Message from Part C’s State Family Resource Coordinator, Information & Referral…

Dear Parents/Families,

Every year the U.S. Department of Education requires all states to submit an Annual Performance Report (APR) in order to receive federal funding. As part of this APR states must provide information about families receiving early intervention services and family outcomes.

Nevada collects and reports information on three family outcomes related to receiving early intervention services. This report, following the perspective of family-centered services, covers families who are currently receiving early intervention services for at least 6 months and determines if families feel their providers have helped them:

1. Know their rights under early intervention.
2. Effectively communicate their children’s needs.
3. Help their children develop and learn

Again, this Spring you will be receiving the annual family survey. Please take the time to fill it out and turn it in. We want the best information possible about the ways in which early intervention services may or may not have helped your family.

The results of this survey will help guide efforts to improve services and outcomes for children and families across Nevada receiving early intervention services.

If you have questions, please contact me at: ddinnell@dhhs.nv.gov or 1-800-522-0066 Project ASSIST

Sincerely,
Dan Dinnell

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

Dear Parents/Families,

An opportunity to attend... NEVADA’S INTERAGENCY COORDINATING COUNCIL (ICC)

Date and Time of Meeting: Thursday & Friday—March 26-27, at 9:00 a.m. * The ICC Strategic Planning Meeting will begin as soon as the regular ICC meeting is over.

This meeting is a face-to-face only and will be held at the following location:

Reno: Nevada Early Intervention Services Conference Room
2667 Enterprise Rd., Reno, NV 89512

NEVADA’S INTERAGENCY COORDINATING COUNCIL (ICC) was set up 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 are encouraged to participate.

Families and community partners are invited to attend ICC public meetings in person. If you would like more information about attending meetings or how to submit public comments to the Council please contact Dan Dinnell at: ddinnell@dhhs.nv.gov or 1-800-522-0066 Project ASSIST
My name is Alisa J. Koot. I have always been the person with a plan. I am not spontaneous and I avoid risk. Of course, I had a plan for my life and I executed it flawlessly (graduated from college and law school, became an attorney, married a great guy, Ken, gave birth to two beautiful children, a girl, Colette, and a boy, August.)

However, in 2011, life completely deviated from my “plan.” My four month old son suffered a hypoxic event resulting in a brain injury and he was subsequently diagnosed with a seizure disorder.

This event not only changed my view on “planning” one’s life but also introduced me to an area I knew nothing about, children with special needs. Our family immediately became involved with Nevada Early Intervention Services (NEIS). For me, the learning curve was steep. I believe that was, in part, due to the fact that I was in denial about August’s diagnosis.

Regardless of my inability to accept the diagnosis initially, our NEIS coordinator emphasized that Ken and I were August’s advocates and that we must “fight” for everything that could benefit our son. As an attorney, I was used to being my client’s advocate, but being an effective advocate for August is entirely different because what is at stake is personal.

I applied to be an ICC Parent Representative because I believe my experiences, knowledge, and skills can help other families who have a child with special needs. I hope that by serving on this committee I will further my advocacy and leadership skills. I want to be able to guide other parents whose lives have taken a detour. My goal is to assist parents with the NEIS system and help them be an advocate for their children.

A PARENT IS A CHILD’S BEST ADVOCATE, AND EVERYONE HAS THE ABILITY TO BECOME A STRONG ADVOCATE. HOWEVER, TO BECOME AN EFFECTIVE ADVOCATE, YOU MUST SPEND TIME PREPARING AND LEARNING IMPORTANT ADVOCACY SKILLS.

Nevada PEP, as the statewide Parent Training and Information Center, offers classes such as “FAMILIES ARE IMPORTANT” for families to better understand Early Intervention, their Individual Family Service Plan (IFSP) and the Transition process from Early Intervention into the community or school districts. In “SKILLS FOR EFFECTIVE PARENT ADVOCACY” participants will learn the importance of advocacy and effective strategies to help children with disabilities. Communication techniques will help you feel confident advocating for children. For more information on these and other classes, contact PEP statewide at 1-800-216-5188 or visit their website at: www.nvpep.org/
Mark your calendars! The Nevada Disabilities Conference is a major, statewide event that will provide a one stop platform for connecting to the resources, trainings, best practices and support for creating healthier lives for individuals with developmental disabilities, advocates, caregivers and families of children with special health care needs and the professionals who serve them including administrators, educators, and healthcare/service providers.

The last conference garnered almost 400 attendees who enjoyed two days of an outstanding program with several national Keynote presenters, and numerous vendors/resource tables.

Also the National Association of Councils on Developmental Disabilities selected Reno/Sparks as their conference host city for 2015, and will combine with the Nevada Disabilities Conference, bringing national experts in the field of disability to our state.

Again, this is a great opportunity for families and individuals affected by disabilities or special health care needs, administrators, healthcare professionals, educators, students, caregivers, advocates, policymakers, service providers to learn about various possible topics of interest, such as:

- advocacy
- Assistive Technology
- early intervention
- education
- futures planning
- recreation
- health & dental care
- mental health
- building community
- family support
- service supports
- independent living
- inclusion
- transition
- self-determination
- respite
- and more.

For more information contact Family TIES Statewide at ndc2015@familytiesnv.org or (866) 326-8437 / www.familytiesnv.org

WEBSITE ONLINE
Nvdisabilitiesconference.org

Nevada Disabilities Conference Scholarships may be available. Please check the website for more information on Scholarships for the 2015 Nevada Disabilities Conference.

This event provides a truly unique opportunity 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. Registration starts April. Plan on it!!!

Get started early!!! Plan ahead—check with your local support organizations... Sometimes there are resources available to help cover some or all of the costs of transportation, hotels, meals, and registration for families to be able to attend conferences...

A limited number of scholarships for parents and family members of children with disabilities are available on a first-come, first-served basis from the Nevada Governor’s Council on Developmental Disabilities (NGCDD). Click on Projects & Activities where you can access the paperwork for the Consumer Leadership Development Fund Applications. Start early!!!

Interested individuals may apply for these scholarships through the Consumer Leadership Development Funds Application at: http://www.nevadaddcouncil.org/consumer-leadership-3/.

Scholarship recipients will have their registration fees paid directly by the Council and be reimbursed after the conference for travel, hotel, and per diem costs [meals] not covered by the conference. Recipients must use the least expensive mode of transportation and will be reimbursed for hotel and per diem at the GSA.gov rate. The maximum reimbursement is $500 per individual or $750 per family.

Questions may be directed to the NGCDD Executive Director: Sherry Manning at (775) 684-8619 or smanning@dhhs.nv.gov, or visit their website at: http://www.nevadaddcouncil.org/
Essential Allies: **Families as Advisors**, E.S. Jeppson & J. Thomas, Institute for Family-centered Care. This publication was developed to help bridge the gap between providers’ past training and experience and new expectations of collaboration and partnership with families.

Words of Advice: **A Guidebook For Families Serving As Advisors** - This workbook is for the person who has never served in an advisory role. It offers guidance for thinking through the benefits and demands of advisory roles for consumers, presents some fundamental principles for being a successful advisor, and suggests practical tips for dealing with the common challenges that families encounter in these new roles.

Families As Advisors: **A Training Guide For Collaboration** - This companion volume to Essential Allies and Words of Advice completes the series by presenting a set of integrated training activities to encourage discussion and promote creative thinking about new partnerships with families.

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

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**Family TIES directs** Nevada’s **Family-to-Family Healthcare Information and Education Center** and provides statewide support to families of children and youth with special health care needs by:

- Assisting families as they navigate public and private systems, including health systems and insurance plans,
- Assisting families in accessing services and resources for their children and in partnering with providers and caregivers,
- Listening to families as they describe their encounters with systems and helping guide them to possible solutions,
- Working with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs,
- Promoting discussion and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in Nevada.

For more information call **1-866-326-8437** or visit their web site at: [http://www.familytiesnv.org/](http://www.familytiesnv.org/)

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**Advocacy & Leadership Skills**

[http://www.geneticalliance.org/advocacy-leadership-skills](http://www.geneticalliance.org/advocacy-leadership-skills)

**The Genetic Alliance** has created an **Advocacy ATLAS** in partnership with Parent to Parent USA and Family Voices with support from the Health Resources and Services Administration. It has a page with all kinds of resources on Advocacy & Leadership skills. Please take the time and look over what is available. You may find some information useful in a current situation.
**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—Carson City:
  - Carson City's Early Childhood Expo on Saturday, March 7th, 9:00am to 1:00pm at the Boys & Girls Club, 1870 Russell Way, Carson City. Free event for families. Free transportation to and from the fair provided by JAC buses. Learn about community resources, services, and programs for young children. Entertainment, food, raffle, and prizes.
- Nevada Early Intervention Services—Reno:
  - Family Support Group, open to all parents, sponsored by Down Syndrome Network of Northern Nevada & NEIS - The 1st Thursday each month [except for Summer months activities or other events] 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: lischoen@health.nv.gov
  - Hands and Voices meets at NEIS, Enterprise Rd., usually the 4th Thursday of every other month on the “odd” months, at 6:00 pm. Contact 351-1959, or email: info@nvhandsandvoices.org
  - 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.
  - The Continuum Early Intervention team will be participating in Carson City’s Early Childhood Expo on March 7. This family friendly event is being held at The Boys & Girls Club of Western NV to bring awareness of early childhood services to Carson and the rural communities.

**Southern Nevada Early Intervention Services**

* Contact your Developmental Specialist/Service Coordinator for more information.

- Easter Seals Nevada—Las Vegas:
  - 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:
  - Parent meeting for families of children (any age) with Prader Willi Syndrome, at the NEIS Valley View location. Contact Erica Magana (Bilingual) at 486-9265 emagana@adsd.nv.gov, or Shirley Farkas 486–9263 sfarkas@adsd.nv.gov
  - A Bunny Hop on March 27th, from 1 – 3 pm. Family fun, activities including arts and crafts, face painting, egg hunt, bunny photo op., cupcake walk, and more! 1161 S. Valley View Blvd. LV 89102.
  - Positively Kids—Las Vegas:
    - Grand Opening Neo-Pediatric Clinic. Do you have a premature, low birth weight or medically fragile baby and would like to see a specialized Neonatologist? Call Positively Kids 702-262-0037 for more information.
  - Therapy Management Group—Las Vegas:
    - Milagros Escondidos family support group, last Thursday of the month, 6-8pm, at 6600 W. Charleston Blvd., Ste. 111
    - TMG is partnering with Family to Family and conducting twice a week inclusive developmental playgroups. Contact: Sarah Petrocelli @ 340-5521 or spetrocelli@tmgnv.com
    - Mom’s Planning Committee met to schedule future events, discuss mission of the group and reach out to other local families. Next meeting scheduled for 2/15 at 1pm, to celebrate Angelman International Day. Future meetings will be at TMG on the 3rd Saturday of the month. Email Martha at mestrada@tmgnv.com or call (702) 595-5437 x 205.

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.)

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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