

TESTIMONIALS from Current and Past Parent Representatives of the Nevada Early Intervention Interagency Coordinating Council (ICC)

Aimee Hadleigh, Nevada ICC Parent Representative (2014 — 2021)

"The two things I have gained most from serving on the ICC are a sense of community, and the capacity to make change in my children's lives and at a local level.

When I was first appointed to the ICC I felt as though I was going through the motions of Early Intervention Services: being present at therapy sessions, carting my troop of kiddos (3 at the time) to doctor's appointments, and complying with all the recommendations given to me.

As I became more involved as a board member, I learned a lot more about NEIS, the services I could request, and how to make the most of our time there. I learned to ask questions and make requests. However, it quickly became more than just ensuring my own kids had the best opportunities, and more about effecting change in the system itself. The ICC also supports parent representatives in attending disability-related conferences. This experience is what really fostered my passion for advocacy. I met parents from other states and learned what was working for their children and how Early Intervention functioned elsewhere. I brought the information I gathered at these conferences back to influence the program locally.

Most importantly, my children have watched me become a powerful advocate and, consequently, are becoming strong advocates for themselves. I am so thankful to be part of such a great committee that is always open to listening to parents and supporting them." ~ Aimee Hadleigh, ICC Parent Representative

Alisa J. Koot, Nevada ICC Parent Representative (2015 — 2017)

"My name is Alisa J. Koot. I have been married to my husband Ken for 12 years and have two children, a girl, Colette (8) and a boy, August (5).

Because August has cerebral palsy, I have been given the unique opportunity to be a State Interagency Coordinating Council (ICC) Parent Representative.

Before I had my son, I had never heard of Nevada Early Intervention Services or the ICC. I am now fortunate to be able to be a part of this committee and use my experiences, knowledge and skills to help other families who have children with special needs. By serving on this committee, I have been able to increase my advocacy and leadership skills but also have met many great people and learned about great resources in the state of Nevada for people with disabilities.” ~ Alisa Koot, ICC Parent Representative

Candace Coleman, Nevada ICC Parent Representative (2011 — 2013)

"My name is Candice Coleman. David (my husband) and I have a beautiful, sweet, and very curious toddler named Molly Paige Coleman. Over two years ago she was diagnosed with Robertsonian Translocation Down syndrome, born premature, and had 3 holes in her heart (that ended up leading to surgery at two and a half months old.) She currently does Early Intervention at Advanced Pediatric Therapies and is doing great!

My occupation at the time was a Para-professional for special needs at a high school in Colorado. I knew I had to do all I could to help advocate for my daughter, all special needs communities, and families who share this common bond. So I became quickly involved in a lot of programs, before we moved here to Nevada.

I am now involved as a board member for the Down Syndrome Network of Northern Nevada (DSNNN), was a co-chair for the 2012 Buddy Walk, was sent to the Down Syndrome Affiliates In Action Conference (DSAIA) by the DSNNN and lobbied to three of our senators, a first parent contact for Family Ties of Northern Nevada, and on the ICC Family Support Resource Subcommittee to help give resources to other families and be aware of what's going on in Early Intervention (EI).

It's wonderful to be involved in lots of programs and find as many resources as possible. Being on the ICC subcommittee has been one of those great programs and resources. It helps keep you updated on everything in

the EI world, helps you keep other families informed, and gets your foot in the door for other programs. I feel the more educated you are, the better success for you, your child, and your community. I highly recommend joining!” ~ Candice Coleman, ICC Parent Representative

Candace Emerson, Nevada ICC Parent Representative (2017 – 2023)

"As a mother, it would be quite the understatement to say my plate is full. In addition to the things that come along with raising typically developing children, I had the opportunity to raise two exceptional boys. My oldest son, Ethan, is seven years old and was born with a hearing difference. Along our journey, we learned that he also has Asperger's Syndrome. Despite his unique needs, he is a joy to raise and I am constantly in awe of his intelligence. My youngest little guy is four-year-old Jacob and even though he has an overall developmental delay, he is making huge strides and has the sweetest heart.

In my nearly eight years of being a mother, I have learned so very much about the world of special needs parenting. Both of my boys received and greatly benefited from Early Intervention services. Throughout their time in the program, our family learned a lot in regards to promoting their development and utilizing strategies to assist with their unique needs. However, it was not until I took the next step of taking my seat at the table and getting involved as a parent, that I realized all of the opportunities available to families and caregivers.

Right before Jacob exited the Early Intervention program, I learned of the opening to join our state's Interagency Coordinating Council (ICC) as a Parent Representative. Joining this board afforded me the opportunity to advise and assist in the development of and implementation of a statewide system of early intervention services for young children with developmental delays or disabilities and their families. I was able to bring my firsthand parent perspective to the table and represent families with children in Early Intervention in Southern Nevada.

Throughout my time on the ICC, I have learned that it is essential to give parents a voice in order to improve services and make them even more

specific for our children. *Not only do we, as parents, know our children best, we are their number one advocate from the time of birth. State boards like the Interagency Coordinating Council (ICC) are the perfect place for parents to share their experiences, gain knowledge and help their family, as well as many others throughout their community. I highly recommend you speak with you service coordinator about ways to get involved and take your family's journey to the next level". ~ Candace Emmerson, ICC Parent Representative*

Christine Riggi, Nevada ICC Parent Representative (2014 – 2019)

*"It so important for you as a parent to be involved with your State's Early Intervention Interagency Coordinating Council (ICC). **When you attend an ICC meeting you get to see people working hard to be sure to provide you and your family with quality supports and services for your little one who has challenges.** If you want to understand your services and how they work, please come to an ICC meeting. There are parents and other reps who are waiting to hear from you."* ~ Christine Riggi, ICC Parent Representative

Diana and David Rovetti, ICC Parent Representatives (2007 – 2009)

"When our son, Jack, was born with Down syndrome, we had very little knowledge of the alphabet soup of services that would be available to our new baby: PT, OT, SLP, SCC, IFSP, IEP, IDEA, NEIS, ICC. After being experienced parents to three daughters age 7, 8 and 10, we knew raising a son with Down syndrome would be challenging and most likely an overwhelming experience.

When Jack was six-weeks-old, he began receiving services from Nevada Early Intervention Services, NEIS, then called the Special Children's Clinic. We were thankful for the much-needed support, but we still did not understand the early intervention system. We were unsure how to navigate it to get the most out of it for our new baby boy.

We started attending support group meetings for parents of babies with Down syndrome. Our three daughters attended Sibshops for siblings of kids with special needs. Attending functions gave us some of the information and support that we needed to be effective parents of a baby with special needs--but we knew there was more out there.

We requested to be on, and were appointed by the governor to serve on the Nevada Interagency Coordinating Council (ICC). The Council is made up of department heads and leaders of government agencies that serve babies, age birth to three, with special needs. This was the Mother Lode of who's-who of people we needed to know. Being on this Council, we could get information and help directly from department heads--and we frequently did. When someone couldn't help us, they would give us the name and phone number of someone who could.

We became trained members of the Volunteering Visiting Parents at Family TIES of Nevada and the Down Syndrome Network of Northern Nevada. Diana also went through and graduated from an eight-month training course called Partners in Policymaking.

We don't volunteer for everything and we don't accept every opportunity that comes our way. We do things we find interesting or challenging, or things that we believe will help Jack in the long run. We're happy, and Jack is doing very well.

We believe there are those who make things happen, those who watch things happen, and those who wonder what happened. Our advice to parents with children with special needs--get involved! Make things happen for your child. There are plenty of opportunities. Getting involved can also change your family for the better!

Top five reasons to volunteer your time to state agencies:

- 1. Get to know the system*
- 2. Develop relationships with people who work in or are in charge of the system*
- 3. Get to know what services are available and how to get those services*
- 4. Meet other parents*
- 5. Provide valuable input to improve services for other families"*

~ David and Diana Rovetti, ICC Parent Representatives

Janina Easley, Nevada ICC Parent Representative (2014 – 2018)

"On an Easter Sunday, my husband Cody and our daughter Alexis welcomed Averì Rachele into our family. Averì has cerebral palsy, cortical visual impairment, epilepsy, plus a few other challenges. Averì opened our family's eyes to a world we knew little to nothing about. Here began our journey through Early Intervention, specialists, therapists, and the unknown.

As we began to learn from Averì and her many disabilities, we also felt more comfortable going out in public, meeting new people and explaining to friends and family who Averì was. Advocating for Averì became a big part of who we were and we strived to make sure she got what was best for her. Advocating grew into a mom's group with other Early Intervention moms who wanted to meet and learn from others who also have traveled down a similar long and winding road.

*I was introduced to Nevada's Interagency Coordinating Council (ICC) by my development specialist who saw my passion to advocate and educate. **I went to my first ICC meeting and was deeply interested in learning more, and how I could give a voice to children and families with disabilities. I became an ICC member and felt that I could now be a voice for Averì and others.** I have learned much and have much to learn. I have applied to attend NEVADA PARTNERS IN POLICYMAKING for 2016. I look forward to my continuing education through the ICC."*
~ Janina Easley, ICC Parent Representative

Jason Adams, Nevada ICC Parent Representative (2017 – 2018)

*"I currently sit as a parent rep on two Nevada Boards – Nevada Early Intervention Interagency Coordinating Council (ICC), and Persons with Deaf, Hard of Hearing, and Speech Impairments Board. **As a father who has had a disability all my life, I hope my lifelong personal experiences will help others to be more proactive with education and policies put in place for all of our special needs kids so***

that they too can become successful citizens.” ~ Jason Adams, ICC Parent Representative

Jenny Casselman, Nevada ICC Parent Representative (2010 — 2012)

*"It is an honor to serve as a parent advisor to Nevada's Early Intervention Interagency Coordinating Council (ICC). As the parent to a T21 Angel, Kenley, this is a wonderful opportunity to offer insight as a special needs parent and advocate. Collaboration with public and private organizations that serve our children is a great way to assist them in achieving their own personal best. Advocacy follows many different paths, but getting involved with the organizations that help us shape our child's future is invaluable. **We learn the most from those around us and the ICC and subcommittees are an excellent way for parents to get involved, meet parents and the special needs advocates in our communities.***

At the end of the day, we all want our children to succeed and we know they will - in their own way. Our daughter is a blessing to our family and without her; we would never have known the amazing diversity that makes our world wonderful! Thank you again for the opportunity!" ~ Jenny Casselman, ICC Parent Representative

Kellie Hess, Nevada ICC Parent Representative (2021 —)

"On December 8, 2018, our lives were blessed with the birth of our little, heart warrior, Nash. We found out early into the pregnancy that he had trisomy 21 and a severe heart defect. It was a lot to digest especially since our first son Braxton was still so young. We delivered Nash at the University of Utah hospital since they have a fantastic cardiology team. He had to stay in the NICU for a month. We learned so much while we were there, but we had no idea of the services that were available in our rural area. The hospital reached out to the Nevada Early Intervention Services (NEIS) so we could start services as soon as we could go home.

We knew we would need extra services and professionals to help him reach his full potential. When we had our first meeting with NEIS in our home, I was blown away. They had every type of therapist that we needed and they came to us! They helped

us get into other helpful programs that we didn't know were available to him. I am so thankful for the progress that our little guy has made.

It seems like a lifetime ago that he was home with an NG tube, oxygen, and pulse oximeter. He had his open heart surgery at 6 months old, and we haven't had any hospital stays since. It has been such a blessing to have these amazing people with their tips and positive influence to help our entire family. They gave us peace of mind that he was developing at a good pace, and we were doing the right things.

I am excited to advocate for my son and for the other children in our community. It is such a wonderful program, and I am so thankful for it!" ~ Kellie Hess, ICC Parent Representative, Elko, NV

Kimberly Palma, Nevada ICC Parent Representative (2008 – 2010)

"My name is Kimberly Palma. I have five children, three of them are girls and two are boys. I've had the opportunity to go through Nevada Early Intervention Services (NEIS) twice now. First, 8½ years ago with my oldest daughter Karina, who has a rare genetic syndrome, 2q37 deletion syndrome. And more recently with my fourth child, my son Johnathan, who also has a very rare syndrome of his own, WAGR Syndrome. He just transitioned from early intervention this past July. I have seen firsthand the great impact NEIS has made in our lives.

*I was the NEIS parent support group president from 2001-2003. I graduated from Partners In Policymaking, a program of Family TIES. I am a parent representative of Family TIES and have been serving on the ICC Family Support Resource Subcommittee, and now on the State's Interagency Coordinating Council (ICC). **I hope to make a difference by continuing to support NEIS for families across Nevada and to help empower families, so they can advocate for themselves.**"*

~ Kimberly Palma, ICC Parent Representative

Kirsten Bandiero, Nevada ICC Parent Representative (2009 – 2011)

"My name is Kristen Bandiero, and in September 2005 my husband Anthony and I welcomed our beautiful baby boy Carson into the world. At 15 months old, I began to suspect Carson had some developmental delays, and when he was 18 months old

I called Nevada Early Intervention Services for assistance. Shortly after Carson's evaluation I was referred to a Neurologist who diagnosed him with Autism. I soon learned that NEIS was not only there to help make my son's life easier, but to give our family the support and reassurance it needed to make it through these emotional times.

I also began to help other families navigate through the beginning stages of receiving an Autism Diagnosis by starting a resource and support organization called ACT Now Nevada.*

*I felt early intervention to be so critical to a young child with a disability and began to focus on how I could help more kids from birth to 3 years old. That's when I became involved with the Interagency Coordinating Council (ICC). I enjoy taking part in policy making and will always be passionate about improving our state's services and helping families to better understand the early intervention process. My hope is that Early Intervention gains the recognition of its importance by all families in Nevada. **My role as an ICC representative is to ensure families continue to receive the support and compassion needed to cope when learning the strategies to help their children with disabilities.**" ~ Kristen Bandiero, ICC Parent Representative*

Lisa Cridland, Nevada ICC Parent Representative (2013 – 2019)

*"It has been a pleasure to be a member of Nevada's Interagency Coordinating Council (ICC) for Early Intervention Services, and the Family Support Resource Subcommittee. I have learned so much about the way things work for our loved ones with disabilities, (or as we call them, their super abilities). I have used some of the things I have learned, with my family. **It is great working with members of the committee that are so willing to help others. It is amazing all the work and laws that are passed to help those that are in need of advocacy in their lives.** I am proud to be a part of this group of people that help others have a fulfilling and fair life.*

As a representative of the ICC I had the opportunity last Summer to go to the Office of Special Education Projects' Leadership conference in Washington, DC and it was a real eye opener. It was so interesting to see the way the other states run their Early Intervention programs. The other states had a lot of similarities to Nevada, but a lot of differences too. Being on the committee helped me understand how important it is, as a parent, to speak up for our children and be an advocate for other children and families that cannot speak for themselves.

I am grateful for these opportunities to learn as much as possible to help my family and other families." ~ Lisa Cridland, ICC Parent Representative

Lisa Hunt, ICC Parent Representative (2020 — 2022)

"My youngest, Maddon, was 5 months old when we noticed he was not tracking objects as my other children had. Soon after, he was diagnosed with Bilateral Optic Nerve Hypoplasia ("ONH").

In search of answers and support within the Las Vegas community, my husband and I anxiously walked into the Nevada Early Intervention Services (NEIS) building knowing nothing about the organization.

Over the past 2 years, we have worked hand in hand with several of the NEIS professionals to aid Maddon in staying on track developmentally and preparing him to be successful in his transition to the educational world. NEIS continues to provide us valuable resources and roadmaps that push Maddon to reach his full potential.

I am grateful for the opportunities that lie ahead to advocate for the families and children who too often are unable to advocate for themselves. I look forward to supporting Nevada's Early Intervention Interagency Coordinating Council (ICC) and Nevada families!" ~ Lisa Hunt, ICC Parent Representative

Lorraine O'Leary, Nevada ICC Parent Representative (2011 – 2017)

*"I became a parent rep on the ICC to advocate for Nevada families with the mindset that I would be advocating based on my prior experiences in the system. I thought that I'd simply share the issues, concerns and challenges that my own family faced, in hopes to improve the process for others. Though I did that, I have grown much more as an advocate since joining the ICC. I've realized that my voice is much stronger now and I am much more actively involved in voicing my opinions at public hearings and to legislators and others. Parents are the most knowledgeable resource for legislators yet often the least utilized. My advocacy also motivated me to return to school to get a Masters degree in Special Education. Now, I am helping children and families directly in the classroom. **I started the ICC with the thought that I'd be helping others but realized that it has helped me grow exponentially as a parent and community member.**" ~ Lori O'Leary, ICC Parent Representative*

Melissa West, Nevada ICC Parent Representative (2011 – 2012)

"My husband and I welcomed our first-born in October 2007. Tyler was the apple of our eye and babbled from four months on. We loved the "talking" he did, but the actual words didn't come. I voiced my concerns to our pediatrician, but was told not to worry until Tyler was 2 years old. Tyler's birthday came, but our wishes for his words to come were not granted. I was referred to Nevada Early Intervention Services. Tyler began working with a Developmental Specialist (DS), as well as a community speech therapist. Within two months, Tyler had over 100 words! As a parent, it was nice to have someone model various strategies to encourage speech and offer support.

*After working with our DS and the NEIS director to meet Tyler's needs, I was asked to apply for a parent advisor position on Nevada's Interagency Coordinating Council (ICC). **Advocating for children's and families rights is important to me, and***

I am proud to serve Nevada's families. ~ Melissa West, ICC Parent Representative

Nora Behrens, Nevada ICC Parent Representative (2007 — 2010)

"My name is Nora Behrens and my husband Scott and I are the parents of a wonderful little boy named Bryan. Bryan has cerebral palsy as well as other disabilities. Because Bryan was involved in Nevada's Early Intervention Services I became familiar with some of the programs available to families of children with disabilities, but as a family we felt pretty isolated.

When Bryan was 2 years old I participated in the Partners in Policymaking program which was an incredible introduction to the bigger network of disability services, programs, and social networks. It was then that I learned about some of the ways that parents can become involved in the programs that serve their families.

In order to meet other parents of children with cerebral palsy, I started the CP Parent Network. I really enjoy being a resource for other parents and spending time with them and their children.

*Another way that I have met other parents as well has been on the Interagency Coordinating Council. **This position has been a great way to learn about how state-run programs operate, how the legislature and budgeting affects these programs, and how a few dedicated people can really make a difference for the families of Nevada's children with disabilities.***

I have advocated for Early Intervention funding at the Nevada legislature as well as represented the interests of the ICC to the Governor's office. These opportunities to advocate for young children with disabilities and their families as well as working with people around the state who have similar goals has been a very fulfilling experience for my family and one I would recommend to any parent." ~ Nora Behrens, ICC Parent Representative

Shannon Springer, ICC Parent Representative (2008 – 2010)

"My name is Shannon Springer. I am married to my best friend and have two beautiful children, Avery who is six and Joy who is eight. When Joy was 2 yrs old, I learned that she had autism. I immediately felt all alone and did not know what to do. There was not really anything for her so I got involved in trying to make a system change for her and all of the kids. My focus has been to educate parents and educators that not all kids learn the same way. I started a resource library called Autism Matters filled with educational materials that I have acquired through the years and made them available to everyone.

*I got involved in Partners in Policy Making. This experience changed my direction, my focus and my life. It made me realize that together we will make changes. **I later found a great opportunity to become a member of the ICC where I can make important changes when it comes to early intervention. I am very excited to be a part of something that will make positive changes."***

~ Shannon Springer, ICC Parent Representative