust workshop @ Airport, pg 4
- 26 Date Night, pg 8

### April 2010 (National Autism Awareness Month)

- 9 Safety Rally @ STA Plaza
- 30 Autism Forum

Mark your calendar

### The 3rd Annual COMMUNITY Fun Run

**Saturday, April 17, 2010.**

Sponsor a team and join the fun!

This 3 mile run is great training for Bloomsday.

The Arc of Spokane  
127 W. Boone Ave  
Spokane, WA 99201

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### **Navigator Position Open**

The Family Support 360 Program is currently seeking a "Navigator" to assist individuals with developmental disabilities and their families identify needs for support, develop a plan of action, and obtain access to relevant supports.

The ideal candidate will have knowledge of resources, be from rural, Russian, Native or Hispanic communities and have a heart for helping others.

This is a part time paid position and interviews will take place week of March 11 - training to begin April 5th.

If you are interested please contact Rosslyn Bethmann @ 509 328 6326 or [rbethmann@arc-spokane.org](mailto:rbethmann@arc-spokane.org).

## **SAVE THE DATE!**

*March 20<sup>th</sup> 2010*

*The Arc of Spokane Family Support Team*

*In partnership with the County's*

*Spring Resource Fair*

### ***Family Support Conference***

***Register on-line @ [spokaneparentcoalition.org](http://spokaneparentcoalition.org)***

***Don't forget - 2<sup>nd</sup> Annual Silent Auction***

***(We would love your tax-deductible donations)***

*To volunteer or donate items*

*contact Roz @ 328 6326*

