



IDEA Part C Summer to Fall Family Newsletter

September-October 2014 Volume 4 No 5

Message from Part C's State Family Resource Coordinator, Information & Referral.....

Dear Parents/Families,

An opportunity to participate... **MEETING NOTICE**

NEVADA EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL (ICC)

Date and Time of Meeting: **Thursday, October 16, at 9:00 a.m.**

Meeting will be held via Video Conference at the Following Locations:

- **Las Vegas:** Nevada Early Intervention Services
1161 South Valley View Blvd., Conference Room
- **Reno:** Nevada Early Intervention Services
2667 Enterprise, Conference Room
- **Elko:** Nevada Early Intervention Services
1020 Ruby Vista Drive, Conference Room

Nevada's **Interagency Coordinating Council (ICC)** has a federal mandate to advise and assist Nevada in the development and implementation of a statewide system of early intervention services for young children with developmental delays or disabilities and their families. Families and community partners are invited to all ICC meetings.

It is especially important to hear from families and I encourage you to participate. If you would like more information about attending meetings or how to submit public comments to the Council please contact me at: ddinnell@dhhs.nv.gov or Project ASSIST at 1-800-522-0066

Sincerely,
Dan Dinnell

*New Web Address: <http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>



Dan, Eric and Cheryl

NEVADA's EARLY INTERVENTION SERVICES

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Please enjoy the stories shared of families who have "been there and done that!" — See page 2.



The University's **Nevada Center for Excellence in Disabilities** is seeking motivated, interested **parents** of children with developmental disabilities in Southern Nevada, to become candidates for **NEVADA PARTNERS IN POLICYMAKING, Class of 2015**. ***Limited Space!**

PARTNERS IN POLICYMAKING is a very intensive and innovative national model of leadership training, designed to teach parents and self-advocates the power of advocacy and to change the way people with disabilities are supported, viewed, taught, live and work. ***This FREE** class starts early next year.

PARTNERS IN POLICYMAKING is about...

- Leadership skills and developing positive partnerships with elected officials and other individuals who make policy decisions about services that you and/or your family use.
- Systems change—creating, working towards, and achieving a vision of shared values about people with disabilities.
- Becoming confident in oneself, competent in the knowledge and information received, and comfortable in sharing the life experiences and expertise one brings to the program.

If you are interested, visit their website: <http://nced.info/pip/> or contact **Diana Rovetti**: rovetti@unr.edu

Been there, done that!



Harlan

"Diaper changes seemed so inconsequential when your baby won't breathe. Harlan was born at 34 weeks, spent a few weeks in the Neonatal Intensive Care Unit (NICU) and went home with no problems. Less than a week later, he stopped breathing while I was feeding him and proceeded to have a series of major apnea episodes. This was just the beginning of his struggles.

Unlike most newborns, Harlan never slept. Instead, he besieged my ears with endless wails and pounded on my chest with pint-sized fists. I pulled him closer and he pushed away. As he got older he turned to pummeling his head into the floor for hours with no apparent motivation. And I, like most parents, turned to the medical professionals who assured me relentlessly that there was nothing wrong. If it wasn't for our amazing Developmental Specialist at Nevada Early Intervention Services (NEIS) who drove out to our house at any time of day to offer even the slightest relief, I would have felt so alone. It took over three months of my questioning every specialist Harlan ever saw as to why his right eye never closed before one doctor finally took me seriously and realized that the entire side of his face was completely paralyzed.

And so like many parents of children with special needs, I learned to fight for him and to be his advocate. I learned to sign with Harlan, took him to NEIS play groups and signing classes, as well as all his in-home therapies. But the hardest part of all was looking at his sweet little face, tormented, one side unable to express the pain he's in, and wanting more than anything to hold him to my chest and love him. We learned to love in greater ways, to sing bigger songs, and dance with a rhythm no one else understands. Three years later, I am still learning how to be the best advocate for my kids (I now have three), especially Harlan, who has since been diagnosed with Autism.

I am currently participating in the PARTNERS IN POLICYMAKING class at UNR, which was recommended to me by his Developmental Specialist. For nine months we meet one Saturday a month for an all-day class packed full of intelligent and diverse guest speakers, and invaluable information about advocacy for the special needs community. From other parents, I am learning how to navigate the complex world of special education; from guest speakers I am learning the importance of being involved in legislature, and from self-advocates I am learning compassion. While I have learned so much about how to best help my son thrive including, acquiring services, planning successful IEP meetings at school, how to best transition into adulthood, etc., the most valuable aspect of the class is the people. The group consists of parents of children with disabilities, people who work in the field, and most importantly, those who live with special needs. These self-advocates compel me to be a better mother and a better friend. I didn't realize how powerful it was going to be to hear their voices, their opinions, their needs.

I make decisions every day for Harlan without ever asking him what he wants. Because of this PARTNERS IN POLICYMAKING class, I can now look to Harlan's future and know that it will be full of things *he* wants. As a mother, we always think we know what is best for our kids. I've learned that there is great value in stepping back and taking the time to listen to these special kids in all the ways they communicate with us." ~ Aimee Hadleigh, ICC Parent Representative

EARLY INTERVENTION PROGRAM ACTIVITIES OR EVENTS FOR FAMILIES AND FRIENDS

NORTHEASTERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

NORTHWESTERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

⇒ **Advanced Pediatric Therapies—Reno:**

- **Community Play Group** 2nd and 4th Friday each month, 10:30 am.

⇒ **Nevada Early Intervention Services—Reno:**

- **Family Support Group**, by Down Syndrome Network - Usually every 1st Thursday of the month [except for Summer months activities] from 5:45 pm at NEIS-Enterprise. Call 775-828-5159 or e-mail dsnninfo@gmail.com to R.S.V.P.
- **Family TIES** provides family support in filling out **Medicaid/SSI and other Social Services applications** every 2nd Monday from 10am-12noon at NEIS-Enterprise, by RSVP only! Please call 775-823-9500 to RSVP.
- **RAVE** will have **Respite Applications** available every 2nd Monday from 10am-12noon at NEIS-Enterprise.
- **Friends of Special Children** is looking for new board members to join their non-profit organization that supports families in Early Intervention. This non-profit has supported families at NEIS in so many ways both financially and physically. If you are interested in being a part of this great cause, contact Lori Schoen at 688-0379 or email: lschoen@health.nv.gov
- **Hands and Voices** meets at NEIS, Enterprise Rd., May 16th and the 4th Thursday of every other month at 6:00 pm.

⇒ **The Continuum—Reno:**

- **Grandparents raising grandchildren with special needs — Support Group**, 3700 Grant Dr., Reno. First Thursday monthly, with free childcare on site. For more information call Amanda Aitchison at (775) 737-8756.

SOUTHERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

⇒ **Easter Seals Nevada—Las Vegas:**

- Easter Seals Nevada is hosting **playgroups** on Fridays. Come Join the Fun! For more information call or email Ella Philander, at 428-4335 or ella.philander@eastersealsnevada.org

⇒ **Nevada Early Intervention Services—Las Vegas:**

- **Health Fair** - Sponsored by **Family TIES & NEIS**, Monday, August 18th, 9:00 am -12:00 pm. Doolittle Community Center at 1950 J Street (corner of W. Lake Mead and J Street), Las Vegas

⇒ **Positively Kids—Las Vegas:**

- If you like to golf come for our **Annual Swing for the Kids** event. October 6th 2014. Call Sylvia at 702-577-3106.
- Join us for our **Annual Family Duck Fest** at Town Square. September 13th Noon-4pm. Lots of fun for the whole family.
- Like us on **Facebook**, see all the great things we have happening! <https://www.facebook.com/positivelykids>

⇒ **Therapy Management Group—Las Vegas:**

- **Milagros Escondidos** family support meetings the last Thursday of each month, 6pm-8pm, at 6600 W. Charleston Blvd., Ste. 111
- TMG offers a **weekly playgroup** for children in our program. A variety of themes with coordinating activities for children 18 to 36 months will be introduced each week. Contact: Sarah Petrocelli @ 340-5521 or spetrocelli@tmgnv.com

Coming July 2015— NEVADA DISABILITIES CONFERENCE II

Mark your calendars!!! The NEVADA DISABILITIES CONFERENCE is a major, statewide event designed to meet the informational and networking needs of individuals with disabilities or special health care needs, family members, caretakers, policymakers, advocates, administrators, educators, students, staff and service providers. The last conference garnered 394 attendees who enjoyed over 2 days of an outstanding program with 48 sessions, several national Keynote presenters, and 38 vendors/resource tables.

Also the NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES selected Reno as their annual conference host city for 2015, and will combine with the NEVADA DISABILITIES CONFERENCE, bringing as many as 200 professionals and leading experts in the field of disability to our state and the conference, offering more resources, and bringing national attention to Nevada.

This event provides a truly unique environment where people can attend educational breakout sessions relevant to their specific needs, interact with policymakers, network with others and learn about the wide range of services available in Nevada. . . **Plan on it!**

For more information contact **Family TIES** – www.familytiesnv.org

More Resources... More Information... More Opportunities...

The Part C Family Newsletter has opportunities to suggest and share... You are invited to submit articles, share your story, or include your child in a Family Spotlight, with a photo. (All items are subject to editing and review.)

September is **National Grandparents Month**, a time to acknowledge and appreciate grandparents and all of the love and support they bring to our lives. Grandparents often play very important roles in the lives of children with a disability or special health care need.

EARLY CHILDHOOD SPECIAL EDUCATION *LIBRARY*—

There are a great many things to learn... check them out!!!



Book—“Understanding Your Special Needs Grandchild” - Grandparents of children with special needs, unlike parents and teachers, don't always have the facts they need to understand their grandchild. This special resource offers grandparents the information they need to realize the valuable role they play in the lives of their grandchild, giving advice on how they can offer support to better their grandchild's self-esteem and quality of life in school, at home, and with others.

Library materials are available for use statewide. For more information, contact your service provider or coordinator. If you have questions or recommendations for the Library, please contact me at **Project ASSIST** toll free **1-800-522-0066** or ddinnell@dhhs.nv.gov

September is National Preparedness month!... and we often see the media and their mention of disasters and the effects on communities. So being prepared is a good thing, as disasters usually don't give a lot of warning. That makes advance planning for possible difficulties important, especially if you have a child with special needs who may need additional assistance and health or safety precautions. These resources from around the Web can give you information, advice and resources that will help you and your family to “be prepared”.

Preparing for Disaster for People with Disabilities and other Special Needs

Source: Red Cross—http://www.redcross.org/images/MEDIA_CustomProductCatalog/m4240199_A4497.pdf

What It Is: PDF booklet with ideas on making an escape plan and keeping it up, with reminders of things you need to figure out but might not think about.

Emergency Preparedness for Families of Children with Special Needs

Source: Consortium for Infant and Child Health (CINCH) Children with Special Health Care Needs Work Group <http://www.hampton.k12.va.us/schoolinformation/emergency/EmergencyPreparednessforFamilies.pdf>

What It Is: A PDF booklet to help families plan, including advice and forms to fill out and keep handy.

Special Populations: Emergency and Disaster Preparedness

Source: U.S. Department of Health and Human Services

What It Is: Web page with links to resources in a variety of categories, including Disabled, Hearing Impaired, Visually Impaired, Health Care Providers and First Responders, Children, Diabetes, and Lessons Learned from Prior Disasters. <http://sis.nlm.nih.gov/outreach/specialpopulationsanddisasters.html>

FREE.... Enrollment in the national **EARLY INTERVENTION FAMILY ALLIANCE (EIFA)** to *all families* who have a child in early intervention. . . **Keep informed! Obtain Answers! Impact Policies!**

The Early Intervention Family Alliance is a national leadership organization dedicated to improving outcomes for infants and toddlers with disabilities and their families, open to all.

Members receive email alerts and updates on key early intervention topics and can join the **EIFA list serve** to participate in active discussions and share experiences. Web: www.eifamilyalliance.org

<http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST>

Nevada's Early Intervention website is filled with information and resources, including a “Links” page of all kinds of useful websites with information, and a Frequently Asked Questions page.

To receive the newsletter electronically and to make sure you don't miss out on useful information, please send your e-mail address to Dan Dinnell at ddinnell@dhhs.nv.gov

