



# SPIN NEWS

The Newsletter for Parents of Children with Special Needs

SPECIAL  
PARENT  
INFORMATION  
NETWORK

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SPIN is co-sponsored by the Disability & Communication Access Board and the Department of Education. Services include a phone line for information referral and support, a quarterly newsletter, an annual conference and community workshops. SPIN is guided by an Advisory Committee made up of parents, teachers and people with disabilities.

## SPIN

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## Time Runs Out on Some Key Legislative Reforms

As longtime veterans of advocating for children with disabilities reflect on the outcomes of the 2014 Legislature, there is a sense of lost opportunity for some of the reforms that died in the final days and hours of the Session. These included mandated coverage of autism diagnosis and treatments, more open testimony to the Board of Education, and regulations to cover giving epinephrine (Epi-pens) to students with severe allergic reactions.

Of course, there is always the expectation that only a small fraction of the bills that are introduced in January will make it through the 60 days of legislative debate. Still, special factors added to the frustration over seeing key bills stall in the 11th hour, including:

- **Initial optimism over a big budget surplus.** An \$844 million surplus at the end of last session led many to ask for additional monies for long needed reforms--like air conditioning for Hawaii's hottest classrooms. In March the projections for future \$\$ coming in were revised down, causing many of these money requests to be rejected.
- **Feedback from legislators**

that certain bills were on track to become law. This was particularly true of the autism bills where families have been testifying for 3 years in a row.

- **Miscommunication during last minute conferencing.** An unexplained hitch on the last day for bill approval caused a number of education bills to be killed abruptly.

**Despite these disappointments, there is still plenty to cheer about.**

Go to page 2 and 3 to see what bills are awaiting final approval by the Governor and what you can do to gear up for next year's legislation. As Benjamin Franklin once said, "Energy and persistence conquer all things!"



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# 2014 Bills that Passed the Finish Line



The following pieces of legislation affecting students with disabilities and their families are likely to become law unless vetoed by the Governor:

## HEALTH INSURANCE COVERAGE



Although the autism insurance bill, **Senate Bill 2054**, failed to require coverage by a certain date, it did require an 2014 analysis of the potential costs of providing this coverage, leaving the door open for action next legislative session. A cost study is also required through **House Concurrent Resolution 100** on the costs to insurance companies of covering orthodontia and other medical treatments for children with orofacial anomalies (like cleft lip and palate).

## IDEA ELIGIBILITY AGE LIMIT



Up until this year, Hawaii was one of only two states that did not provide special education services from age 3 through 21. Now, because of a federal circuit court decision (*E.R.K. vs. Hawaii DOE*), services are required up to the 22nd birthday for special education students who still have not met their IEP goals or graduated with a high school diploma. **Senate Bill 2134** makes the required age changes to Hawaii's education statute.

## YOUTH RISK BEHAVIOR SURVEY



A resolution (**SCR 51**) will help to gather more key risk data about Hawaii's middle and high school students—including bullying, smoking, suicidal thoughts and attempts, and poor eating habits. Hawaii's data can then be compared to 46 other states. The Youth Risk Behavior Survey—given every two years—will now require parents to “opt out” of having their child take the survey rather than requiring parent permission up front.

The following State Departments received additional monies in their budgets to meet the needs of children and young adults with disabilities:

## DEPARTMENT OF EDUCATION



In anticipation of serving more students with disabilities aged 20 to 22 because of **SB 2134**, the Department of Education asked for and got \$3.6 million dollars for SY 14-15. The details are still being worked out between DOE attorneys and attorneys for the plaintiffs in the *E.R.K.* decision as to what services will look like. Disability advocates are hoping they include supports in the community and supports to assist students to transition to higher education.

## FAMILY HEALTH SERVICES DIVISION



The Family Health Services Division in the Department of Health received \$1.5 million to provide hearing and vision screening to public school students. They also received an additional \$1.2 million for early intervention services--case management, therapies and early education--for infants and toddlers from birth to age three who have a developmental delay.

## DEVELOPMENTAL DISABILITIES DIVISION



The Developmental Disabilities Division (DDD) was able to get roughly \$1.2 million in matching funds to expand Medicaid Waiver Services to children and adults with developmental disabilities. This will result in over \$2.4 million in additional waiver services in the coming year. A related resolution (**HCR 17**) will require the DDD to form a task force to meet sometime after July and review the state's definition of “developmental disabilities.”

# General Bills Affecting Children & Youth



While not specifically aimed at children with disabilities, the following legislation will provide benefits to our keiki with special needs:

## SECLUSION & RESTRAINT IN SCHOOL



When **House Bill 1796** is fully implemented in August 2016, it will ban the use of **seclusion** (keeping a student alone in a room) and limit the use of **physical restraints** to situations where the student's safety or the safety of others is in danger. It also bans the use of drugs or restrictive devices to control behavior. The bill gave the Department of Education \$250,000 for the coming school year to begin training of teachers and other staff.

## MINIMUM WAGE INCREASE



With many students with disabilities starting out in entry-level jobs, the plan to raise the minimum wage from \$7.25 (currently) to \$10.10 by January of 2018 will help more folks earn a higher income. **Senate Bill 2609** also helps employers of workers who receive tips (like restaurant workers) by providing a higher tip credit towards business taxes.

## PRESCHOOL FUNDING



Preschool Open Doors got \$6 million to help low-income families send their children to private preschools. In addition, the Department of Education got \$3 million to set up 21 preschool classrooms on school campuses in communities with limited preschool options. Hopefully these new preschool classrooms will offer additional opportunities for preschoolers with disabilities to share activities with their peers.

## What to do in the Interim?

The period that the State Legislature is not in session is called the "interim." Whether you are new to the legislative process or a seasoned veteran, there are activities throughout this time period that help keep up the movement toward better services and opportunities for our children with disabilities. Here are a few:



As the button says, "Vote!" Hawaii's primary election is on August 9th and the general election is November 4th. You'll have an opportunity to vote for both state and U.S. Congress representatives. There will also be a constitutional amendment on the November ballot asking if public money can be used to fund private preschools.



Find out more about how laws are made. On the Hawaii State Capitol website--[www.capitol.hawaii.gov](http://www.capitol.hawaii.gov)--you can click on the **Citizen's Guide to the Legislative Process** and also find out who your legislators are.



Get advance notice on upcoming hearings and bills. The **State Council on Developmental Disabilities** has a great email notification system. To ask to be included, go to [hiddce-network@doh.hawaii.gov](mailto:hiddce-network@doh.hawaii.gov).



## State Office of Elections

The **Office of Elections** is available for voter education presentations. A presentation includes an overview of the mechanics of voting in Hawaii and "Election Accessibility for People with Disabilities."

If you are interested in having a presentation for your organization that serves people with disabilities, have an upcoming event that you would like to display election information, or would like to have voter information sent to you, please contact **Anthony Akamine** at the Office of Elections at [anthony.akamine@hawaii.gov](mailto:anthony.akamine@hawaii.gov), or 453-VOTE (868)453-8683.

# CONGRATULATIONS!



This year, SPIN singled out some key parents and professionals whose efforts make a positive difference in the lives of children and young adults with disabilities and their families in Hawaii. These Most Valuable Players were honored at our 2014 SPIN Conference, “Hit a Home Run with SPIN!”, on Saturday, April 5, 2014 at the UH Campus Center.

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## PARENTS OF THE YEAR

**Kiele Pennington** started off wanting to learn as much as possible about autism so she could help other families she may meet. Although her daughter at the time was just a toddler, she sought and attended workshops and training opportunities and holds the record for the Rainbow Book Warriors as *Parent of the*



*Youngest Child* who’s completed the training program.

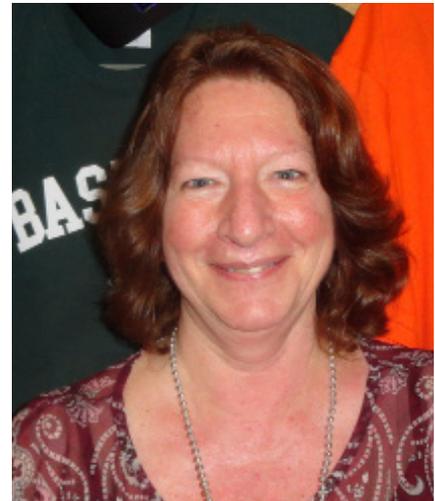
She eventually moved from Maui to Oahu to obtain services for her daughter. As a mother of three and a loving wife to her husband, no one can compare to making such a difference for her family and the greater autism community. Most recently, this mom has become the state coordinator for the TACA (which stands for Talk About Curing Autism) Hawaii Chapter.

As a change agent, she has worked tirelessly to support families in the autism communities and has established “coffee hours” across the islands for families as well as youth to get together to provide support and information. She has also put on large events such as Picnic at the Plaza and the great Country Stew Cook-Off, raising

awareness and funds for autism. Kiele continues to go the extra mile as she always has time to lend an ear and shoulder to parents and professionals alike.

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**Sue Emley** is a veteran mom with an impressive list of careers helping children and families. As a Certified Occupational Therapy Assistant in Hawaii schools for twenty-five years, she has helped children with disabilities improve their fine motor coordination. Her own experience of helping her son battle childhood cancer, and then of nurturing her family through the grief process when he lost that battle, made her a committed manager of the American Cancer Society’s Families Can Survive Program.



Sue was also a dedicated member of the Traumatic Brain Injury Consulting Team working to improve understanding and supports for students who experience a traumatic brain injury, Family Consultant for Project Laulima helping to improve the system of care for children with co-occurring developmental disabilities and mental health challenges, and most recently, the Program Coordinator for Parents for Public Schools.

What makes Sue such a valuable advocate is first and foremost her heart. And it is also her ability to see problems from many sides—as a mom, helping professional, a systems advocate and a community organizer. Overall, it is her gift of being able to see the positive in any situation.

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# 2014 SPIN Conference Awardees!



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## FAMILY CHOICE AWARDS

**P**atricia (Paddy) Tholen, who is Irish to the core, is a Parent Educator for children with special



needs in Maui District where she has worked for decades with a variety of programs, including IMUA, Head Start, and DOE preschool to ensure that young

keiki with disabilities receive developmentally appropriate practices. She was formerly the Maui 619 Coordinator, bringing together services for all special education preschool students.

Paddy has a deep bond with children, and no matter when you talk to her, she is gushing about whatever child she is working with. What parent doesn't love that! She's also the hostess with the mostest who has the gift of building relationships between all the members of her team—parents, agencies and school folks.

She provides support and empowers families as they navigate the school system. SPIN is especially grateful that she makes a special effort each year to guide young families from Maui to attend our conference. Paddy never seeks recognition for her efforts, and keeps her focus always on the children.

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**S**hrene Naki--who despite being new to the game--has put in quite a performance to improve the lives of all children,

and especially children with special needs, and their families on her island of Molokai. In an effort to help her own son Makena, who was being cruelly bullied at his middle school, she met with his teachers and



administration, but the bullying continued. Students with disabilities are often the targets of bullies far more often than their regular education peers which can be devastating to a student's physical and emotional health.

Shrene then courageously wrote a letter to the editor in the *Molokai Dispatch* about the need to take action against bullying. Though she took some heat from her community for speaking out, her ohana pushed forward. Through her efforts, a group called Families Against Bullies was formed and began meeting with school personnel and community members.

Shrene has also enlisted the support of Hawaii Families as Allies and the Molokai Community Children's Council, taking on the role of its secretary. Together, as a team, school attitudes improved, and there is much less physical bullying on campus. So the next time you ask yourself, "what could one person do to make a difference?" remember Shrene Naki.

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# 2014 SPIN Conference Awardees (cont.)

## PROFESSIONALS OF THE YEAR

**J**oanne Miyasato is a dedicated educator for the Department of Education who is always working tirelessly to support, promote and help behind the scenes to make positive things happen for young children, their families and staff.



Joanne was instrumental in the launching and development of the first classrooms for preschool children with disabilities in Central District back in the late 70's. Today, as the 619 Coordinator for preschool special education, she coordinates services in DOE's largest district to more schools, families and children than any other.

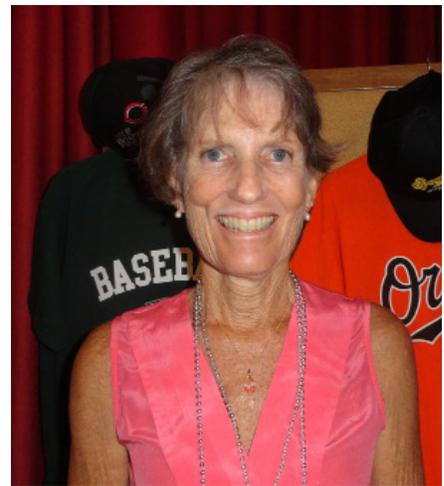
Joanne has been involved in the Sequenced Transition to Education in the Public Schools (STEPS) Project since its inception here in Hawaii back in 1997 and has been the sustaining force for the Central STEPS team, "Simply Central," ensuring positive and smooth transitions for children and families moving between early intervention, Early Head Start, community preschools, Head Start, DOE 619 preschool, kindergarten and other services in their areas.

Joanne does not perceive the work she does as a job, but a vocation to help others. She wants every young child and their family to have the best opportunities, to do well and reach their full potential.

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**P**atricia Sheehey is the parent to eight biological children—six boys and two girls--as well as two hanai daughters. Taking on her responsibilities with heart and determination included advocating for the educational needs of two children with disabilities, and making sure her son with significant disabilities was given the dignity of choice and belonging in his community. And now as the resource care provider for her two-year old granddaughter, Patricia has once again stepped up to the plate to provide the love and support that all children need in order to thrive.

Patricia has been an incredible educator to hundreds of students with disabilities. She worked for many years as a special education teacher on the Big Island then eventually



returned to the university and earned her Doctorate in Exceptionalities at UH Manoa. As an Associate Professor in the Department of Special Education, she has a particular interest in mentoring young teachers in how to partner with families.

Patricia's generously contributes her time and expertise as an advisory member to many boards and councils, including her current membership on the Special Education Advisory Council and her three-year commitment to the Dyslexia Working Group. She has also shared her knowledge with numerous parents and helping professionals over the years as a SPIN conference workshop presenter.

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## SPIN Conference Awardees (cont.)

### PROFESSIONALS OF THE YEAR

**D**r. Dan Ulrich is an incredible child psychiatrist who brings to the plate his professional training, multi-faceted work experiences and his experiences as a dad. These learned and life skills have added



tremendously to his ability to work collaboratively and achieve solutions as the Medical Director of the Department of Health's Child and Adolescent Mental Health Division.

Dr. Ulrich attended medical school at the University of Pennsylvania and graduated as a triple board resident from the University of Hawaii John A. Burns School of Medicine specializing in pediatrics, child psychiatry and adolescent psychiatry. During his years in the Pediatrics Residency Program, he focused his limited free time and energy working towards system change for Lesbian, Gay, Bisexual, and Transgender (LGBT) youth, and was a popular doc serving youth in the corrections system. A favorite presenter at the SPIN Conference, Dr. Ulrich has served families in East Honolulu, military families, and now families statewide.

Dr. Ulrich exhibits grace under pressure and has shared his personal experiences as a parent to comfort other families who are faced with many of those same challenges in their lives. He understands the day-to-day nuances of the raising a family, and has created a supportive and nurturing environment to meet those special need challenges. Dr. Ulrich is always at the top of the list for many families and professionals.

## TAKE THE PARENT SURVEY



The Hawaii Department of Education, as a part of the U.S. Department of Education Office of Special Education Program's monitoring requirements, is conducting a parent survey.

Parents will be given the survey at their child's annual Individualized Education Program (IEP) meeting.

The survey will give parents the opportunity to voice their opinion on the school's efforts to partner with parents and improve educational services for their children. All parents are encouraged to complete the survey.

For more information, contact Karen Sato at 808-203-5560.

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## TRAVEL TRAINING



**A**bilities Unlimited (AU) is a local non-profit organization committed to building inclusive communities that empower individuals with disabilities. We do so by providing quality direct support to individuals with disabilities under a number of state contracts with the Department of Health and the Department of Human Services.

Beginning in 2012, we expanded our services to include our Travel Training Program, which we run in partnership with the City & County of Honolulu and Paratransit, Inc. Our Travel Training Program offers any individual with a disability, 13+ years of age, with free bus training to and from specific points on Oahu. Since the program's inception, AU has trained over 80 individuals with disabilities to navigate the public bus system.

If this service is of interest to you, please contact Kirk Jarrett, AU Travel Training Coordinator, at 808-532-2166 or [kjarrett@abilitiesunlimitedhi.org](mailto:kjarrett@abilitiesunlimitedhi.org).

*Submitted by:*

*John Kuwaye, Abilities Unlimited Travel Trainer*

# KEEP AN EYE ON THESE...



CARE Hawaii is sponsoring the following workshops:

- 6/17 Co-Occurring Disorders**  
**7/15 De-Escalation Strategies**  
9:00 a.m. - 1:00 p.m.  
2201 Waimano Home Road, Hale E  
Call 791-6082 or email [veronica.mendoza@carehawaii.com](mailto:veronica.mendoza@carehawaii.com)

- 6/21 Understanding Evaluations**  
Presented by the Learning Disabilities Association of Hawaii  
9:00 a.m. - 10:30 a.m.  
Call LDAH at 536-9684.

Alaka'i Na Keiki presents the following workshops:

- 6/14 The Orchestra without a Conductor: Exploring the Challenge of Executive Function**  
**6/21 School Based Strategies for Motivating Student Learning and Managing Students' Challenging Behaviors**  
**6/28 Application of Emotional Intelligence: A Seminar for Parents and Service Providers**

- 10/5 21st Annual Children & Youth Day**  
State Capitol and surrounding grounds  
For more information, visit [www.HawaiiCYD.org](http://www.HawaiiCYD.org).

- 10/10 21st Annual Children and Youth Summit**  
State Capitol  
Registration will open in August and is limited to the first 300 participants (21+ years old).  
Contact Senator Chun-Oakland at 586-6130.

All workshops are from 10:00 a.m. to 2:00 p.m. and held at 1100 Alakea Street, 9th Floor, Honolulu, RSVP to [alakaiinc@aol.com](mailto:alakaiinc@aol.com) or call 523-7771.

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## WEBINARS

The Hilopa'a Family to Family Health Information Center is sponsoring the following webinars:

- 6/19 Improving Birth Outcomes: 4 More Kids to Move the Dial  
<https://www3.gotomeeting.com/register/641537390>
- 7/17 Health Coverage and Financing - The ABC's and 1-2-3  
<https://www3.gotomeeting.com/register/654046374>
- 8/6 Love Me Tender: Safety and Injury Prevention  
<https://www3.gotomeeting.com/register/670647014>
- 8/14 Let's Talk Story: Transitioning to Adult Health Care  
<https://www3.gotomeeting.com/register/680750214>
- 9/18 Fetal Alcohol Spectrum Disorders - What's the 411 on FASD?  
<https://www3.gotomeeting.com/register/686469486>
- 10/1 Twist and Shout: Physical Activity, Nutrition, Obesity and Growth  
<https://www3.gotomeeting.com/register/692494254>
- 10/16 Advocacy is not an "A" Word  
<https://www3.gotomeeting.com/register/697374446>
- 11/5 HELP! Making a Bright Future Work for You - Resource Overview  
<https://www3.gotomeeting.com/register/702272734>
- 12/3 QUEST Integration: Moving the Health of Hawaii Forward  
<https://www3.gotomeeting.com/register/717701366>



Webinars are from 12:30 p.m. - 1:30 p.m. HST. For more information: Oahu (808) 791-3467; Moloka'i (808) 660-0063; Hawaii (808) 333-3053; Kauai (808) 240-0485; Maui & Lanai (808) 270-1536. For General Information email [info@hilopaa.org](mailto:info@hilopaa.org); Medicaid Questions or Concerns email to [ombudsman@hilopaa.org](mailto:ombudsman@hilopaa.org) or [qexa@hilopaa.org](mailto:qexa@hilopaa.org) and Training Information to [training@hilopaa.org](mailto:training@hilopaa.org).