



SPIN NEWS

The Newsletter for Parents of Children with Special Needs

SPECIAL
PARENT
INFORMATION
NETWORK

September 2016
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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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Hawai'i - 974-4000
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Reclaiming Your Super Powers

The beginning of a new school year is stressful for most families. There are clothes and supplies to buy, new teachers to meet, new bus schedules to juggle. These pressures get piled onto the everyday stress that parents of children with disabilities experience.

A number of studies have shown that parents of children with disabilities are more likely to experience major disruptions in their family life--hospitalizations, marital distress, extra expenses that strain the budget--and a greater number of daily problems or worries, compared to parents of typically developing children. These daily stresses include things like challenging bed-time routines, homework hassles, medication management, and frequent doctor or therapy appointments.

The stresses above are considered *external stressors*--they result from the situation and often involve our relationships with others. Two other types of stress affect parents of children with disabilities or medical conditions--*internal* and *physiological stress*.

Internal stress comes from a parent's own personal expectations and attitudes. For example, when your child doesn't make an expected milestone on time (like learning to walk or learning to read) you may feel guilt, frustration, sadness or worry about the future.

Physiological stress is the stress on

your body caused by the extra amounts of energy you expend in parenting a child with a disability. This physical stress may cause you to have an unhealthy diet, lack of time to exercise and too little sleep.

SO... now that we have identified all of the pressures on parents of kids with disabilities, what can we do to make our lives less stressful and more enjoyable?

⇒ Start by checking out your potential sources of support on page 5.

⇒ Plan to join us on April 22, 2017 as we celebrate another SPIN Conference,

entitled most appropriately, **"Superheroes of SPIN."**

⇒ Look through the stress management ideas found at <https://www.verywell.com/parent-disability-stress-tips-2162645>.

⇒ Find something funny to watch on TV or in the movie theater.

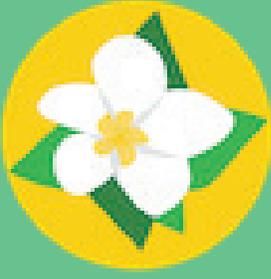
⇒ Try to learn and practice yoga or mindfulness.

⇒ Stop and smell the plumeria!



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The Special Education Advisory Council (SEAC) . . .

The **Special Education Advisory Council**, or **SEAC** (pronounced *see-ack*), is Hawaii’s state advisory panel under Part B of the Individuals with Disabilities Education Act. Congress intentionally created the requirement for these panels to be made up of a majority of parents of children with disabilities and persons with disabilities to ensure that their voices be heard by the Superintendent and others in the Department of Education when addressing policies or programs for students with disabilities.

SEAC’s 27 members also include teachers, administrators, department reps and community folks. All have been appointed by the Superintendent and serve without pay. SEAC’s most common responsibilities include:

 advising on the unmet needs of children with disabilities,



commenting on rules and policies regarding the education of students with disabilities,



reviewing and commenting on special education due process hearing decisions,



participating in the Annual Performance Report process, and



reviewing and supporting the DOE’s budget and legislation related to students with disabilities.

SEAC also prepares an annual report each June that includes specific recommendations to the Superintendent. It can be found, along with meeting agendas and minutes, and past testimonies on SEAC’s website: www.seac-hawaii.org.

Leading by Convening

This school year, the leadership in the Department of Education has agreed to partner with SEAC in using the **Leading by Convening** process to help solve complex issues related to special education. Leading by Convening (LBC), also referred to as “the Partnership Way,” is a tool, developed by **IDEA Partnership**, that can be used to positively change practice around the delivery of special education services.

LBC has three main habits that must be developed for successful interactions:

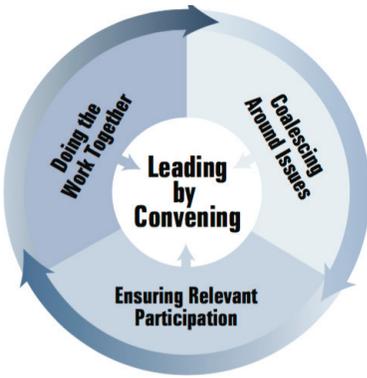
▶ **Coalescing around issues:** having groups of people come together around shared concerns or problems of practice that they want to fix;

▶ **Ensuring relevant participation:** participants show a willingness to do the work necessary by responding to the invitation and doing the preparation necessary to move forward; and

▶ **Doing the work together:** valuing diversity, modeling respect, practicing shared leadership and encouraging personal investment in the work.

You can find more about LBC on this website: <http://www.nasdse.org/publications-t577/leading-by-convening.aspx>.



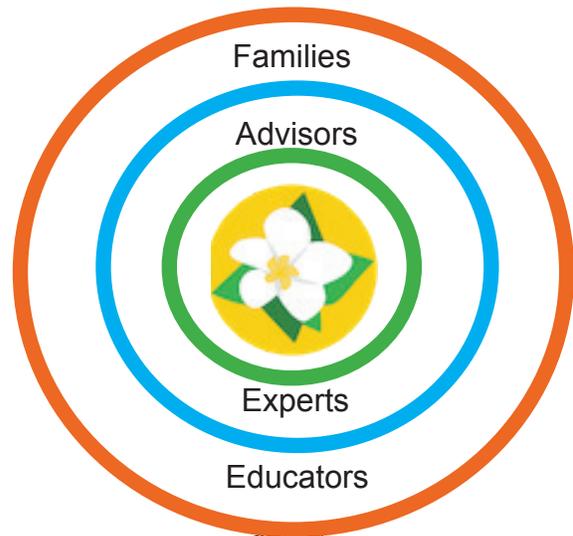


... invites you to join **Leading By Convening**

Options for Engaging

- ▶ 1. Attend a SEAC meeting as a guest (see our website below for meeting dates).
- ▶ 2. Click on the **Leading by Convening** menu tab on SEAC's website. We'll be posting information and surveys as we discuss key information. www.seac-hawaii.org.
- ▶ 3. Email us with your input or for more information : seac.hawaii@gmail.com.
- ▶ 4. Call and talk to SEAC staff @ 808-586-8126.

Engaging Everybody



FOUR BIG ISSUES HAVE BEEN IDENTIFIED FOR PROBLEM-SOLVING IN SY 16-17
 It's a two-way communication loop: SEAC needs to hear your experiences with these issues AND your feedback on possible solutions & recommendations suggested through discussions at SEAC meetings.

1. STAFFING SHORTAGES

- staffing allocation methodologies
- recruitment of special ed staff
- retention issues
- use of contracted personnel

2. INCLUSIVE EDUCATION/LRE

- defining inclusion
- co-teaching
- serving more students in gen ed
- related services in inclusive settings
- lack of preschool inclusive options

3. PROFESSIONAL DEVELOPMENT

- induction and mentoring
- when/ how to provide training
- training for principals
- role of DESs in training

4. STUDENT ASSESSMENTS

- time spent on assessments
- authentic assessments
- testing accommodations
- alternatives to Smarter Balanced
- opt out of testing



Nobody will ever deprive the American people of the right to vote except the American people themselves, and the only way they can do this is by not voting.

-- Franklin D. Roosevelt

Over the last decade, and especially during this long presidential election cycle, a number of folks have gotten discouraged with the voting process. That's why we're taking a minute in the SPIN Newsletter to give you a little pep talk. We want to remind you that most of the legislative protections our children with disabilities enjoy--the Individuals with Disabilities Education Act and the Americans with Disabilities Act to name just two--came about from families of folks with disabilities advocating at a grass roots level, and then turning out at the voting booth. Families voting for their local legislators and council members help determine whether or not there is enough funding for education, health care, a social service safety net and accessible transportation.

With all of these reasons to vote, there's one that tops them all: you are setting a good example to your children that you take seriously your duty as a citizen of this great country and beautiful state.

TALK STORY WITH YOUR ISLAND LEGISLATORS

The **Hawaii State Council on Developmental Disabilities** has a long tradition of helping to facilitate legislative forums on Neighbor Islands. The purpose of the forums is to educate state and county officials on disability issues and to hear from candidates for state and county offices about their positions on issues important to individuals with disabilities and their families. Some of the most popular themes of past forums have been employment, housing and anti-bullying efforts. Of course, adequate funding for education is another important issue.

The DD Council is planning four forums in the month of October:

- Oct. 5 Molokai Talk Story
- Oct. 6 Hilo Legislative Forum
- Oct. 12 Maui Legislative Forum
- Oct. 18 Kauai Legislative Forum

(West Hawaii held their forum on September 9th). For more information about times and locations, call or email Daintry Bartoldus-- 808-586-8100 or daintry.bartoldus@doh.hawaii.gov.

ACCESSIBILITY AT HAWAII POLLING STATIONS

Here are some of the accessibility features for voting:

- √ Curbside voting
- √ Direct Recording Electronic Voting Machines
- √ Language access
- √ Sign language interpreters (request 5 days in advance)
- √ Magnifiers and signature guides

For more info, call the **Office of Elections** @ (808) 453-VOTE (8683) or Neighbor Island Toll-Free: 1 (800) 442-VOTE (8683).



OCT	all-day
10	Voter registration deadline
OCT	all-day
25	Early walk-in locations open
NOV	4:30 pm
1	Deadline to request mail-in ballot
NOV	all-day
5	Early walk-in voting ends
NOV	ELECTION DAY
8	Go vote!





Adapted with permission from Hands & Voices "Where Families Find Support"

Often, when we hear the term "Parent Support" we think of a formal meeting, held monthly, at a non-profit meeting room. But support comes in many forms and how families access it and use it is as individual and diverse as our children.

Time and again, parents need the most support right after they discover their child is more "special" than they expected. Other high-need support events are before a change in care (medications, surgical procedures, therapy) or before IEP meetings. There are so many questions, worries, fears and unknowns, and parents are starving for answers and hope. Many times those answers come from Google and are not always the most helpful or insightful. The Internet cannot tell you it's going to be alright or that you are doing a great job.

At SPIN, we are parents talking to parents. We can help you find a name and number, an organization, or agency to call for more help. We talk story to parents who may feel they have no one to turn to. Sometimes it's a quick call and a shared phone number, or request to be added to the newsletter or e-blast list. Other times it's 45 minutes of listening and reassurance. Explaining next steps and empowering families to believe in themselves and their role as their child's best advocate. Here are other ways that families may find the supports they need around them:

Parent to Parent:

- Formal support groups are very helpful to connect families whose children have the same or similar diagnosis or needs. Discussions about doctors, therapies, school services, insurance, going to the store and finding peace at home can happen in group meetings, outings, picnics and other events.
- Informal support is usually outside of those formal meeting groups: school hallways, doctors offices, parent partners, and yes, SPIN. :)

Information:

- Be careful what you look for. Google can be both a blessing and a curse. Trust in known sites and be wary of anyone who offers a cure or quick fix.

Natural Supports:

- Surround yourself with friends and family who can support you when you need it. Don't be afraid to reach out and ask for help, whether it's an hour of kid-free grocery shopping or a play date with cousins at the park.

Professional/Community:

• This is where most of us get our first taste of supports and advice. Professionals are connected to other support networks in your local and global community.

Adults with Disabilities:

• Adult mentors can provide hope for a brighter future and give kids and their parents insights, tips and real-life advice on going to school, finding a job they love and living a full, happy life with a disability.

My friends & family are my

Support System

They tell me what I NEED to hear, not what I want to hear. They are there for me in the bad times and good.

Without them I have no idea where I would be. And I know that their love for me is what's keeping my head above the water.

Transition to Success

Please join us at the “Footsteps to Transition Fair,” hosted by the Department of Education, Honolulu District! This FREE event is geared towards middle and high school students with special needs, their families, case managers, therapists, teachers, and anyone else in their circle of support. It’s not too early to start planning and preparing for life after high school. As you transition to post-graduation and adulthood, it can be a challenge to make the many decisions about life after high school. Will you go to college, get a job, and/or move into your own place? Who do you turn to if you need help with your finances, or need to see a doctor, or want to make new friends? Will your parents continue to make decisions for you, or will you be responsible for your own choices? How do parents access services for their adult child? All of these

questions can be answered at the upcoming “Footsteps to Transition Fair” hosted by the Department of Education in partnership with various community agencies. Knowledgeable guest speaker, Leolinda Parlin of Hilopa’a Family to Family Health Information Center, will explain the transition process in easy to understand steps. A student panel will share their own experiences of the transition process. A variety of State and private agencies will come together under one roof to provide information about their services for students with special needs after high school. This is a great opportunity to meet and network with other students and families to build and add to your support system. There will be door prizes and free light refreshments to enjoy.

We look forward to seeing you there! Call SPIN at 586-8126 to register, or go online at the website listed above.

Footsteps to Transition Fair

Saturday, October 22, 2016

Kaimuki High School

8:00 a.m. – 12:00 p.m.

Hosted by the Department of Education

Honolulu District

Footsteps to Transition Fair 2016 Schedule

8:00 - 9:30	Sign in, visit exhibits, and talk story
9:30 - 10:30	Student panel & keynote presentation by Leolinda Parlin
10:30 - 12:00	Visit exhibits and talk story

An event for middle and high school students with special needs, and their families, to assist in making a successful transition to adult life and independence

RSVP your attendance and access accommodations by Friday, September 23, 2016. To register:

<http://tinyurl.com/2016FTTRegister>
or call SPIN at 586-8126



Footstepstotransition Oahu

What to Expect:

- Meet with adult service agencies and organizations
- Take the first step in developing a transition plan
- Hear stories from students on their path to success
- Network with other families walking in your shoes



Fall Calendar of Events & Workshops



9/24 LDAH FREE Traveling Mini Conference
Kauai: King Kaumualii Elementary school
9:00 am - 2:00 pm RSVP 800-533-9684

10/1 LDAH FREE Traveling Mini Conference
Oahu: Iron's Table & Tavern at Navy
Marine Golf Course
9:00 am - 2:00 pm RSVP 800-533-9684

9/18 Building the Lego's of Autism
10/23 2:00 - 3:00 pm. Liliha Library meeting
11/20 room. Kids work on communication and
social skills as they play and build with
Legos. Free event, but space is limited to 7
families. RSVP to autismhi@gmail.com



Easter Seals Teen Programs
youthenrollment@eastersealshawaii.org

9/17 Girls Group ages 12-20
Animal Hero Learning Service

9/30 Boys Night Out ages 12-20
Laser Tag at Rascals

10/28 Halloween Dance Party ages 12-20
at Green Street location

10/1 Access Surf Day at the Beach
11/5 White Plains, Ewa Beach from 9:00 am -
1:00 pm. FREE surfing event, for all ages
and abilities. Sign up online at accessurf.org

10/7 SEAC - Special Education Advisory
11/4 Committee Meeting 9:00 am - 12:00 pm
Oahu: 919 Ala Moana Blvd.

Public welcome to attend. RSVP 586-8126

10/ Easter Seals Fall Day Camp
10-14 For school aged children. Fee for services.
8:00 am- 5:30 pm, call 536-3765 for info.

10/14 HAEYC (Hawaii Association for the
10/15 Education of Young Children) Conference
10/14 Leadership Symposium
10/15 Early Childhood Conference
Hawaii Convention Center. Call 942-4708 or
email: info@hawaiiaye.org



10/21 24th Annual White Cane Walk FREE
10:00 am-12:00 Hawaii State Capital. The
walk starts at the State Capital Rotunda, goes
through downtown and ends at Iolani Palace.
For more info, call 586-5271

10/22 Footsteps to Transition Fair FREE
8:00 am - 12:00 pm Kaimuki High School
RSVP 586-8126 for students age 14-21 & family

11/12 Breakthrough Epilepsy Conference FREE
for individuals, caregivers and professionals.
9:00 am - 3:00 pm. For more info, visit
www.epilepsyhawaii.org/conference



Autumn is Here!



Special Parent Information Network
919 Ala Moana Blvd., Room 101
Honolulu, Hawaii 96814

*Providing a world of support to parents of
children with special needs*

CALLING ALL SUPERHEROS TO SAVE THE DATE!
April 22, 2017

**31st Annual
SPIN Conference**