



SPIN NEWS

The Newsletter for Parents of Children with Special Needs

SPECIAL
PARENT
INFORMATION
NETWORK

May/June 2015
Volume XXXI, No. 4

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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Victories Large and Small at the Capitol

At the end of the 2015 legislative session, advocates of children and young adults with disabilities took a few minutes to enjoy their hard won victories. This was especially true for parents of children with autism who had brought their pleas for insurance coverage for their children's complicated medical and behavioral needs to multiple hearings over the last three or four years. Getting to the finish line felt more like a marathon than a footrace.

The autism bill that emerged from the Conference Committee at the end of the session reflected compromises with the insurance industry. Still, supporters were grateful to have coverage in the near future despite age restrictions and spending caps.

Two other groups of advocates--those representing keiki managing diabetes and life-threatening allergies (like an allergy to peanuts) and those seeking added coverage for keiki with facial and oral birth defects--also high-fived each other after a long race. You can read summaries of these bills and others on page two and three.

Of course, all bills passed in the last days of the Legislature must also survive the threat of a veto by Governor Ige. He has 45 days from the end of the session to either sign a bill into law, allow it to become law without his signature, or veto (reject) it. Should he veto a bill, the Legislature has the option of getting back together to try to override the veto.

One other important legislative event worth noting was an informational briefing on the Department of Education's progress toward special education reforms. Senator Michelle Kidani, Chair of the Senate Education Committee, and Representative Roy Takumi, Chair of the House Education Committee, heard presentations

from Deputy Superintendent Ronn Nozoe and Special Education Advisory Council (SEAC) Chair Ivalee Sinclair.

The focus was on recommendations made by WestEd, national consultants on education, for improving special education services in Hawaii. SEAC made the point that the performance gap between special education and general education students is actually growing. They asked that the community be included in and kept informed of reform efforts. Learn more by going to SEAC's website: <http://seac-hawaii.org/west-ed-report/>.



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2015 'Marathon' Bills Cross over the Finish Line



The following legislation reflects dedicated advocacy by parents and others and hours and hours of testimony over several years to achieve the desired goals:

AUTISM HEALTH INSURANCE COVERAGE



The final version of **Senate Bill 791** requires all insurance carriers to cover diagnostic and treatment services for children with autism up to age fourteen. Coverage for applied behavioral analysis (ABA) services are capped at \$25,000 per year and requires that they be delivered by a licensed provider. Since Hawaii does not currently have an licensing program, a companion bill--**Senate Bill 40**--is establishing a Behavior Analyst Program to license ABA providers in the state.

OROFACIAL HEALTH INSURANCE COVERAGE



Children born with cleft and palate and other conditions involving the mouth and teeth often require orthodontic treatment--like braces--to ensure the best outcome from re-constructive surgery. **House Bill 174** requires insurance carriers to provide up to \$5,500 per treatment phase for medically necessary orthodontic services for children born with facial defects that affect eating, chewing, speech and breathing. Coverage takes effect on July 1, 2015.

EPI-PENS & DIABETES CARE IN SCHOOLS



Students with life-threatening allergies and students with diabetes may need an epinephrine injection (epi-pen) or insulin to prevent medical complications while at school. **House Bill 10** allows school volunteers to administer the epi-pen when students are unable to do so themselves. It also allows school personnel to assist with the testing and management of diabetes and students to self-test and self-manage their diabetic symptoms, when possible. Parents must provide the necessary supplies.

More 2015 Bills Impacting Students with Disabilities

HAWAII ABLE SAVINGS PROGRAM



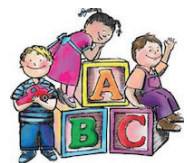
The Achieving a Better Life Experience (ABLE) Act, signed into law in December 2014, allows children and adults with disabilities to have tax-free savings of up to \$14,000 a year without losing Medicaid or SSI income. **House Bill 119** creates the Hawaii ABLE Savings Program to encourage Hawaii residents with disabilities and families of children with disabilities to set up tax-free savings accounts to assist in their support.

MOVIE CAPTIONS IN HAWAII THEATERS



For movie lovers who are Deaf, hard of hearing or visually disabled, **House Bill 1272** (already signed into law as **Act 39**) is a big step towards accessibility. It requires movie theater chains who operate in two or more locations to offer at least two open captioned showings of each movie per week (when the movie is produced with that capability). Movie goers can also request audio description of available movies.

PUBLIC PRE-KINDER-GARTEN PROGRAM



Creating an Executive Office on Early Learning Public Prekindergarten (via **House Bill 820**) will help to promote high quality instruction for preschoolers served in public preschool classrooms and charter schools. The focus is on serving four-year olds who do not have access to quality preschool programs in their community. Children with disabilities are to be included alongside their non disabled peers in these programs.

2015 Budget Highlights and Potential Bills for 2016

DEPARTMENT OF EDUCATION BUDGET



This year the Department of Education sought and won more money for bus transportation, teacher recruitment and retention, school food services and skilled nursing services. However, the funds awarded by the Legislature were less than requested. One solution offered was to seek more Medicaid reimbursement dollars for skilled nursing and transportation. Legislators also turned down the Department's request for \$12 million to expand the availability of technology, including iPads and laptops for individual students.

DEPARTMENT OF HEALTH BUDGET



Legislators honored requests from the Department of Health for \$3 million for the Genetics Services Project and \$254,000 to expand metabolic screening of newborns. However, only about \$800,000 was funded of the Developmental Disabilities Division's request for roughly \$2.3 million to expand its home and community based waiver services to COFA (Compact of Free Association) residents. These include individuals from the Marshall Islands, Palau and Micronesia. Services to COFA children with developmental disabilities should not be affected.

BILLS THAT FELL SHORT OF PASSING



A number of bills affecting student with disabilities came close to the finish line but failed to pass. These included bills to address bullying and cyberbullying in and out of school and a bill to extend Medicaid coverage to individuals with disabilities who are working. Called 'Medicaid Buy-In' the program is currently available in most states and encourages people with disabilities to seek employment without worrying about losing medical coverage. Most of the dedicated supporters of these failed bills will try again next year.

Links to Additional Legislative Information

Updates on Governor Ige's actions on 2015 bills
<http://governor.hawaii.gov/bills/>

A full listing of bills that were passed by the 2015 Legislature
<http://www.capitol.hawaii.gov/ad-reports/main.aspx> (Click on Bills that Passed under Legislature)

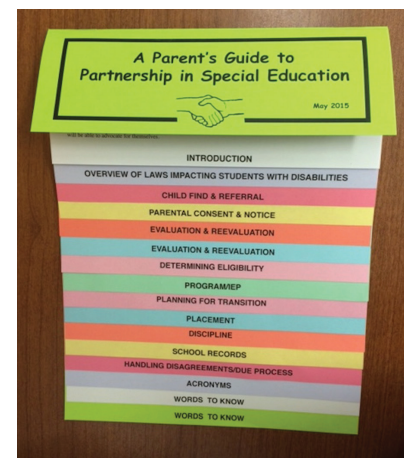
A full listing of resolutions that were passed in 2015
<http://www.capitol.hawaii.gov/ad-reports/main.aspx> (Click on Resolutions Adopted under Legislature)

A Citizen's Guide to Participation in the Legislative Process
<http://www.capitol.hawaii.gov/citizensguide.aspx>

Parent Guide Now Available

Many of SPIN's faithful readers have been waiting patiently for the updating of the popular *A Parent's Guide to Partnership in Special Education*. Written by SPIN with support from the Special Education Advisory Council and the Department of Education, the *Guide* provides easy to follow information about the steps in the special education process as well as special terms and acronyms parents hear in IEP meetings.

The *Guide* is meant to support and not replace the Procedural Safeguards Notice given to parents each year. It is written in parent-friendly language with a 'flip' format that allows readers to jump to the section they would like to read. SPIN is also working on a digital version that will contain



links to useful documents and websites. This electronic version should be up on SPIN's website by June (www.spin.hawaii.org). In the meantime, feel free to request your copy of the print version of the *Guide* by calling (808) 586-8126 or emailing spin@doh.hawaii.gov.

June is National Effective Communication Month



The Public Broadcasting System shares ways to have meaningful conversations with our kids.

1) **Ask specific questions.** A well-meaning but general question can get one-word answers. Instead, try asking a specific question that

will let your child know you are paying attention and encourage him to respond with a specific answer.

2) **Physical actions** like making eye contact, bending down to your child's level and tilting your head shows them you are really listening.

3) **Accept your child's feelings.** In response to your keiki's statement, you might say "I'm glad to know that" or "I understand." Sometimes this acknowledgment is all your child needs to hear.

4) **Pause to consider your child's question.** Even if the answer will still be "No", pausing and saying "Let me think about what your saying and get back to you" helps your child feel you are considering their question and lessens the chance for a power struggle.

5) **Avoid attacking your child's character.** If your child acts out, instead of saying "bad girl, how dare you speak to me that way!" you could say "That kind of language is not OK." In this way you are separating the behavior from the child.



--For more on this article, visit www.pbs.org/parents/talkingwithkids/strategies.html.

For children who are non-verbal, they may mix different forms of communication to express themselves. Encourage effective communication by mixing it up and modeling language in various ways.



Motoric: Direct physical manipulation of a person or object (for example, taking one's hand and pushing towards a desired item).



Gestural: Pointing, showing, gaze shifting (for example, a child looks or points to a desired object then shifts his gaze to another person, requesting that object).



Vocalization: Use of sounds, including crying, to communicate (for example, a child says "ah-ah-ah" to draw your attention).



Sign language: Communication with a conventional signed language system.



Using objects: The child hands an object to you to communicate (for example, the child hands a cup to his parent to indicate "drink").



Using photos: Use of two-dimensional photographs to communicate (for example, pointing to, or handing photos of various objects, actions or events to express desires).



Pictorial: Use of two-dimensional drawings that represent objects, actions or events (for example, handing a line drawing of a "swing" to his parent to indicate he wants to swing).



Written: Use of printed words or phrases to communicate (for example, the child writes "too loud" to indicate the noise level around her is bothering her).

--Written by Susan Stokes under a contract with CESA 7 and funded by a discretionary grant from the Wisconsin Department of Public Instruction
<http://www.specialed.us/autism/nonverbal/non11.htm>



Effective Communication in Your IEP Meeting

Tips for Parents & Professionals



1. Communicate with your child before the meeting. Ask how school is going, and if they would like to change anything. Find out what they like and dislike and what they want or need.
2. Write down any questions or concerns before the meeting, so you don't forget. You can submit these questions as a written proposed agenda to the school before the meeting. Bring extra copies.
3. Be an active listener. Make sure you make eye contact with people as they are speaking. Give each speaker your full attention and allow them to finish their thoughts before speaking up. Don't fidget.
4. Parents are a full and equal member of the IEP team. If someone says "The team feels.." you should also agree with the statement. If you do not agree, you could say "I am an equal member of this team, and I do not feel that way". Do not allow yourself to get into a "us versus them" situation. Be kind.

2015 Parent of the Year Awards



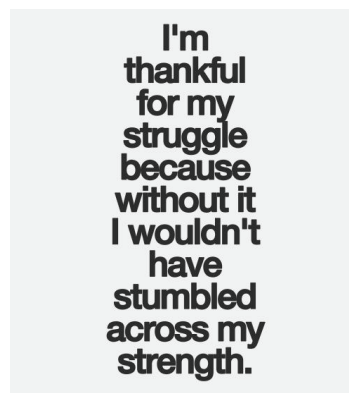
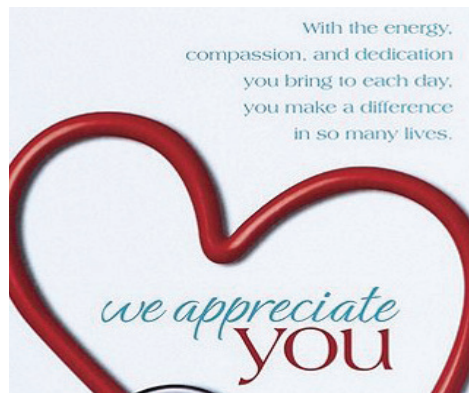
Kau'i Rezentes

Kau'i is a Kamehameha graduate who works at Hilopā'a Family to Family Health Information Center. She is the mom to Ava, who, at 11 years old is the most medically fragile child in Hawaii. Kau'i serves on Hawaii's SEAC and the Western Regional Genetic Alliance Advisory Council and is Vice President of Family Voices. She embodies *aloha*, advocating for and mentoring families, sharing the message that tomorrow is another day, and it will be a good day as long as you stay true to yourself and love your child.



Lisa Jaso

Lisa is a single mother to four children and thirteen grandchildren. She is a resident of Ka'ahumanu homes where she is the President of the Residents' Association. Lisa gives back to her community by volunteering for Summer Fun, after-school tutoring and organizing dances. She has been active in both the East and West Honolulu CCCs for the past nine years and has taken on the role of caregiver to her four-year old granddaughter who has special health care needs. Lisa is a gem in our community that shines in every heart she touches.



2015 Family Choice Awards



Tom Smith

Tom works for Bayada Behavioral Health but he also works for his community. He is the Professional Co-Chair at the Windward CCC for the past 6 years, serves on the Special Education Advisory Council and co-chairs the Coalition for Children with Special Needs. He has worked alongside families and community advocates on various policies including Chapter 60, the State Performance Review and Response to Intervention policies. Tom is truly a collaborative community partner working for us all.



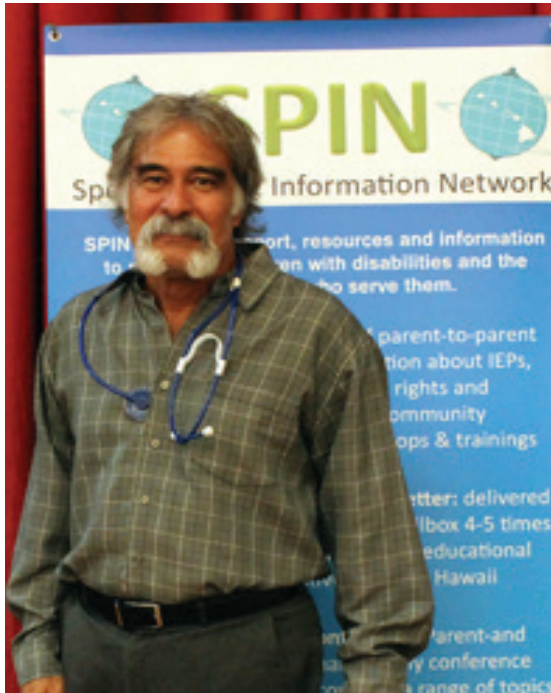
Matt MacDonagh

Known by his students and families as Mr. Mac, Matt is a teacher at Castle High School. He has a special kind of tough love in his teaching that has lasting impacts on his students. He works tirelessly after hours as a Special Olympics coach and transporter, picking up and dropping off athletes who need a ride. Mr. Mac works hard to create sustainable job opportunities for his students while at school and after graduation. He was nominated by parents for his dedication, caring influence and his ability to help students achieve independence.



Debbie Kobayakawa accepted the award for Matt MacDonagh, as he was not able to attend.

2015 Professionals of the Year



Art Souza

Art is a Complex Area Superintendent from the island of Hawaii and is the perfect partner for any family member. He has his roots in community development education and is a leader in Hawaii's Community of Practice cohort. He is an avid national speaker and is known for his incredible vision and ability to bring various stakeholders together. Art is a mentor, a shepherd and the embodiment of family-professional partnerships.



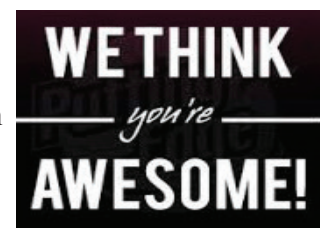
Dr. Patricia Heu

Dr. Heu is the Branch Chief of the Children with Special Health Needs Branch. She is a graduate of the Hawaii Pediatric Residency Program & the School of Public Health. She has moved forward initiatives for the Newborn Hearing & Metabolic Screening programs and, for the past 3 years, provided extra special support to the Early Intervention Program. Dr. Heu is the author of the Rainbow Book, and her passion for family-centered care is evident in everything she does.



Dr. Bobbie-Jo Moniz-Tadeo

Bobbie-Jo is the Program Director for Imua Family Services on Maui. When both of her children were born with their own unique medical conditions, it fueled Bobbie-Jo's determination to help others. She is a graduate of the MCH LEND program, an alumni instructor at Argosy University and the Professional Co-Chair on Hawaii's Early Intervention Coordinating Council, working to improve the lives of Hawaii's children & families.





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Summer Events & Workshops



- | | |
|----------------|--|
| 6/6 | THEAsurf is a free surfing program for children with special needs. They will be at Poipu Park on Kauai June 6 and Launiupoko Park in Laina on June 8 from 10:00 am - 4:00 pm both days. Visit Therasurf.org for more information. |
| 6/6 | KELII presents their 2nd annual Car Show and Family Event at Kapolei High School. 11:00 a.m. - 6:00 p.m.
Car, truck & bike show, food & vendors.
Register at www.keliiifoundation.webs.com |
| 6/15-19 | LDAAH presents 5 Clinics in 5 Days!
June 15: Present Levels of Achievement
June 16: Transition Plan
June 17: IEP Goals & Objectives
June 18: Modifications & Accommodations
June 19: Least Restrictive Environment
All sessions are free and are from 10:00 am to 11:30 am at 245 N. Kukui St, in Honolulu. Call 536-9684 to register. Child care available! |
| 7/11 | Access Surf will be hosting a Day at the Beach at White Plains from 9:00 am - 1:00 pm. Free surfing event, for all ages and abilities. Sign up @ www.accessurf.org |
| 8/13 | LDAAH at Lanai Community Center 2:30 - 5:00 pm. Free traveling Mini Conference. Call 800-533-9685 |
| 8/21-22 | Family Learning Vacation sponsored by the Hawaii School for the Deaf and Blind . Includes workshops for parents and kids, in a 2-day program designed to strengthen family relationships and communication. Call Roz Kia at 808-733-4999 or email Billy_Kekua@notes.k12.hi.us for info on cost and registration. |
| 8/27 | LDAAH at Molokai Community Center 3:00 - 7:00 pm. Free traveling Mini Conference. Call 800-533-9684 |

