Advocating for YOUR Child From Within the System.

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Council Member for the Nevada Governors Council on Developmental Disabilities
- Council Member 2011-
- Council vice-chair 7/2012-9/2014
- Evaluation Committee Chair 2011

Recipient of the 2015 NV Family Advocate Award
Most Importantly

I am a father...........

- Adapptative switch guru
- Non expert Medical device mechanic
- Medical Billing Non Expert
- My kids Medical expert

I am an ADVOCATE

• The Reason for doing what I do is......
Family
Some Definitions......
Advocating in the beginning
Becoming a better advocate
The benefits of the work
Resources to becoming a better advocate
Ways to get involved
Advocating for YOUR Child From Within the System.

• Advocate/Advocating
  verb (used with object), advocated, advocating.
  1. to speak or write in favor of; support or urge by argument; recommend publicly:
  Noun 2. a person who speaks or writes in support or defense of a person, cause, etc. (usually followed by of): an advocate of peace.
  3. a person who pleads for or in behalf of another; intercessor.

• System
  a coordinated body of methods or a scheme or plan of procedure; organizational scheme: a system of government.
In the beginning

- Carepage
- Letters, Inserts and Feedback (Positive/Negative)
- Hospitals, Staff
- “Speak up”
How do we advocate?

- Share your story
- Share what you are passionate about
- Network

Diagram:
- Your Story
- Network
- Passionate
Introduce yourself and your family

Shape your story to the appropriate group and make the conversation personal.

Explain your needs (target your needs to the audience)
Practice your story.

Our Stories are emotional,

too much emotion may lose our audience.

Professionals- (Insurance, Doctors, Teachers, Students) often have limited amount of time. Focus on how your story affects them and how they can improve, benefit and help you.
Sometimes people, specially professionals need to be reminded:

: that they too are human.

: Why it is that they choose their profession.

And that – THEY MADE A DIFFERENCE!!!
Our Story is something like this...

1. Junhyo at birth, given no hope

2. Our Family, Junhyos number one cheer squad and support

3. Facebook page, a place to share updates
   Share accomplishments and give credit to all his supports
   Family, Friends, Teachers, Doctors, Support Staff, Secretaries, Nurses

Junhyos Journey
Empowerment

Education is Power!!!

Become familiar with State and Federal Laws
- The Individuals with Disabilities Education Act

www.idea.ed.gov

Americans with Disabilities Act

www.ada.gov

Empowered & Involved
- Your Story
- Network
- Passionate
Become familiar with Insurance Information and coverage. ASK- Use the Journalistic Approach:

• WHO (contacts, direct questions, complaints)
• What (Can be ordered, limits, amounts)
• When (How often can it be ordered, filled, seen)
• Where (providers)
• WHY (denied, limits)
Learning to navigate the system does not happen over night..........

- It is not easy
- It is not a one time lesson
- It can not be done by simple reading
You can go with the flow and sometimes feel like...

Some networking, each family has a vessel... while the water is calm and we follow in line.
The Title, disability or diagnosis

- Is no longer Center Stage
- What is Center Stage is the common goal and needs.
The river

- It is WORTH IT!!
- It is LIFE Changing
- It is POSSIBLE
- It is easier to navigate the river ("SYSTEMS") when you....?
NETWORK

- When to find common goal
- To learn what others know of the path (experience)
- AND TAKE ON THE RAGING RIVER TOGETHER.
Often we come across systems that are old, antiquated or that exclude or are difficult to navigate.

Sometimes we come across a system that is not all what it seems to be.

• Those systems need change and we need to speak up to cause change.

“Nothing Changes if, Nothing Changes”
The Council engages in advocacy, system’s change and capacity building activities for people with developmental disabilities and their families in order to promote equal opportunity, self-determination, and community inclusion.
Sixty percent (60%) of the Council must be made up of individuals with disabilities and/or parents of individuals with disabilities.
Funding to People First of Nevada

- Self advocacy group that brings people together with a common goal.
  "To be Heard"

- Signature Stamp

- Person First Language Bill
Statewide Employment summit that culminated in an executive order creating the “Governors Task force on Integrated Employment”

First state wide disabilities conference 2013 followed by second 2015

Let’s build a world together [video](#)
ABLE act (Achieving A Better Life Experience)
Educate Healthcare Providers
Introduce Service guides in Spanish
Consumer Leadership Application
Why Do I Want to be Involved?

- Improve community supports
- Improve the system
- Learn the system
- Have the system work for you

What Do I Get out of it?
Learned about Medical Travel Expenses reimbursement

Medical Equipment in Early Intervention
  Dynavox, chairs, accessible toys

Over $10K in Outstanding Medical Bills Paid - being connected with the proper persons at Medicaid to process claims.

Reimbursement for Conference (opportunity to Attend School presentation, met school administration in charge of accessible equipment and voice our needs met at school.)
How did Networking Help Junhyo?

- IEP Training and Assistance and Support
- School adaptive equipment
- Dynavox Training for Parents and Teachers
- Reimbursement for teacher paying out of pocket
- School Ipad
- Tobii for School
How did it continue helping the Ontiveros

- Respite care for family time and time with kids
- Less stress of medical bills and coverage
- Job search and internship opportunities for siblings
- College assistance information for siblings
- Trips and Flight miles
- Opportunities to be part of hospital/parent groups
- Additional networking........
How do can I learn more and get involved?
NGCDD
Nevada Governors Council On Developmental Disabilities

Partners In Policymaking

National Association of Councils NACDD

INTERAGENCY COORDINATING COUNCIL (ICC)
HTTP://WWW.PARENTCENTERHUB.ORG/
Questions ??

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