



King County Parent Coalition for Developmental Disabilities

A Program of The Arc of King County

KING COUNTY PARENT COALITION FOR D.D.

Tuesday, June 8, 2010 , 7- 8:30pm;

Highland Recreation Ctr, 14224 Bel-Red Road, Bellevue, Art Room

Speaker:

Scott Leonard, King Co. Developmental Disabilities

Scott will present an Overview of the different Federal, State and local government systems that may impact or enhance the lives of people with D.D. (DDD, Social Security, the CSO [state Community Services Office}, Medicaid, Waivers, DVR/Employment.)

Scott is the Benefits specialist for our county. He has helped hundreds of families and individuals. This meeting will be of interest to families of adults, teens and pre-teens but all ages are welcome.

Business: Annual Picnic is Tuesday, July 13 (Renton Community Center.) - Sign up for tasks.

To become a member or donate to The Arc go to: www.arcofkingcounty.org

June 2010 HANDOUTS

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425-882-2010, phone & fax

The contents of these handouts are for informational purposes only. Inclusion in these handouts should not be viewed as an endorsement by The King County Parent Coalition or The Arc of King County.

The Arc of King County, 233 Sixth Ave. North; 206-364-6337; www.arcofkingcounty.org/

KCPC 2010 MEETING SCHEDULE

BELLEVUE MEETINGS 2nd TUESDAY OF EACH MONTH PLACE: HIGHLAND RECREATION CENTER 14224 BEL-RED RD., ART ROOM; BELLEVUE	
JANUARY 12th	Donna Patrick Washington State DDC Council
FEBRUARY 11th	Emergency Preparedness: 'Becca Flora American Red Cross Volunteer- Community Disaster Presenter <i>PLEASE NOTE THIS MEETING IS ON THURSDAY AND WILL BE IN THE MULIT-PURPOSE ROOM OF THE HIGHLAND CENTER</i>
MARCH 9TH	Housing Meeting
APRIL 13TH	Ray Jensen, King Co. DDD; Lauren Bertagna, Region IV, DDD, Field Services Administrator
MAY 11TH	Jackie MacLean, Director Dept. of Community and Human Services; Karen Hoffman SIS Trainer (DD Assessment)
JUNE 08TH	Scott Leonard KCDDD: Benefits Information
JULY 13, 2010 ANNUAL PARENT COALITION PICNIC:	Renton Community Center; 1715 SE Maple Valley Highway, Renton, WA 98057-3900; 425-430-6700
AUGUST 10th	
SEPTEMBER	DATE TO BE ANNOUNCED LOCATION TO BE ANNOUCED-HIGHLAND CENTER CLOSED
OCTOBER 12th:	Linda Rolfe, Director, DDD
NOVEMBER 22nd	– probable date of 21 st Annual Legislators' Forum, Tukwila
DECEMBER	- NO MEETING, Happy holidays



Our condolences go to Parent Coalition members William and Feliciana, parents of Kathryn Lee. Kathryn Lee Burke of Shoreline, Washington passed away on April 20, 2010. Kathryn, known as Kate or Katie, was born in New Haven, Connecticut on February 23, 1961. Kate lived in a variety of group and adult family homes throughout King County. Her last several years were spent under the care of Banchemo Friends Services in Shoreline, Washington. Kate was well known for her sociable nature, determined spirit and her unwavering love and loyalty to her family and friends. Kate is survived by her parents, William T. Burke and Feliciana D. Burke of Seattle, Washington.

Published in The Seattle Times on May 2, 2010

EVENTS

Thursday, June 17, 2010; 9:00am-4:00pm; DDD Field Office, 1700 East Cherry Street, Seattle, WA 98122; 2nd Floor, Lunchrooms A&B; Division of Developmental Disabilities; Region 4

DDD101/Autism

Designed for:

Service Providers of People with Developmental Disabilities:
Community Residential Providers, Adult Family Home Providers, Medicaid Personal Care/Respite Providers
Case Resource Managers, Families

Training will include:

Best practices, evidence based strategies and methodologies for individuals with Autism Spectrum Disorders; visual strategies/structured teaching, social stories; social thinking; picture exchange communication system; applied behavior analysis; discrete trial training; pivotal response training; relationship development intervention; sensory processing dysfunction; functional behavior assessment/positive behavior supports; developmental-individual difference-relationship based model and Greenspan floor time strategies for children with Autism; learning styles; People First language; self-determination; disability awareness-low and high tech supports; preparing for transition-School to Work for students with disabilities; transition for students with Autism Spectrum Disorders; travel training for individuals with Autism.

Instructor:

Monica E. Meyer, Consultant, Technical Assistance and Training
Monica Meyer Consulting provides training, technical assistance, and consultations specializing in classic autism and other low incidence developmental disabilities. Contracted services have been provided to State RHC, residential, school, employment providers, transition to post school activities including post secondary education and employment, social skills training using Social Stories and Social Thinking curriculum. Monica Meyer Consulting also offers assistive and adaptive technology in all areas of disabilities that promotes skill development and independence.

Continuing Education Credit Available

To Register, please follow these steps:

1. Email your registration request to: dd4fso@dshs.wa.gov
2. In the subject line, type the word: **Autism**
3. In the body of the text, type your name, who you represent, and how many are coming to the training.
4. You will receive a confirmation by email with the expectation that you will be promptly in attendance; if that changes, please notify us in advance so that someone else may attend.

Please make accommodation requests 3 weeks in advance.

Wednesday, June 23, 2010 & Thursday, June 24, 2010; 6/23:1:00pm-5:00pm; 6/24:10:00am-4:00pm ; Division of Developmental Disabilities; Region 4 presents;

Non Verbal Communication Strategies

Designed for:

Service Providers of People with Developmental Disabilities:
Community Residential Providers, Adult Family Home Providers, Medicaid Personal Care/Respite Providers

The Workshop:

Identifying formal and informal language and strategies; building communication systems; tactile strategies/tangible symbols; offering choices, the Wellspring; environments for independence; activities for long-term success.

Everyone leaves the workshop with a choice board and tangible symbols in hand. All participants receive a notebook that includes handouts for the construction and use of the tools discussed in the workshop, steps to build on these systems and a variety of community resource guides for seeking further education.

Instructor:

Jennifer White of Able Opportunities, Inc. has 30 yrs working in schools & adult service agencies, 16 yrs working in rehabilitation, 26 yrs playing & working in the Deaf & Deaf-Blind communities of Seattle & Alaska, 23 yrs consulting as a Deaf & Hard of Hearing Specialist & Deaf-Blind Specialist for schools & statewide service agencies, 20 yrs specializing in concrete communication systems for individuals who are non-linguistic due to a range of diagnoses, expert witness, consultation for teams working with deaf, hard of hearing & deaf-blind students, certified CRP and IL Vendor for DVR, DDD, DBS,L&I, nationally accredited through CARF.

Please plan on attending both days.

Attendees will eat lunch at a local restaurant as a group on day 2. Plan on purchasing lunch.

Location: DDD Field Office, 1700 East Cherry Street, Seattle, WA 98122
2nd Floor, Lunchrooms A&B

Continuing Education Credits Available

To Register, please follow these steps:

5. Email your registration request to: dd4fso@dshs.wa.gov
6. In the subject line, type the word: **Communication**
7. In the body of the text, type who you are and how many are coming to the training.
8. You will receive a confirmation by email with the expectation that you will be promptly in attendance; if that changes, please notify us in advance so that someone else may attend.

PLEASE REQUEST SPECIAL ACCOMMODATIONS 3 WEEKS IN ADVANCE.

July 8, 2010; 4:30 pm-7:00 pm; AtWork! Artist Reception & Showing

1935 152nd PL NE, Bellevue, WA 98007

AtWork!, provider of employment services for people with disabilities, has decorated the walls of its new headquarters building with art work executed by artists with disabilities. The public is invited to the Artist Reception and Showing. The artists participate in the Creative Activities/VSA arts of Washington program, dedicated to serving artists at any stage of their creative development.

CA/VSAAW is a nonprofit organization dedicated to providing arts opportunities created by, for and with people with disabilities throughout the state of Washington. AtWork! is a private non-profit organization that provides assessments, skill exploration and training, job development, and ongoing job coaching and support for individuals with disabilities.

To let us know you are coming or for more information please contact:

Winter Taylor at (425) 274-4000 or wintert@atworkwa.org

July 13, 2010 KCPC Summer Potluck-Picnic



King County Parent Coalition for Developmental Disabilities

SUMMER POTLUCK - PICNIC

Please bring your family! (rain or shine)



Date: **TUESDAY, July 13, 2010**

Time: **6:00 to 8:00 PM** 6:00 socializing and photos, 6:30 potluck, 7:15 program
(Note: concerning traffic, there is no Mariners game this night.)

Place: **Renton Community Center, 425-430-6700**
1715 Maple Valley Hwy., Renton Exit 4 & I-405, directions below
Banquet Facility (air/conditioned) Wheelchair accessible.
There will be a children’s play area on the patio.

Awards will be presented:

Ray Jensen, King Co. D.D.D. – 20 years of working with the Parent Coalition

Legislators: announcement coming soon.

Program will be at 7:15PM.

Hot Dogs and delicious chicken provided.

What to bring: A - K **Main Dish to serve 10**
 L – R **Green/fruit Salad to serve 10**
 S - Z **Dessert to serve 10**

*Please be generous.
We don’t want to run out
of food!*

Provided: Drinks, plates, cups, napkins and utensils, tables and chairs

Parking: In front and back of Center.

Directions: From the North: Take I-405 southbound to Exit #4 (Renton-Enumclaw). Go through the first stop light, turn left on Maple Valley Hwy (South 169). This will take you under I-405. Continue ahead to the 2nd light and turn right.

From the South: Take I-405 northbound to Exit #4 (Maple Valley-Enumclaw). This exit will divide. Take the first exit to Maple Valley-Enumclaw (South 169). At the stop sign, at the end of the off ramp, turn right. Continue ahead to the 2nd light and turn right.

Questions: Betsy McAlister, 425-882-2010, bmcalister@arcofkingcounty.org

July 17 on 2nd Ave. (just east of the Issaquah Community Center); Challenge Day Race

Life Enrichment Options and the Issaquah Rotary are sponsoring the thirteenth annual Challenge Day Race. There will be three racing sessions. Session #1, from 9:00 AM to 10:30 AM; session #2 from 10:30 AM to noon; and session #3 from 1:00 PM to 2:30 PM. This gravity car race is for people with physical or mental disabilities.

This event allows the participants to experience the fun of a gravity car race. The racecars are 7 feet long and 29 inches wide. Two racers ride in each car. The driver is an able bodied person 11 years old or older. The co-driver is a racer with special needs. Two cars propelled by gravity, race down the street to the finish line. Each car has brakes so that the driver can safely stop it.

The physical requirements for the special racers are:

Height – not taller than 5 foot 2 inches

Weight - not more than 130 pounds

Age - 5 years old through adults

There will be 16 special kids in each session. The Issaquah Rotary will be providing a pizza lunch for the participants, their families and the volunteers. Lunch will be from 12:00 to 1:00. Race day check-in will start at 8:15 and will end at 12:00. OUTDOORSFORALL will be there with their adaptive cycles. The adaptive cycles will be available all day. When the special children are not racing they can ride the adaptive cycles.

For more details and to register, call Leo Finnegan at (425) 392-5682 or E-mail to finneganleo@aol.com.

Note: The special racers should be at the Issaquah Community Center at least a half hour before their race session – to sign-in, get their T-shirt and have their picture taken in one of the race cars.

**July 18, 10:00am – 2:00pm; Parent to Parent of King County Presents:
Western Adventure at the M-Bar-C Ranch**

Dust off your hat and boots and join us for an end of the year cowboy bash at the M-Bar-C Ranch on Whidbey Island! Location: 5264 Shore Meadow Road, Freeland, WA

Boys and girls can ride horses, be cowhands, dress up in the costume shop, explore the western town, eat chow, take a wagon ride, play games, do arts and crafts, and run, pretty much any place they want.

Please let us know how many cowpokes are comin' ... RSVP to Cathy Murahashi, cmurahashi@arcofkingcounty.org 206-829-7039 and check out www.m-bar-c.org for more information. Thanks y'all!

General Information: -We would like number of adults and kids per family; -Age range of kids
-Any major food allergies.

-Wear sturdy shoes (tennis shoes are ok, sandals are not); -Jeans/pants are great for the kids for riding horses; -Dress for the weather.

-Lunch of hotdog, fruit, chips, cowboy punch will be provided (you may bring a sack lunch if desired)
Parent to Parent is a Program of The Arc of King County

August 6 – 8, 2010; 2nd Annual BABY JAMBOREE:

An exciting learning opportunity for families with infants & toddlers who are blind or visually impaired) "Baby Jamboree" is a collaborative project of Washington Sensory Disabilities Services, Washington State School for the Blind, Department of Services for the Blind, Early Support for Infants & Toddlers (Infant Toddler Early Intervention Program), and the Seattle Lighthouse for the Blind.

In a relaxed and supportive setting in Vancouver, Washington (on the campus of Washington State School for the Blind), families will learn about their child's visual impairment and what it means for his/her development and learning. They will leave the weekend feeling like the "experts" on their child's visual impairment, with a better understanding of their child's individual needs.

(Note: Families are asked to invite one of their early intervention team members to attend and learn with them.);

Moms and dads (or other caregivers) will:

Meet other families facing similar challenges

Learn from older children and adults who are blind or visually impaired

Participate in learning sessions

Get one-on-one support and information from birth-to-three specialists in vision impairment

Children who are blind or have low vision will:

Participate in infant/toddler groups with specialists

And siblings will:

Have a ton of fun and learn through SibShops for brothers and sisters!

For more information, or to receive an application, please call:

1-800-572-7000 or email: wds@psed.org

Applications are available for download at: www.wsdsonline.org

Applications are due on June 10 (deadline may be extended).

Saturday, August 14, 2010 • Seattle Center; Welcome to Walk Now for Autism Speaks: Puget Sound

Registration opens at 9:00am • Opening Ceremonies Begin at 10:00am

Our 2010 campaign is underway as we combine our walks into one massive community event on Saturday, August 14th at the Seattle Center!

<http://www.walknowforautismspeaks.org/faf/home/default.asp?ievent=332538>

August 21, 2010; Megarama Day; Down Syndrome Community

A western Adventure at M Bar C Ranch. For more information: <http://www.megaramaday.com/>

October 5 - 6, 2010; Inclusion and Adolescent Transition in Autism Spectrum Disorders Seattle, WA

The Inclusive Classroom, with Paula Kluth, Ph.D.; Bridges to Adulthood for Learners with ASDs, with Peter Gerhardt, Ed.D.

Conference Location: Doubletree Hotel Seattle Airport; 18740 International Blvd.; Seattle, WA 98188; (206) 246-8600

To register: Phone: (920) 749-0332 or go to: <http://store.spectrumtrainingsystemsinc.com>

INFORMATION & ANNOUNCEMENTS

To: King County Parent Coalition Members for DD

From: Betsy McAlister, 425-882-2010, bmcalister@arcofkingcounty.org

Parent Coalition rosters available

If you are interested in receiving a KCPC roster which lists fellow members, please contact me and I will mail you a roster. Some members like to use the roster for networking and contacting each other. Rosters are available to parent coalition members.

News Release from www.dshs.wa.gov Washington State Department of Social & Health Services
MAY 14, 2010 NO. 010-058

FOR MORE INFORMATION:

Heidi Robbins Brown, Deputy Assistant Secretary, Medicaid, 360-725-1040

John Anderson, ProviderOne Project Manager, 360-725-1008

Ken Evans, ProviderOne Services Card Manager, 360-725-1183

New Medicaid Services Card attracts scam artists



OLYMPIA – A North Central Washington family reported an apparent “phishing” scam by an unidentified telephone caller who asked them for \$327 and private financial information in exchange for sending them a new ProviderOne “Blue Card.”

The couple refused, and they later discovered that the toll-free telephone number he had given them was bogus. In the call, he identified himself as “Chris Cassidy, ID No. 582,” and claimed he worked for a private firm hired by the

government.

It was the latest in a handful of apparent scam attempts linked to the new Services Cards – a plastic identification card that was mailed to about one million Medicaid and medical assistance clients around the state during April and early May. The cards are part of the launch of ProviderOne, a new Medicaid payment system.

The cards are absolutely free and have no value or personal information recorded on them. Like the plastic ID cards used by private health insurance plans, they merely help providers establish the client’s identity and eligibility for services. No representative of the Medicaid program or the Department of Social and Health Services will call and ask for money or personal financial information in exchange for the cards.

Medicaid officials said clients who receive the cards need to make sure they take the card along with them when they visit their doctor, dentist, clinic or pharmacy. It is also a good idea to write down the

new ID number on the front of the card. If they lose their card, their provider can use that number and their date of birth, Social Security Number, or address to verify eligibility.

Clients or providers with questions about the new cards can call the Department at 1-800-562-3022 or they can find more information about the cards on the Internet at <http://dshs.wa.gov/ServicesCard/>.

Information about the new cards is also posted on YouTube in a new Department video brochure. Clients and family members, as well as providers, are invited to view the video at <http://www.youtube.com/WAstateDSHS>.

EDITORS: FOR MORE INFORMATION OR BACKGROUND

Tammy Firkins, Communications, ProviderOne Project, 360-725-1008

Jim Stevenson, Communications, HRSA, DSHS 360-725-1915 or pager: 360-971-4067

An electronic photo of the new Services Card is available by e-mailing stevej2@dshs.wa.gov.

DSHS does not discriminate and provides equal access to its programs and services for all persons without regard to race, color, gender, religion, creed, marital status, national origin, sexual orientation, age, veteran's status or the presence of any physical, sensory or mental disability.

Jennifer M. Gau ~ Washington Department of Social and Health Services ~ Public Affairs ~ (360) 902-7829 ~ jennifer.gau@dshs.wa.gov

Partners4housing website information

<http://www.partners4housing.com/>

Our website is a place to provide solutions to the housing crisis faced by our citizens with disabilities. We believe in the power of community. We invite people with disabilities, their families and friends, and people passionate about inclusion, community living and the rights of people with disabilities to [join us](#). Contribute your housing ideas, blog, explore. Let's envision a nation where all people with disabilities have access to affordable housing and the support they need to live their best life.

Spread the Word: Outdoors for All Summer Day Camp Program.

Scholarships Available! DDD/Respite Dollars Accepted!

This summer the Outdoors for All Foundation will host 24 different Day Camps for children with and without disability ages 5 – 21 in and around King County. Outdoors for All Day Camps provide an active camp environment with programming focusing on building each camper's social development, self-confidence and fine and gross motor skills. Activities include cycling, swimming, hiking, water sports and much more!

If you know of a child who would be interested in our program, please encourage them to contact us or learn more on our website. This year's Day Camp programs will offer the same great quality programming as well as fun and energizing activities Outdoors for All is known for. For more details about the camps we are offering, take a look at our Day Camp brochure available on-line at http://outdoorsforall.org/documents/Brochures/Brochure_DayCamp.pdf.

SPECIAL: Anyone who registers for 3 camps or more by June 1st will save \$75 on the total camp fees.

***Scholarships are available for all camps and DDD/Respite dollars can be applied to camp fees. Scholarship applications can be found on our website at http://outdoorsforall.org/documents/Forms/Form_FinancialScholarship.pdf.

If you have questions regarding which camp is right for you, don't hesitate to contact me at 206.838.6030 x209 or anneby@outdoorsforall.org. We look forward to providing a summer of memories for you and your family!

Anne Eby; Day Camp Manager; Outdoors for All Foundation
2 Nickerson Street, Suite 101; Seattle, WA 98109
t: 206.838.6030 x209 f: 206.838.6035
www.outdoorsforall.org

NEW (AND FREE) IPHONE APP LAUNCHED FOR CREATING INDIVIDUAL EDUCATION PROGRAMS (IEP) CHECKLIST

The Parent Educational Advocacy Training Center (PEATC) has launched an iPhone App designed to help families and teachers plan for educational services for students with disabilities. The IEP Checklist iPhone App was developed in response to the rising need for families with children with disabilities to have on-the-spot intelligent assistance working with schools to develop Individual Education Programs (IEPs). The App can be downloaded from the PEATC website www.peatc.org or by entering "IEP Checklist" into the iTunes store search bar. The App is free, and is compatible with the iPhone and iPod Touch.

Fund for postsecondary education and enrichment goals

This fund offers financial assistance to young adults with Down syndrome who want to enroll in postsecondary programs or take classes that will help them with employment, independent living and life skills. To date, over thirty students have received grants from the National Down Syndrome Society (NDSS) to help cover the costs of pursuing their postsecondary education and enrichment goals. The 2010 [application form](#) can be downloaded in PDF format. Application deadline is July 16, 2010. This information has recently been updated, and can be read by visiting this link: http://www.disability.gov/education/financial_aid/scholarships.

Developmental Disabilities Life Opportunities Trust Video: Part One

Thanks to Diana Stadden

You may have heard about the Life Opportunities Trust, well, now's your chance to see it! DDLOT has just recently released a new video called "Opportunity Knocks" that shares more about what the Trust is and how it can help individuals with developmental disabilities and their families prepare for the future. Already there have been 1,200 Trusts opened. Don't miss this opportunity to see the benefits of opening a DDLOT Trust!

[Go to IFBT website to view the video](#) | [Go to the DDLOT website](#)

Developmental Disabilities Life Opportunities Trust Video: Part Two

Last month we showcased a new video about the Life Opportunities Trust called "Opportunity Knocks". A second video in the series has just been released, entitled, "Planning for the Unexpected". This newest video details more about how investing in the Trust can help individuals with developmental disabilities and their families prepare for life's unpredictable expenses.

With over 1,300 Trusts opened, the DD Life Opportunities Trust has become a resource that many are depending on to meet their future (expected and unexpected) needs. Don't miss this chance to see more about the ways a Trust can help you prepare for the future.

[Go to IFBT website to view the video](#) | [Go to the DDLot website](#)

For information on this and other important topics, visit:

<http://www.informingfamilies.org/>

The Informing Families Building Trust Listserv is a joint effort of the Washington State Developmental Disabilities Council (<http://www.ddc.wa.gov>), the Washington State Division of Developmental Disabilities (<http://www.dshs.wa.gov/ddd/>) and other community partners.

“Medicare and the New Health Law – What it Means for You”

Starting tomorrow and throughout this week, Medicare beneficiaries across the country should begin receiving copies of a brochure “Medicare and the New Health Law – What it Means for You” in their mailboxes. The mailing from CMS outlines key provisions of the Affordable Care Act for people with Medicare as well as members of their families. The mailing is being sent in both English and Spanish.

Because Medicare is a trusted resource for beneficiaries and their family members, the mailing encourages them to log on to www.medicare.gov or call 1-800-MEDICARE to get their questions about Medicare or the Affordable Care Act answered and reminds them to be on the alert for possible scams.

The first benefit that many people with Medicare will receive as a result of the passage of the new law is a one-time check for \$250, if they enter the Part D donut hole and are not eligible for Medicare Extra Help. Beginning next year, the Affordable Care Act ensures that Medicare beneficiaries will get free preventive care services like colorectal cancer screening and mammograms, in addition to a free annual wellness visit. The law also includes new tools to help fight fraud by helping Medicare crack down on criminals who are seeking to scam seniors and steal taxpayer dollars.

The brochures can also be found at: <http://www.medicare.gov/Publications/Pubs/pdf/11467.pdf> (English) and http://www.medicare.gov/Publications/Pubs/pdf/11467_S.pdf (Spanish).

Please share this information with your members, partners and constituents.

Recreation Resources for Special Needs Children and Young Adults

provided by Life Enrichment Options (LEO); www.leoorganization.org

Thanks to Chris Weber and LEO for this information.

Parks and Recreation

My Parks and Recreation

www.myparksandrecreation.com

The community connection for sports, recreation, parks, trails and entertainment for ten Eastside cities

Issaquah Parks & Recreation

www.ci.issaquah.wa.us

Contact Ross Hoover at 425-837-3346

Many programs for special needs, also summer camps.

Si View Parks and Recreation

www.siviewpark.org

425-831-1900

Individuals have the choice of participating in both inclusive and specialized recreation programs.

Mercer Island Parks and Recreation

www.mercergov.org

Contact Ryan Daly at 206-275-7863

Programs for special needs, also summer camps.

Redmond Parks and Recreation

www.redmond.gov/recreationarts

Contact Barbe Wolf at 425-556-2330

Many programs for special needs, also summer camps.

Renton Parks and Recreation

www.rentonwa.gov

425-430-6748

Offers a variety of inclusive recreational opportunities as well as adaptive programs for persons with disabilities.

Bellevue Parks and Recreation

www.ci.bellevue.wa.us/highland

425-452-7686

The Highland Community Center provides programs that give people with disabilities opportunities for recreation, socialization and learning.

King County Specialized Recreation

www.arcofkingcounty.org/guide/recreation/organizations/king/

206-296-4136

King County Parks & Recreation offers Specialized Recreation programs specially designed for people – age 16 and older – with developmental disabilities. People with special needs are encouraged to participate in all recreational programs offered for the public also.

Sports

Special Olympics

www.sowa.org

Issaquah softball and basketball – call Leo Finnegan at 392-5682

Other areas of King County – call Susie Arnold at 206-362-4949 ext 208

Washington Special Olympics offers year round sports training and athletic competition in a variety of Olympic-type sports for all children and adults with developmental disabilities.

Challenger Baseball

425-557-0103

“Little League” baseball for those with special needs.

Footloose Disabled Sailing Association

www.footloosesailing.org

206-382-2680

The non-profit, educational and charitable organization uses sailing as a recreational and therapeutic outlet to people of all disabilities age 5 and older. Footloose offers creative programs to meet the needs and desires of interested participants ranging from the simple pleasure of a boat ride, to learning to crew, to learning the full aspect of being a skipper. Lessons, events and day sailing on Lake Washington are offered.

Community Integration Services Swimming

www.cisaquatics.com

425-830-7746

Community Integrations Services offers private swimming sessions for children of all ages with autism, developmentally delays and physical challenges. Private sessions are held in warm water pools in the Bellevue area. Harriet Ott, CTRS, ATRIC

Agnew Aquatics

www.agnewaquatics.com

21122 SE May Valley Rd, Issaquah

A relaxed, friendly environment with productive, goal-specific swim instruction. Not specifically for special needs, but classes are small and the instructor has experience with special needs.

Camps

Camp Sealth – Camp Fire USA (Central Puget Sound Council)

www.campfire-usa.org

Contact Inclusion Coordinator at 206-463-3174 Ext 35

Although not designed as a special needs camp, Camp Sealth on Vashon Island can serve campers age 5 – 18 with a wide variety of physical disabilities, learning and developmental disabilities, behavior disorders, and general medical conditions. Sporadic sessions are available for children with diabetes, asthma, PKU and glutenintolerance.

Outdoors For All Foundation (Previously Ski For All)

www.outdoorsforall.org

425-462-0978

The Outdoors For All Foundation provides year round instruction in outdoor recreation for people with physical, developmental and sensory disabilities. Activities include canoeing, inline skating, rafting, cycling, snow shoeing and hiking.

Camp Berachah

www.campberachah.org

253-939-0488 or 800-859-2267

Camp Berachah in Auburn has been serving families for over 34 years through sponsored programs throughout the year. Offers weekly special needs camps for children age 5-18 throughout summer. Examples of conditions included are: ADHD, autism, Asperger Syndrome, partial blindness, deafness, Down Syndrome, and physical limitations which would require accommodation. Campers are pre-screened to determine placement.

Camp BLAST (Being Leaders and Sharing Talents)

www.wallingfordboysandgirlsclub.org

Wallingford Boys & Girls Club

206-547-7261

Designed for high-functioning developmentally disabled children age 9-17, the camp's goal is to help participants develop confidence, independence, and improve their understanding of health and

safety. Activities include multi-cultural cooking, movies, art, and field trips to pools, beaches, parks, zoos, the aquarium, fire and police stations, libraries, bowling, swimming, hiking and more. Camps are held at various Seattle locations.

Camp Burton

http://www.campburton.com/youth_new_horizons_camp.html

206-463-2512

Camp Burton on Vashon Island provides two types of summer camps for developmentally disabled

youth and adults: The Youth New Horizons Camp for ages 13-24; and Camp Parkview for adults. Activities include swimming (at the local pool), canoeing, games, archery, dancing, and campfires. Campers must be able to care for their personal needs (eating, dressing, and restroom) with minimal assistance and be able to participate in most camp activities.

City of Seattle Parks & Recreation Department Special Needs Youth Summer Camp

www.cityofseattle.net/parks/specialpops/index.HTM

206-684-4950

Contact michael.figueroa@seattle.gov

Offer recreational day and overnight camps for children age 4-21 with developmental and learning disabilities, attention deficit hyperactivity disorder (ADHD), behavioral and social problems, visual and hearing impairments, physical disabilities, and medical conditions.

Overnight camps are held at Camp Long in West Seattle, while day camps are at Lower Woodland Park. Year-round offerings include day and after school programs, swim lessons, bowling, Special Olympics and teen socials. The Specialized Programs staff will also work with individuals or family members who would prefer to integrate into other Department programs but need some type of accommodation such as an interpreter.

CYO Camps

<http://seattleooyam.org>

1-800-950-4963

Providing a positive, supportive community in which each camper is valued and appreciated.

YMCA

www.ysummer.org

Groups

Athletes For Kids

www.athletesforkids.org

Contact Teresa Bretl at 425-260-2109

A mentoring program that serves children with special needs by improving their social and emotional development through a personal relationship with a high school athlete. It is designed to dramatically improve confidence, self-esteem, and ability to relate to peers before entering the difficult teen years.

Bridge of Promise

www.bridgeofpromise.org

Contact Rosie Gremmert---206-437-3975

Bridge of Promise enriches the life of people with developmental disabilities by providing engaging recreational, social and educational opportunities.

Bridge Disability Ministries

www.bridgemin.org

425-885-1006

Their mission is to alleviate isolation for persons with physical and / or developmental disabilities by improving mobility, promoting inclusion, and enriching the community.

Camp Fire Saturday Club

www.campfire-usa.org

sissi-h@campfire-usa.org

206-461-8550 or 800-451-CAMP

The King County Saturday Club provides recreation for children of all abilities ages 4 through 12 by encouraging children in interactive and noncompetitive play, both independently and as part of a group, depending on their interests.

Volunteers of America

www.voaww.org

425-259-3191

Offers recreation programs for those with developmental disabilities.

Sammamish/Issaquah Young Life Capernaum

<http://sammamish.younglife.org>

Contact Natalie Knell at 425-392-0515

Young Life Capernaum Ministries is dedicated to improving the quality of life for young people with disabilities provided by caring people who strive to help provide teens with disabilities the life that every kid wants, filled with love, support, excitement and challenge.

VSA Arts of Washington

www.vsaaw.org

206-443-1843

VSA Arts of Washington is a non-profit organization dedicated to providing arts opportunities by, for, and with persons age 7 and older with special needs. Includes dance and music. They advocate for equal access to the arts and the arts in education for all by creating quality programs, both targeted and inclusive, to create a strong avenue for artistic and creative development. They also offer professional development opportunities for emerging and professional artists with special needs and help forge links between artists with special needs, arts communities, and the general public.

Trips

Sundial Special Vacations

www.sundialtour.com

1-800-547-9198

Vacations designed especially for the developmentally disabled and escorted by experienced staff.

Trips Inc. Special Adventures

www.tripsinc.com

1-800-686-1013

Provides all-inclusive vacation packages for travelers ages 16 through adult with intellectual and developmental disabilities.

Friendship Adventures

www.friendshipadventures.org

Contact Maureen Browning at 425-444-3132

Trips and one-day outings and events. Camping, theme parks, out of state sporting events, dances and more. Big group went on a cruise last year. Activities fit mostly high school and adult populations, but do not preclude youngsters.

Activities

Museum of Flight

www.museumofflight.org

206-764-5720

Museum admission is free of charge on the first Thursday evening of every month 5-9 pm.

Pacific Science Center

www.pacsci.org

206-443-3631

Individuals with a disability may bring a companion/assistant with them, free of charge. Note that only the companion/assistant can be admitted for free.

Seattle Aquarium

www.seattleaquarium.org

206-386-4300

Individuals with a disability may bring a companion/assistant with them, free of charge. Note that only the companion/assistant can be admitted for free.

Woodland Park Zoo

www.zoo.org

206-684-4800

There is a \$2.00 discount for individuals with a disability.

Washington State Parks Disability Pass

www.parks.wa.gov/passes.asp

360-902-8500 or 360-902-8844

This pass is offered to Washington State residents who are developmentally disabled, legally blind, deaf or who meet the disability definition used by the Social Security Administration. It offers 50% discount on nightly camping/moorage, free watercraft launching and trailer dump.

Golden Access Passport (US Department of Interior, National Park Service)

www.nps.gov

The Golden Access card is available to United States citizens of any age who have a disability that impairs any life function. The individual must be eligible to receive benefits for this disability from the Federal Government, through such agencies as the Social Security or Veterans Administrations. It is not necessary that the person actually be receiving benefits at the time of application for the card. The Golden Access card is a lifetime passport to National Parks and other federally managed recreation areas which charge entrance fees. The card will waive entrance fees for the card holder and all persons accompanying him or her in a private vehicle.

Events

Autism Day at Jubilee Farms

www.autismdaywa.com

Contact Lynne Banki at 425-313-5752

11 am – 3 pm., August 7, 2010

A free, fun-filled event designed for families touched by autism. A chance to relax in a beautiful setting surrounded by people who understand. Various individuals, companies, service providers and organizations provide free activities with our children in mind.

Recreational Resource Internet Lists

Summer Camps and Programs for Children with Special Needs

<http://www.cshcn.org/resources/campcalendar.cfm?intro=yes>

Children's Hospital produces a free guide listing summer camps and programs in Washington State for children with special health care needs or disabilities.

The American Camping Association

www.aca-camps.org

A website with information on camps serving people with special needs at. You can also look at www.kidscamps.com to search for camps in other states for children with special needs.

Arc of King County community recreational opportunities listings:

<http://www.arcofkingcounty.org/guide/recreation/organizations/king>

Summer Learning Opportunities

Children's Institute for Learning Differences (CHILD)

www.childrensinstitute.com

206-232-8680

Provides social, emotional, developmental, and neurological strategies for children ages 3 to 18 with challenging learning differences and behavior disorders with the goal of helping them develop the essential skills that are critical to success.

Lakeside Center for Autism

www.lakesideautism.com

425-657-0620

Summer preschool offered.

Information on free to low cost health insurance:

<http://www.kingcounty.gov/healthservices/health/personal/insurance.aspx>

A feature on Little Heroes about a wonderful team in Maple Valley:

Thanks to Laurence Tryon

<http://www.komonews.com/sports/heroes/95372839.html>

LOCAL ISSUES

Redmond Reporter Article featuring The Arc of King County

Extending support, beyond high school: Transition Academy provides opportunities for special needs students in competitive workforce

By **MARY STEVENS DECKER**

Redmond Reporter Reporter

May 12 2010

In October 2009, the Redmond Reporter launched a series of stories about the Lake Washington School District's (LWSD) Transition Academy, a unique, downtown Redmond facility that helps high school graduates with developmental disabilities practice "real world" skills for employment and independence.

All throughout Redmond and neighboring cities, Transition Academy students and graduates volunteer or work at schools, non-profits, retail businesses, restaurants, retirement homes and more.

But the current economy and depressed job market have made that outcome increasingly tenuous. Transition Academy students and grads must compete with individuals in the general population for the few jobs that are out there.

What can their families or others do to help them lead full, productive lives?

NO MORE YELLOW BUS

Nancy Young is the mother of 2009 Transition Academy graduate Andrew Young, who also graduated from Eastlake High School in Sammamish.

Andrew was born with a chromosomal anomaly which had "pervasive impacts, including a significant speech delay, some physical limitations such as balance, strength and fine motor skills and cognitive and academic challenges," said Nancy, who is an administrator in the Northshore School District.

She voiced effusive praise for Transition Academy co-director Richard Haines, describing him as "very caring ... with the ability to negotiate certain things that can be scary for parents of a special needs child."

For example, Transition Academy students are taught how to ride public transportation on their own.

In spite of Andrew's challenges, said Nancy, "He has always had an interest and a desire to be part of the community, whether it was at Eastlake or the world around him. We were grateful to find educators willing to extend that support, beyond high school."

However, Nancy added, "When kids are still under the umbrella of the (public) school system, up to age 21, there are supports such as job coaching. At 21, that goes away. We call it 'no more yellow bus.'"

And when jobs are scarce in general, it creates a dire dilemma for the families of developmentally disabled adults.

"Just as things dried up for the regular population, it's even more difficult for folks who need supports or accommodations in the workplace," Nancy noted.

LIMITED WAIVERS

Washington State's Division of Developmental Disabilities (DDD) can provide "waivers" for additional job support, but the amount, duration and scope fluctuate, depending on an individual's needs and the dollars the state receives through a federal match.

Betsy McAlister, who is a special needs parent in the LWSD and assistant coordinator of the King County Parent Coalition for Developmental Disabilities, shared some news with the Redmond Reporter about the state's recent budget deliberations.

"In other areas of the DD budget, we took cuts, but in the employment area, legislators saw the importance of the funding for transition graduates and allocated funding for approximately 1,401 eligible DDD clients statewide. Up until the age of 21, the responsibility of the funding falls to

the school district. The funding below will allow individuals to access job coaches/supported employment," said McAlister.

- Employment and Day (Transition) Funding is provided for supported employment for 629 individuals who are expected to graduate from high school during the 2009-11 biennium. Employment and day services include job creation and job supports for paid employment. Services are provided at an average per client funding level of \$515 per month.

"We call these folks non-waiver grads," said McAlister.

- Employment and Day to Waiver Funding is provided for supported employment and other services for 429 clients of DDD who graduate from high school during the 2009-11 biennium. This will fund 429 students who had been eligible for "state-only" services, rather than community-based, and move them to the waiver, said McAlister.

- Waiver Graduate Employment Services Funding is provided for supported employment and day services for approximately 343 people graduating high school or transition services. These students are currently on a Home and Community Base Waiver and supported employment and day services are a component of the waiver.

CREATING A LIFE

Nancy is grateful that Andrew has obtained a waiver through DDD, which will allow him to live with his parents while he receives a little more job coaching. Due to his health issues, it's unlikely he'll be able to work full-time, so his family has looked for the types of social/recreational activities that are strongly encouraged at the Transition Academy.

"We call it 'creating a life' — finding active things to do in the community," said Nancy.

Some days, Andrew volunteers at an elementary school within walking distance of his family home. Other days, he takes two buses, independently, to Seattle Children's Hospital where he has a mentor and is hoping to get a part-time job. He also exercises at the Redmond Athletic Club, likes to eat lunch at the Village Square Cafe in downtown Redmond and participates in Special Olympics and Young Life.

While he has come a long way through the LWSD's special education programs and especially the Transition Academy, letting Andrew "do his own thing" still provokes some anxiety for his family.

Nancy explained, "When you have a typically developing 18-year-old, they are pushing to get away from you, be on their own. It is the opposite with a special needs teen or young adult. It's a matter of gently coaxing, 'You're gonna be on your own, you'll be fine, you can do this,' while also anticipating some 'skinned knees.'"

And the state has only limited funding to continue job and life coaching, "yet there are so many who need it," Nancy emphasized.

"These are real-life people, this is someone's child. If they don't have a life, there's a ripple effect on the family."

KEEPING US GROUNDED

Redmond Athletic Club (RAC), 8709 161st Ave. NE is one of many Redmond businesses that has a supportive relationship with the LWSD Transition Academy.

Andrew has been working out at RAC, under the guidance of trainer Nuu Faaola, for about two-and-a-half years. Faaola has tailored a cardiovascular and strength-training regimen especially to Andrew's needs, such as his bone structure.

Working with Andrew is both delightful and humbling, said Faaola, a former pro football player for the New York Jets.

"He's always smiling," Faaola noted. "It's a reality check for us. When I start to complain, I look at him, how hard he works and what a great attitude he has. It keeps me grounded. I learn more from him than he learns from me."

STRENGTH IN NUMBERS

What's the best way for families of developmentally disabled young adults and others to advocate for facilities like the Transition Academy and other job coaching programs?

McAlister invites participation in The King County Parent Coalition. There is strength in numbers. Sharing concerns and resources, families and others can help to ensure that people with disabilities continue to be treated with dignity and given options to help them thrive in the community.

As well, the LWSD Transition Academy is always looking for local business partners who appreciate diversity and need loyal, enthusiastic interns or employees.

For more information about the King County Parent Coalition (a program of The Arc of King County), visit

www.arcofkingcounty.org/our-services/king-county-parent-coalition

For more information about the LWSD Transition Academy, visit www.lwsd.org/school/ta

To see more photos of Andrew, please visit Reporter staff photographer Chad Coleman's photo blog, [Focus Northwest](#); Redmond Reporter Reporter Mary Stevens Decker can be reached at mdecker@redmond-reporter.com or (425) 867-0353, ext. 5052.

WAC (Washington Administrative Code) Rules

To: King County Parent Coalition Members for DD

From: Betsy McAlister, Margaret-Lee Thompson, and Joanne O'Neill

From time to time, the Aging and Disability Administration Services will send out WAC rules. Occasionally, in our packets we will be highlighting new rules. The first one is listed today on

amendment to in-home classifications. Below the announcement is information to help explain the rules.

Subject: CR-103 for amendment to in-home classifications

> May 20, 2010

>

> TO: Interested Parties

>

> FROM: Aging and Disability Services Administration

>

> SUBJECT: CR-103 for amendment to in-home classifications

>

> The Aging and Disability Services Administration (ADSA) has completed
> adoption of amendments to WAC 388-106-0125 and has adopted new WAC
> 388-106-0126.

>

> The department has completed this rule making to allow the reduction of
> in-home base hours for each of the 17 classification groups, as directed by
> the Washington State 2009-2011 Budget (Engrossed Substitute House Bill 1244,
> Section 205(1)(b) and Section 206(5)). As instructed by the Legislature,
> classification groups with greater care needs receive a smaller percentage
> reduction than classification groups with lesser care needs. The department
> also adopted new WAC 388-106-0126 to maintain base hours for children and
> youth under the age of 21.

>

> To view the CR-103 and rules, go online to:

> <http://www.dshs.wa.gov/pdf/ms/rpau/103P-10-11-050.pdf>

Information explaining WAC rules is from the OSPI website:

<http://www.k12.wa.us/ProfPractices/adminresources/RulesProcess/FAQ.aspx#20>

“WAC stands for Washington Administrative Code. *WACs are administrative codes, or rules, that are adopted by agencies, including OSPI, to enact legislation and RCWs.* (laws) The Washington Administrative Code contains all rules that have been adopted, as well as the history of all previously existing WACs and amendments in Washington.

When proposing a rule those involved often refer to the steps in the process in terms of the rule-making forms agencies must file with the Office of the Code Reviser.

In order to help you understand the different steps and forms, below is an explanation of each step of the process.

- The first major step is the filing of the Pre-Proposal Statement of Inquiry (also called the CR-101 form):

When the CR-101 form is filed, notice is provided to the public that the agency is considering developing a new rule, amending an existing rule, or repealing an entire rule or sections of a rule.

- **The second major step is the filing of the Notice of Proposed Rule Making (also called the CR-102 form):** *The CR-102 form can not be filed until 30 days after the CR-*

101 form has been published in the Washington State Register. After this 30 day period an agency can file a CR-102 form at any time.

The CR-102 announces to the public that a change to an OSPI rule is being proposed. Included on this form is a brief description of the rule, the associated WAC number, a copy of the proposed rule text, as well as the date, time, and location of the public hearing(s), the deadline to submit comments, and the process for submitting comments. If appropriate, a Small Business Economic Impact Statement (SBEIS) is filed with this notice.

- **The last step is the filing of the Rule-making Order (also called the CR-103 form):** *The CR-103 form can not be filed until on or after the intended adoption date identified on the CR-102 form (Expedited and Emergency rules are exceptions). The maximum time allowed between the publication of the CR-102 form and the filing of a CR-103 form is 180 days. If this deadline is not met the rule making is withdrawn.*

The CR-103 form is used to adopt into WAC the proposed rule text that was filed using the CR-102 form. When the CR-103 form is signed by the Agency Director the rule is adopted. Usually, unless specified otherwise, a rule becomes effective 31 days after filing.

10. How long does it take from the time a rule is proposed (CR-102 form) until it becomes final (CR-103 form)?

A rule can become final between 28 days after filing the CR-102 form and 180 days of the publication of the CR-102 form. No rule can be adopted before the intended adoption date identified on the CR-102. Those rules that are not finalized within 180 days after the publication of the CR-102 form are withdrawn from the process and can no longer be adopted without filing a new CR-102 form.

There are two exceptions to this time frame:

1. **Emergency rules** are filed using the CR-103 form. In most situations they become effective immediately.
2. **Expedited rules** are filed using an expedited process. Once the rule is proposed there is a 45 day period before the rule can be adopted. On the 46th day, or any day after that, the rule can be adopted and usually becomes effective 31 days later.

STATE ISSUES

June 16, 2010: Work session on Autism; Olympia

Thanks to Diana Stadden

There will be a work session on autism, focusing on the consequences of the increase in prevalence and looking at research that may help identify the causes for this. Keep in mind that this is a work session only, it is not a public hearing that allows public comment. The public is welcome to attend and listen to the panels which will be presenting on this issue. Check with TVW.org afterwards as they will likely tape the work session.

House Human Services Committee

Wednesday, June 16, 2010; Senate Hearing Room 3; Olympia, WA; 10 am – 12:00 noon

NATIONAL ISSUES

[Boston University Medical Campus; School of Medicine](#)

Study Finds Alzheimer's Disease Link in Eyes of Children with Down Syndrome:

Findings May Lead to Eye Tests for Brain Disease in Alzheimer's and Down Syndrome

A team of researchers has discovered that the protein that forms plaques in the brain in Alzheimer's disease also accumulates in the eyes of people with Down syndrome. The new findings in Down syndrome show that the toxic protein, known as amyloid- β , that causes Alzheimer's pathology in the brain also leads to distinctive cataracts in the eyes. The discovery is leading the researchers to develop an innovative eye test for early detection of Alzheimer's pathology in both disorders.



Lee E. Goldstein (Photo courtesy of Lightchaser Photography)

The research, led by Lee E. Goldstein, M.D., Ph.D., associate professor at Boston University School of Medicine and the Boston University Alzheimer's Disease Center, and Juliet A. Moncaster, Ph.D., associate director of the Molecular Aging & Development Laboratory, also at Boston University, was presented at the annual meeting of the Association for Research in Vision and Ophthalmology in Fort Lauderdale, Florida and reported in the May 20 issue of PLoS One. The research included investigators at the Brigham & Women's Hospital; Massachusetts Eye and Ear Infirmary; Massachusetts General Hospital; Harvard Medical School; Rush University Medical Center; Children's Hospital Boston, and the University of Washington, Seattle.

"People with Down syndrome develop symptoms of Alzheimer's-type dementia often by the age of 30," said Goldstein, senior corresponding author on the PLoS One article. "This is because they have an extra copy of a key Alzheimer's gene that leads to increased amyloid- β accumulation in the brain. We discovered that this same protein starts to accumulate very early in the lens of the eye, even in children," explained Goldstein.

"The lens provides a window to the brain," said Moncaster, co-lead author of the study. "The lens can't clear protein deposits the way the brain does. Our findings show that the same amyloid- β protein that aggregates in the brain also accumulates in the lens and leads to these unusual cataracts in Down syndrome."

“The results are striking,” added David G. Hunter, M.D., Ph.D., Ophthalmologist-in-Chief at Children’s Hospital Boston and Vice Chairman of the Department of Ophthalmology at Harvard Medical School. “We have known that these cataracts are prevalent in people with Down syndrome and are sometimes seen at birth, but we never knew how they were related to the disorder—now we know,” said Hunter. “These distinctive cataracts appear only in people with advanced Alzheimer’s disease and much earlier in Down syndrome.”

According to the National Down Syndrome Society and the National Institute of Child Health & Development, Down syndrome is the most common chromosomal disorder and the leading genetic cause of intellectual disability. In the US, one of every 800 newborns and more than 400,000 people have Down syndrome. Although the disease is incurable, life expectancy for people living with Down syndrome has increased dramatically in recent decades — from 25 in 1983 to 60 today.

“We are developing an eye scanner to measure amyloid- β in the lens,” said Goldstein. “This approach may provide a way for early detection and monitoring of related pathology in the brain. Effective treatments for the brain disease in Down syndrome and Alzheimer’s disease are on the horizon, and early detection is the key for successful intervention,” he said. “The path to effective treatment is what drives our research.”

Lead co-authors on the PLoS One publication are Juliet Moncaster (Boston University School of Medicine), Roberto Pineda (Massachusetts Eye and Ear Infirmary, Harvard Medical School), and Robert Moir (Massachusetts General Hospital, Harvard Medical School). Co-authors of the study are Suqian Lu, Mark Burton, Joy Ghosh and Anca Mocofanescu and Rebecca Folkerth (Brigham & Women’s Hospital, Harvard Medical School), Maria Ericsson (Harvard Medical School), Stephanie Soscia and Rudolph Tanzi (Massachusetts General Hospital, Harvard Medical School), Richard Robb and David Hunter (Children’s Hospital Boston, Harvard Medical School), Jerome Kuszak (Rush University Medical Center), and John Clark (University of Washington, Seattle). The corresponding author of the study is Lee Goldstein (Boston University School of Medicine and Boston University Alzheimer’s Disease Center).

The five-year research effort was supported by the National Institutes of Health (National Institute of General Medical Sciences, National Institute on Aging), American Federation for Aging Research, Alzheimer’s Association, American Health Assistance Foundation, Cure Alzheimer’s Fund, National Disease Registry Interchange, Sun Health Research Institute, Florida Lion’s Eye Bank, and an anonymous foundation. The investigators disclosed that at the time of the study Drs. Tanzi and Goldstein were scientific consultants to Neuroptix Corporation and with Dr. Moir to Covance, Inc. The authors reported no commercial research funding or other competing interests.

This entry was posted on Friday, May 21st, 2010 at 2:27 pm.



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May 21, 2010



Tuesday, May 25, 2010 - Page updated at 06:41 AM

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Britain bans doctor who linked autism to vaccine

By MARIA CHENG

AP Medical Writer

The doctor whose research linking autism and the vaccine for measles, mumps and rubella influenced millions of parents to refuse the shot for their children was banned Monday from practicing medicine in his native Britain.

Dr. Andrew Wakefield's 1998 study was discredited - but vaccination rates have never fully recovered and he continues to enjoy a vocal following, helped in the U.S. by endorsements from celebrities like Jim Carrey and Jenny McCarthy

Wakefield was the first researcher to publish a peer-reviewed study suggesting a connection between autism and the vaccine for measles, mumps and rubella. Legions of parents abandoned the vaccine, leading to a resurgence of measles in Western countries where it had been mostly stamped out. There are outbreaks across Europe every year and sporadic outbreaks in the U.S.

"That is Andrew Wakefield's legacy," said Paul Offit, chief of infectious diseases at the Children's Hospital of Philadelphia. "The hospitalizations and deaths of children from measles who could have easily avoided the disease."

Wakefield's discredited theories had a tremendous impact in the U.S., Offit said, adding: "He gave heft to the notion that vaccines in general cause autism."

In Britain, Wakefield's research led to a huge decline in the number of children receiving the MMR vaccine: from 95 percent in 1995 - enough to prevent measles outbreaks - to 50 percent in parts of London in the early 2000s. Rates have begun to recover, though not enough to prevent outbreaks. In 2006, a 13-year-old boy became the first person to die from measles in Britain in 14 years.

"The false suggestion of a link between autism and the MMR vaccine has done untold damage to the UK vaccination program," said Terence Stephenson, president of the Royal College of Paediatrics and Child Health. "Overwhelming scientific evidence shows that it is safe."

On Monday, Britain's General Medical Council, which licenses and oversees doctors, found Wakefield guilty of serious professional misconduct and stripped him of the right to practice medicine in the U.K. Wakefield said he plans to appeal the ruling, which takes effect within 28 days.

The council was acting on a finding in January that Wakefield and two other doctors showed a "callous disregard" for the children in their study, published in 1998 in the medical journal *Lancet*. The medical body said Wakefield took blood samples from children at his son's birthday party, paying them 5 pounds (about \$7.20) each and later joked about the incident.

The study has since been widely rejected. From 1998-2004, studies in journals including the *Lancet*, the *New England Journal of Medicine*, *Pediatrics* and *BMJ* published papers showing no link between autism and the measles vaccine.

Wakefield moved to the U.S. in 2004 and set up an autism research center in Austin, Texas, where he gained a wide following despite being unlicensed as a doctor there and facing skepticism from the medical community. He quit earlier this year.

Offit said he doubted Britain's decision to strip the 53-year-old Wakefield of his medical license would convince many parents that vaccines are safe.

"He's become almost like a Christ-like figure and it doesn't matter that science has proven him wrong," Offit said. "He is a hero for parents who think no one else is listening to them."

Wakefield told The Associated Press Monday's decision was a sad day for British medicine. "None of this alters the fact that vaccines can cause autism," he said.

"These parents are not going away; the children are not going to go away and I most certainly am not going away," he said on NBC's "Today Show."

Wakefield claimed the U.S. government has been settling cases of vaccine-induced autism since 1991.

However, two rulings by a special branch of the U.S. Court of Federal Claims in March and last year found no link between vaccines and autism. More than 5,500 claims have been filed by families seeking compensation for children they claim were hurt by the vaccine.

Wakefield has won support from parents suspicious of vaccines, including Hollywood celebrities.

McCarthy, who has an autistic son, issued a statement in February with then boyfriend Carrey asserting Wakefield was "being vilified through a well-orchestrated smear campaign."

"It is our most sincere belief that Dr. Wakefield and parents of children with autism around the world are being subjected to a remarkable media campaign engineered by vaccine manufacturers," the actors said.

McCarthy, whose best-seller "Louder Than Words" details her search for treatments for her son Evan, wrote the foreword for a new book by Wakefield about autism and vaccines.

In Monday's ruling, the medical council said Wakefield abused his position as a doctor and "brought the medical profession into disrepute."

At the time of his study, Wakefield was working as a gastroenterologist at London's Royal Free Hospital and did not have approval for the research. The study suggested autistic children had a bowel disease and raised the possibility of a link between autism and vaccines. He had also been paid to advise lawyers representing parents who believed their children had been hurt by the MMR vaccine.

Ten of the study's authors later renounced its conclusions and it was retracted by the Lancet in February.

At least a dozen British medical associations, including the Royal College of Physicians, the Medical Research Council and the Wellcome Trust have issued statements verifying the safety of the measles, mumps and rubella vaccine.

This verdict is not about (the measles) vaccine," said Adam Finn, a professor of pediatrics at the University of Bristol Medical School. "We all now know that the vaccine is remarkably safe and enormously effective... We badly need to put this right for the sake of our own children and children worldwide."

Associated Press Writer Kelley Shannon contributed to this report from Austin, Texas

Online: Ruling on Wakefield, <http://www.gmc-uk.org/Wakefield-SPM-and-SANCTION.pdf-32595267.pdf>

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Capitol Insider; Volume 15, Issue 21; June 1, 2010

Medicaid/Medicare/Housing

On Friday, May 28 the House passed H. R. 4213, the American Workers, State, and Business Relief Act of 2010, by a vote of [215-204](#). The \$113 billion measure extends unemployment insurance compensation, blocks cuts in doctors' Medicare payments, increases infrastructure funding, and retroactively extends tax code provisions that expired at the end of 2009. Conservative "Blue Dog" Democrats withheld support until at least some parts of the bill wouldn't add to the deficit. In the final compromise, Democratic leaders dropped two costly provisions---an extension of the increase in Medicaid federal medical assistance percentage (FMAP) to states and the COBRA health insurance subsidy. Fortunately, an important provision for the disability community remained in the House-passed bill: \$1 billion for the National Affordable Housing Trust Fund to build and preserve 1.5 million units of affordable rental housing for individuals with extremely low incomes. The Senate vote on H.R. 4213 has not yet been scheduled. With floor time quickly running out this Congress, disability advocates are working to ensure that the Medicaid FMAP provision is included in other "must pass" bills. The Arc and UCP extend a sincere thank you to all advocates who called their representatives last week in support of the Medicaid FMAP provision.

Civil Rights/ ADA/Olmstead

The Justice Department announced it has filed briefs in three separate cases in Florida, Illinois and New Jersey as part of its continuing effort to enforce civil rights laws that require states to end discrimination against and unnecessary segregation of persons with disabilities. The Department's filings support two private lawsuits seeking relief in Florida and New Jersey, as well as a proposed statewide class action settlement in Illinois. The briefs allege that the three states are failing to comply with the Americans with Disabilities Act (ADA) and the Supreme Court's decision Olmstead decision. Last year, President Obama issued a proclamation launching the "Year of Community Living," and has directed the Administration to redouble enforcement efforts.



Early Learning Action Alliance

2010 FEDERAL LEGISLATIVE AGENDA

The members of the Early Learning Action Alliance are united by the belief that all children in Washington state deserve the opportunities and support they need in their first five years of life to be prepared for school and a bright future.

Coalition Members:

American Federation of Teachers
Washington
Arc of King County
Business Partnership for Early Learning (BPEL)
Child Care Resources
Children's Alliance
Children's Home Society of WA
Children's Trust Foundation
Community Network Coalition
Denise Louie Education Center
Early Learning Public Library Partnership
Economic Opportunity Institute
First Five FUNDamentals
Foundation for Early Learning
Kirlin Charitable Foundation
League of Education Voters
League of Women Voters
Washington
Lutheran Community Services
Northwest
Minority Executive Directors Coalition
of King County
MomsRising
Northwest Early Learning Coalition
Nurse Family Partnership
Olympia Early Learning Center
Parent Trust for Washington
Children/Parents as Teachers State
Office
Reach Out & Read Washington State
Ready by Five
School's Out Washington
SEIU, Local 925
SOAR
Stand for Children
United Way of King County
United Ways of Washington
WA Association for the Education of
Young Children (WAEYC)
WA Chapter American Academy of
Pediatrics
WA Educators in Early Learning
Washington State Association of
Head Start & ECEAP
WA State Child Care Resource &
Referral Network
Washington State Family Child Care
Association
Wellspring Family Services
White Center Early Learning Initiative

• **Prioritize Early Learning Investments in the Budget**

Include a \$1.6 billion increase for the Child Care and Development Block Grant and a \$1 billion increase for Head Start and Early Head Start. When America supports all licensed child care, Head Start and Early Head Start, we encourage children, families, and our nation to reach their full potential. These programs are vital supports for children who need high-quality early learning and afterschool experiences that promote their successful development and for parents working to support their children.

Impact on Washington State

For Washington State, the President's proposed major increases to child care, afterschool programs, and other early learning programs in his 2011 budget could mean an increase of approximately \$29 million annually in Child Care and Development Block Grant funding and funding to sustain the 202 additional Head Start and 852 Early Head Start slots added to serve children through stimulus funds.

• **Pass the Early Learning Challenge Fund (ELCF)**

The ELCF would be the most significant investment in state systems for quality early learning programs in the history of the U.S.. Investing in crucial infrastructure will ensure that our nation's children have bright futures by creating a more coherent system that serves as an umbrella for early childhood priorities.

Impact on Washington State

The passage of the ELCF would help establish badly needed state infrastructure as well as ensure that Washington can provide high quality early learning to a greater number of children in our state. If Washington is successful in the competition for an Early Learning Challenge Grant, even at one fiftieth of the funds proposed to be appropriated under this act, *it could receive as much as \$20 million per year in funding to help ensure the success of a comprehensive birth to five system in Washington state.*

• **Include Early Learning in Elementary and Secondary Education Act Reauthorization (ESEA)**

Update the ESEA to reflect the indisputable evidence that the early years of children's education—those from pre-kindergarten through third grade—establish essential skills and behaviors that support college- and career-readiness. The reauthorization of the Elementary and Secondary Education Act provides a unique opportunity to transform American education.

Impact on Washington State

Changes to ESEA could increase professional development opportunities in early learning, increase funding for schools to increase alignment between early learning and K-12, and help promote an aligned data system between early learning and K-12. Washington currently has 8 school districts with Early Learning Leadership Grants through the Bill & Melinda Gates Foundation that are working towards greater P-3rd continuity for kids. If ESEA is authorized with early learning included, it could enhance and expand these important efforts.

The Early Learning Action Alliance is convened by the Children's Alliance.

Leslie Dozono at (206) 324.0340 x20 or leslie@childrensalliance.org

May 19, 2010

Top of Form

Autism Spectrum Disorders Health Center

Autism Families: High Divorce Rate Is a Myth

Study Shows Divorce Rates Are Similar for Parents With and Without Autistic Children

By [Kathleen Doheny](#)

WebMD Health News

Reviewed by [Laura J. Martin, MD](#)

May 19, 2010 -- Parents of autistic children often hear that the [divorce](#) rate in families with [autism](#) is 80%, but a new study debunks that figure as a myth.

"There really weren't any significant differences in terms of family structure when you consider children with autism and those without," says study researcher Brian Freedman, PhD, clinical director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute in Baltimore.

"In fact what we found is that children with autism remained with both biological or adoptive parents 64% of the time, compared with children in families without autism, who remained [with both biological or adoptive parents] 65% of the time," Freedman tells WebMD.

"That debunks the myth of an 80% divorce rate," Freedman says. An 80% rate is roughly double the U.S. divorce rate for first marriages.

Freedman is due to present his findings Friday at the International Meeting for Autism Research in Philadelphia. About one in 110 children in the U.S. has [autism spectrum disorder](#) (ASD), a group of neurodevelopmental disorders that include autism as well as [Asperger's](#) syndrome and other forms that involve difficulties in social relationships and communication.

The new finding, Freeman says, will hopefully relieve some of the [stress](#) parents of children with autism feel. Families he has counseled often tell him they feel they have gotten two diagnoses at once: a child with autism and a prediction of divorce, when they hear the oft-quoted figure of 80%.

"They talk about how disheartening that is, and how their relationship seems doomed," he tells WebMD.

While the figure of an 80% split-up rate among parents of children with autism is often talked about, Freedman says he searched for the original study and never found one. It may have originated from pure speculation and then was brought up again and again, with no solid evidence.

"Certainly studies of parents of children with autism talk about the extra stress," he says, so perhaps the leap was made that the stress led to an unusually high rate of divorce.

Structure of Families With Autism

Freedman examined data from the 2007 National Survey of Children's Health, including a nationally representative sample of 77,911 children, ages 3 to 17.

He looked at whether the family structure was a two-parent household, with either biological or adoptive married partners, or was not traditional, such as a two-parent household including a stepparent, a household headed by a single parent, or other structures.

The percent of children with ASD living in a two-parent biological or adoptive household was close to the percent of children without ASD in such a family structure -- 64% vs. 65%.

That percent held even when the researchers took into account other factors that could have affected family structure, such as socioeconomic status or demographics.

Structure of Families With Autism continued...

The researchers also considered the severity of a child's autism and whether that had an impact on family structure. "That also did not seem to have an impact," Freedman tells WebMD.

When Freedman took into account co-existing psychiatric and other problems, such as [ADHD](#) or serious behavioral problems, in children with ASD, he found that the likelihood of living in a non-traditional family structure increased slightly.

"Those disorders in fact did seem to have implications for divorce," he says. Even so, he says, "I would not say it dampens the idea of debunking the 80% divorce rate." He points out that the overall percent of 64% of kids found to live in a traditional family structure includes those families whose children had both co-existing diagnoses and ASD and well as those children with ASD alone.

About 10% of children with ASD have one or more psychiatric diagnoses, and 83% have developmental diagnoses, according to a study in the *Journal of Developmental & Behavioral Pediatrics*.

Second Opinion

The new study may help reduce [anxiety](#) among parents of children with autism, says Geraldine Dawson, PhD, chief science officer of Autism Speaks and a research professor at the University of North Carolina, Chapel Hill, who reviewed the study results for WebMD.

"The 80% divorce figure has been part of official lore for decades," she says. "I think it may stem from the fact that we do know parents of children with autism are under tremendous stress."

"It's good news for families," Dawson says of the new study findings. "It really demonstrates that despite the fact that these families are going to be facing a lot of challenges, we don't have to assume that divorce is likely."

In helping parents of autistic children, Freedman tells them that communication is most important in dealing with the developmental disorder. Each parent should be allowed to express their frustrations, he says.

Getting outside support from family or friends is important too, he says.

While there is a tendency for parents to focus attention on the child and his needs, Freedman tells couples to schedule time for themselves regularly so they can tend to their [marriage](#).

One Family's Story

Julie Waldron remembers not only the shock she felt when her son Frankie, now 6, was diagnosed with autism at age 18 months, but how quickly someone told her that her marriage was at risk. She remembers hearing about an 85% divorce rate.

"You're shocked and in a way mourning the diagnosis of your child," she says. Hearing about the high divorce rate was a kind of double whammy, she says.

Even though they felt they were doing well, Waldron and her husband, Peter, decided to go to preventive marriage counseling. "We were mutually concerned that we could be doing damage to our relationship that we had no clue we were doing," he says.

Now the parents of three children, the Waldrons say the diagnosis of autism helped strengthen their marriage because they learned how to cope with the diagnosis and the marital stress it can bring, and to work together.

"You need to find what works for you and your spouse," Peter says. For them, he says, that meant Julie was "the CEO of our children" while he took charge of working and ensuring that their medical care and insurance was taken care of, with each informing the other about goings-on.

JUSTICE NEWS

Department of Justice
Office of Public Affairs

FOR IMMEDIATE RELEASE

Thursday, May 6, 2010

Justice Department Files Lawsuit Against Arkansas Alleging Statewide Violations of the Americans with Disabilities Act

WASHINGTON – The Justice Department announced today that it has filed a lawsuit alleging that the state of Arkansas is systemically violating the Americans with Disabilities Act of 1990 (ADA).

The complaint, filed in U.S. District Court for the Eastern District of Arkansas, encompasses all six Arkansas Human Development Centers (HDCs) and the state's restrictions on services in integrated settings. It seeks to enforce the ADA's requirement that Arkansas provide services to individuals with disabilities in the most integrated settings appropriate to their needs. The lawsuit also addresses the state's systemic failure to comply with the ADA in how it provides services to individuals with developmental disabilities.

"The ADA guarantees individuals with developmental disabilities the right to live in the most integrated setting appropriate to their needs. Arkansas' lack of community services requires individuals with developmental disabilities to choose between receiving services in segregated institutions and receiving no services at all," said Thomas E. Perez, the Assistant Attorney General in charge of the Civil Rights Division. "Arkansas illegally segregates hundreds of individuals in institutions across the state and places hundreds more at risk of needless institutionalization. We are acting now to remedy discrimination against these individuals."

The six Arkansas HDCs are congregate institutions that segregate approximately 1,100 individuals with developmental disabilities from the community. While confined to the HDCs, residents have extremely limited access to community activities and amenities, as well as limited opportunities to interact with people without disabilities. According to the complaint, hundreds of these individuals are segregated illegally in the HDCs in violation of their rights to services in the most integrated setting appropriate to their needs. The lawsuit also alleges that the state restricts development of adequate community supports and services to enable individuals to leave the HDCs and to offer viable alternatives to many individuals who are at risk of inappropriate institutionalization.

The current wait list in Arkansas for home and community-based waiver services for individuals with developmental disabilities who are seeking community alternatives to institutionalization totals approximately 1,400 people. This wait list moves at an extremely slow pace, with most people waiting several years for community services. Individuals currently at the bottom of the list will likely wait more than a decade to receive community services. Yet, the state is actively expanding its HDC institutions at the cost of developing community alternatives.

In January 2009, the Justice Department filed a lawsuit against Arkansas, in accordance with the Civil Rights of Institutionalized Persons Act (CRIPA), regarding the Conway HDC. That CRIPA complaint alleges that conditions at Conway HDC violate the Constitution, the Individuals with Disabilities Education Act and the ADA. Trial is currently set for September 2010. Because the new statewide ADA lawsuit filed today will encompass the department's ADA claims regarding Conway HDC, the Justice Department filed a motion yesterday to dismiss those claims from the Conway HDC suit.

The ADA authorizes the attorney general to investigate whether a state is serving individuals with disabilities in the most integrated settings appropriate to their needs. CRIPA authorizes the attorney general to investigate conditions of confinement in certain institutions owned or operated by, or on behalf of, state and local governments. In addition to residential facilities serving persons with developmental disabilities, these institutions include psychiatric hospitals, nursing homes, jails, prisons, and juvenile justice facilities. Please visit the website www.justice.gov/crt to learn more about the ADA, CRIPA, and other laws enforced by the Justice Department's Civil Rights Division.

10-538; Civil Rights Division; <http://www.justice.gov/opa/pr/2010/May/10-crt-538.html>