

Nevada Early Intervention Fall – Winter Family Newsletter

November - December 2017 Volume 7 No 6

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

Dear Parents (Caregivers),

It was Thanksgiving morning 27 years ago when our youngest son was born 1 month premature with a diagnosis of "something is wrong" [Dr's words]. He was a shock to everyone including our family Pediatrician. Doctors at the hospital were not sure of what to tell us and did not expect a good outcome. They did not think he would live long or if he did, he would most likely be a "vegetable". After two weeks in the Neonatal Intensive Care Unit (ICU), they sent him home when there was nothing more they could do medically. We were told that we should probably see some early intervention professionals. Period. No connection to any programs or agencies provided.

So we got in touch with Nevada's Early Intervention program. It wasn't always easy. Our son was diagnosed with an extremely rare syndrome with significant, multiple disabilities. There were many specialists involved, appointments to keep, and

many operations to go through. There were times when little or no progress was made, and times when new problems were discovered. We were encouraged by caring service providers to keep trying and not give up. We networked with other parents who had similar experiences. With every gain we saw a better future -- maybe not perfect, but not so imperfect as we first believed. Today our son is endeavoring to live a fulfilling life.

Many families have their own stories. Yet the world has changed since then and things are different today. There is more connectivity between the medical community, resources, and families, and though it is not perfect there are so many more opportunities to help our children.

I hope this newsletter will help provide you with information that may help support you and your family.

If you have questions, please contact us: ProjectAssist@dhhs.nv.gov or 1-800-522-0066

Sincerely, Dan Dinnell



Cheryl, Eric, and Dan

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To receive the newsletter electronically and to make sure you don't miss out on useful information, contact us!

"Been there and done that!" — See page 2

Books & DVDs — See page 3

Local Activities — See page 4

An invitation to attend...

NEVADA'S EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL (ICC)

Nevada's **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. It is especially important to hear from families and we encourage you to participate. The next few meetings:

Thursday—November 9, at 9:00 a.m.

Thursday—January 18, at 9:00 a.m.

Where: via video conference in Elko, Las Vegas and Reno.

Always check the meeting agendas for conference room locations and changes—posted at:

<http://dhhs.nv.gov/Programs/IDEA/ICC/Meetings/>

For more information contact ProjectAssist@dhhs.nv.gov or call Project ASSIST at 1-800-522-0066. Or contact your Service Coordinator.

ICC bylaws and membership can be viewed at

<http://dhhs.nv.gov/Programs/IDEA/ICC/Home/>
under "Who is on the ICC?", click on
Current Membership.

The Early Intervention 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. (Subject to review & editing.)

Been there, done that!



The first conference I attended this year was a conference in Los Angeles, CA. This conference was mainly for individuals in the local region. I was the only one from out of state. I did get to see and hear what is going on with resources throughout the state of CA. There is a place called Seeds Educational Service, Inc in San Diego. The lady who presented was Stacy Everson. I was amazed by the services they provide. They teach individuals with intellectual disability about: Friendship/Relationship skills; Abuse awareness and prevention (The stats on abuse were very eye opening as a parent to hear.); Hygiene; Sexuality; Fire Safety, and more. I hope to see resources like this in the Nevada area someday.

The second conference I recently attended was the National Down Syndrome Congress' Convention in Sacramento, CA. It was 4 days. There must have been about 4,000 attendees! The Theme was "Living the Dream". This was the first large conference I have ever attended where it was intended for the entire family. I loved every minute of it. Parents getting to share experiences. Siblings of individual with Down Syndrome got to connect and self-advocates had their own classes. It was amazing that there was something for the whole family.

One of the speakers was Dr. David Stein. He is the author of "Supporting Positive Behavior in Children and Teens with Down Syndrome". I read the book last year and to hear him speak on techniques and the why of his philosophy really made it all sink in! My favorite tool I learned from him was the, "and then" technique. When my little one is giving me a hard time let's say getting ready for school, I can say brush your teeth "and then" you can _____, she can then choose an activity that will interest her like playing with a baby or computer/tablet time depending on the moment. It works so well. I also got to attend some amazing technology classes. I found out about the free apps for visual schedules and countless others that can be helpful from reading to phonics and math.

Besides all of the Pre-Conference Sessions, Sharing Sessions, Keynote Presentations and Workshops, there were so many fun social events and other activities to give the families time to network and make their own connections. I strongly urge anyone who has the opportunity and can go, to attend such conferences that are supportive of families involved with disabilities. They are always so full of new ideas and information to share." — Christine Riggi, ICC Parent Representative

If you are interested in volunteer activities, where you can receive knowledge, share information, gain skills and experience in advocating for others and your family, the NEVADA EARLY INTERVENTION INTERAGENCY COORDINATING COUNCIL (ICC) has a permanent **FAMILY SUPPORT RESOURCE SUBCOMMITTEE (FSRS)** that can always use parents and others who have a passion for supporting early intervention. For more information email ProjectAssist@dhhs.nv.gov or call 1-800-522-0066 or check out the webpage at:

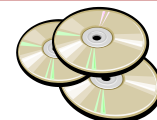
<http://dhhs.nv.gov/Programs/IDEA/ICC/Home/>



— For Families & Professionals —

EARLY CHILDHOOD SPECIAL EDUCATION LIBRARY

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



Planning for the New Year? One of the resources available to families, service providers, students, and teachers working with young children with disabilities or special health care needs is the resource library. This large collection of books and videos is a tremendous source of information for parents and professionals in the care and education of a child with a disability.

"Laying Community Foundations for Your Child with a Disability" This practical guide shows families how to establish a network of people who can provide lasting relationships for their children, and the importance of beginning the process as early as possible in the life of their child. Chapters discuss: • how to assess your child's needs & interests • how to navigate the human side of estate planning • where to look for potential relationships • how to foster long-term relationships for your child.

"The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life" (includes a **CD-ROM**) The authors (who also have family members with special needs) give parents a chronological guide for each stage of financial planning from birth to adulthood. Parents will get comprehensive advice and strategies on how to address: *financial factors—legal factors—government factors—family and support factors—emotional factors.*

"Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations" A particularly useful guide to those just starting out on the journey of dealing with special needs... covers grief, hope, services & supports, understanding the law and inclusion, planning for the future.

"Parenting Children with Special Medical Needs" (2 DVDs) Whether your child has allergies, asthma, a bleeding disorder, cystic fibrosis, diabetes, epilepsy, cancer, an injury, or any other health issue, you'll find essential parenting skills to help children of all ages cope well with challenges, adhere to medical requirements, and live a hope-filled life.

"Successfully Parenting Your Baby with Special Needs" (DVD) This video explains: Early Intervention; The Process of Diagnosis and Referral; How a Child is Evaluated; Creating an Individualized Family Service Plan; How to Access Available Resources and Services; Preparing for Transitions.

"Exceptional Parents" (DVD) It's hard enough to be a parent...but the demands are even greater when your child has a disability...which you slowly discover. Two truly exceptional parents share their stories on this episode of American Family.

"Sleep Better! A Guide to Improving Sleep for Children with Special Needs, Revised Edition" Provides practical information on a variety of topics--from the basics of sleep and assessing sleep problems to strategies for change.

"Toilet Training for Children with Special Needs" (DVD) Provides an overview of practical toilet training techniques and core principles for success.

If you have questions or recommendations for the Library, contact your service coordinator or send an email to ProjectAssist@dhhs.nv.gov

Catalog at: <http://dhhs.nv.gov/Programs/IDEA/ProjectASSIST/Special-Ed-Library/>

APPS FOR CHILDREN WITH SPECIAL NEEDS (<http://a4cwsn.com/>) is one of the most comprehensive lists of Quality Apps available today to help children with special needs. This is a compiled list of 1000 Apps used by Teachers, Therapists and Parents. This list is a result of endless hours of collaboration by professionals from all over the world. The Apps are considered to be among the very best apps to help children and adults with special needs as well as teachers and therapists. Some apps cost and some are FREE!

<http://a4cwsn.com/recent-videos/fb-community-favorite-apps/free-educational-apps/>

Center for Parent Information & Resources (CPIR) — **Rare Disorders Fact Sheet**

"Roughly 7,000 rare diseases/disorders have been identified as affecting the human race." CPIR has released its updated **Disability Fact Sheet** (June 2017) to assist families dealing with rare genetic and other disorders to address the challenges in finding effective treatments and medicine.

<http://www.parentcenterhub.org/raredisorders/>

EI program information > http://dhhs.nv.gov/Programs/IDEA/Early_Intervention_Programs/

NORTHEASTERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

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

NORTHWESTERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

⇒ **Advanced Pediatric Therapies—Reno:**

- **Community Play groups** every 2nd & 4th Friday, of each month. Lots of fun games and activities for the kids. For more information: 775-825-4744.

⇒ **Easterseals Nevada—Reno:**

- **Please join us at our next Discover Your Way** at the Terry Lee Wells Nevada Discovery Museum on Sunday November 5, and December 3, from 10am-12pm. The Discover Your Way program is specifically designed to meet the needs of children on the Autism Spectrum and with sensory and/or perception disorders. Admission is free for members, and remains the same for each Discover Your Way event at \$10 per child (1-17) or senior (65+), and \$12 per adult (18+).

⇒ **Nevada Early Intervention Services—Carson City:**

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

- **NEIS Family Trick or Treat Event** - Monday, October 30, 2017, 4:00 p.m. to 6:00 p.m., (Child friendly costumes welcome!) 2667 Enterprise Road, Reno NV
- **Family TIES** provides family support in filling out **Medicaid/SSI and other Social Services applications** every 2nd Monday from 10am-12noon at NEIS, by RSVP only! Call to RSVP: 775-823-9500
- **Friends of Special Children** - This non-profit has supported families at NEIS in so many ways both financially and physically. If you are interested, contact Gretchen Canepa at 688-0303 or GCanepa@adsd.nv.gov.
- **NEVADA Hands and Voices** meets at NEIS, usually the 3rd Thursday of every other month on the "odd" months, at 6:00 pm. Contact: 775-351-1959, or email: info@nvhandsandvoices.org

⇒ **Therapy Management Group (TMG)—Reno:**

- **Inclusive Developmental Play Group** at Early Head Start. Call Melissa McGovern at: 775-525-4072.

⇒ **The Continuum—Reno:**

- **Carousel Kids** is an inclusive childcare program. We also offer an intergenerational experience with elders from our onsite adult day program. For more information or to schedule a tour, phone: 775-829-4700.
- **Literacy Land—FREE!** Gently used books for children birth-5 years. Or donate to our lending library. Meet, mingle, borrow, share, read, enjoy with your friends at the Continuum! Also, look for our collection bins around town! For further information, please call the Continuum's Early Intervention department at (775) 221-8054 or email at info@continuumreno.com. Visit us at continuumreno.com

SOUTHERN NEVADA EARLY INTERVENTION SERVICES

* contact your Developmental Specialist/Service Coordinator for more information

⇒ **Easterseals Nevada—Las Vegas:**

- **Playgroups** on Fridays. Come Join the Fun! Call Jessica Hartley at: 702-329-0345

⇒ **ISS Baby Steps—Las Vegas:**

- **Inspired Discoveries Playgroup** welcomes children 0-3 years old in an inclusive setting. Please join in our fun adventure! Call: 702-586-3100
- **Fall Harvest** family event on October 27, 2017. BBQ, family games, educational activities as well as screenings provided. Will be at 3027 E. Sunset, Las Vegas, 89120.

⇒ **Kideology—Las Vegas:**

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

- **Saturday, October 21, NEIS Family Fall Fun Festival, from 10am-1pm:** This free event will include community resources, make-n-take activities, games, and of course—treats! The event's theme is "Children's Storybooks." Interested families may contact their developmental specialist for more information.
- **Explore & Learn Developmental Playgroups in Las Vegas, North Las Vegas and Henderson—**Weekly, inclusive community playgroups include engaging, age-appropriate peer activities for families of infants and toddlers with diverse abilities to support child development. Interested NEIS families may contact their Developmental Specialist.
- **Sign Language class at University Medical Center (UMC)—**NEIS staff provide this bi-weekly parent education class on communication skills using sign language to promote understanding between toddlers and their families. All members of the family are welcome to attend. Interested NEIS families may contact their Developmental Specialist.

⇒ **Positively Kids—Las Vegas:**

⇒ **Therapy Management Group (TMG)—Las Vegas:**

- **Milagros Escondidos** family support group, last Thursday of the month, starts at 6:30pm, at East Las Vegas Community Center located at 250 N. Eastern Ave.
- **Inclusive Developmental Playgroups.** Thursdays at Family to Family & UNLV Preschool. Contact Robbi Lucero at: 702-335-1666 or rlucero@tmgnv.com



Nevada's Central Directory website, filled with information and resources, includes a "Links" page with all kinds of useful local, state, and national websites.

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

