

# Helping Families Advocate for their Children's Best Interests

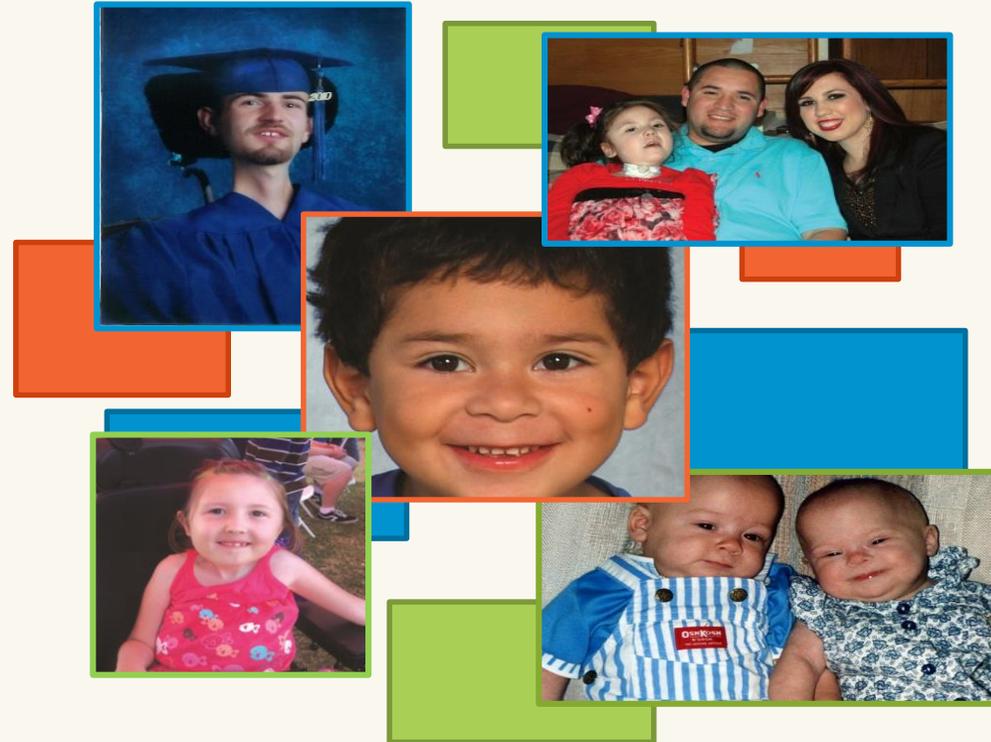
Evidence-based practices in family engagement

Wendi Howe  
Family Support Specialist  
Parent to Parent Coordinator  
Raising Special Kids



# Raising Special Kids

Families Helping Families



## Mission Statement

# Institute for Human Development

The screenshot shows the website for the Institute for Human Development at Northern Arizona University. The page features a dark blue sidebar on the left with the university's logo and navigation menu. The main content area has a white background with a dark blue header containing the site's name and navigation links. A large photograph of a speech language pathologist working with a child is the central focus, with a caption below it. Below the photo is a 'WELCOME' section with a sub-header and a paragraph of text. On the right side, there is a 'LEARN MORE ABOUT IHD' section with a video player thumbnail.

**NORTHERN ARIZONA UNIVERSITY**

Home Academics ▾ Admissions ▾ University Life ▾ About NAU ▾ Quick Links ▾

DEGREES DIRECTORY ENTIRE SITE Enter search term...

## INSTITUTE FOR HUMAN DEVELOPMENT

NAU ▸ SBS ▸ Institute for Human Development ▸ Welcome

Speech language pathologist working with a child

### WELCOME

Access | Attitude | Inclusion

The vision for the Institute for Human Development-Arizona University Center on Disabilities is that people with disabilities fully participate in all life experiences.

LEARN MORE ABOUT IHD

**THE CAMPAIGN for NAU**

**IHD**  
lhd@nau.edu  
TTY: 928-523-1695  
[More Contact Information](#)

- ▶ WELCOME
- ▶ ABOUT
- ▶ PROGRAMS
- ▶ RESOURCES
- ▶ FACULTY AND STAFF
- ▶ RESEARCH
- ▶ DISSEMINATION

# Raising Special Kids' emphasis on family voice and choice is based on the following beliefs:

- Families who raise and support children and adults with disabilities have life-long challenges not experienced by other families.
- Despite well trained and well meaning professionals, families must continually make their needs known in order to get their needs addressed.
- Services for persons with disabilities are hard to understand, hard to navigate, change frequently as the child transitions from one to another, and are provided by many different people throughout a person's lifetime.
- Learning and navigating all of the services and providers in a persons life requires more support than most families have available within their families, social networks, and communities.
- The most effective and long-lasting forms of support help families to advocate for themselves, rather than build dependency on others.
- The most effective providers of support are often other family members whose experiences may be similar to those they support.
- Parent professional collaboration is a skill that can be taught and must be practiced

# How Raising Special Kids helps families

- **Information dissemination**
  - When parents from disadvantaged groups receive information and training that increase their social and intellectual capital, they can create change in the educational system through their individual and collective actions (Bolívar & Chrispeels, 2011).
- **Parent Training and Workshops**
  - Parents gained confidence, responsibility, greater communication skills and new ways of engaging (Bolívar & Chrispeels, 2011).
  - State and district-level policies can be effected through parent training (Bouffard & Weiss, 2008)
- **Connections with community resources**
  - Nation-wide, eighty percent of parents reported that their child has received more appropriate services because they have put to use the information they have learned from the Parent Center (National Parent Technical Assistance Center, 2013)
- **Individual consultations**
  - Parent to parent support, matching parents with similar backgrounds and life experiences, can lead to greater satisfaction and patient outcomes (INSTITUTE & FAMILY-CENTERED, 2012)

# How Raising Special Kids helps families

- Meeting support [IEP, ISP, CFT, etc.]
  - Parents learned how to address issues affecting the school community (e.g., security, the quality of food in the cafeteria) and the need to solve these problems collectively (Bolívar & Chrispeels, 2011).
- Formal and informal partnerships with school districts and charters
  - A new superintendent looked to the Boston Parent Organizing Network (BPON) to connect with all the various and disparate parent groups and help shape the district's new family engagement policies (Weiss & Westmorland, 2008)
- Mentoring
  - Parents who participated in Parent to Parent showed greater acceptance of family and disability and coping efficacy, than parents who did not participate (Singer et al., 1999).
  - Family to Family support can have beneficial effects on the mental health of mothers of children with chronic illness (INSTITUTE & FAMILY-CENTERED, 2012)
- Parent leadership training
  - Parents who participated in a 12 week leadership program showed growth in trust, understanding school system norms and access to information, resulting in improved educational outcomes for their children (Bolívar & Chrispeels, 2011).

# How Raising Special Kids helps families

- Training for professionals and pre-service professionals
  - Professionals benefit from understanding that they do not know the 24-hour reality of parenting a child with a disability (Singer et al., 1999).
- Help with problem-solving and conflict resolution
  - “Parent to Parent is particularly helpful in assisting parents to make cognitive adaptations to disability in the family, in making progress on dealing with specific problems, and in helping parents to become more effective at coping with the demands of parenting a child with a disability while maintaining a desirable family life.” (Singer et al., 1999, p. 228).
- Systems level advocacy
  - Some parent graduates of a leadership program founded organizations that continue to effect changes in educational systems (Bolívar & Chrispeels, 2011).
- Bilingual and bicultural staff advocacy
  - Higher levels of Latino representatives on local school councils were associated with great teacher awareness of student culture/community issues and stronger school efforts to build parent-school relations (Marshall, 2008)

# Parent to Parent

- Raising Special Kids is a founding member of Parent to Parent USA
- Peer to Peer Model
- Parent to Parent Connection
  - Local
  - Regional
  - Statewide
  - National





12 doctors

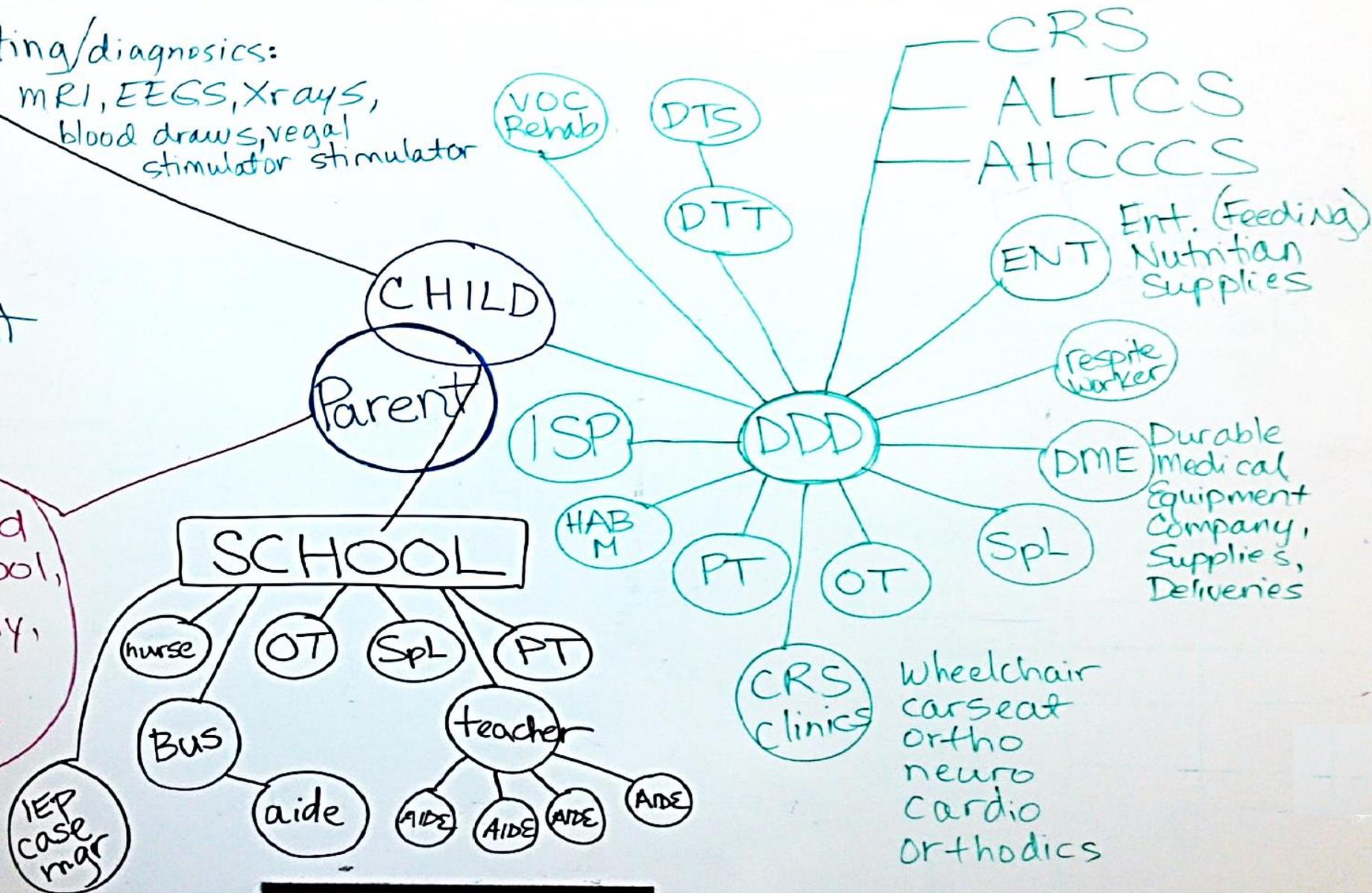
# PARENT PERSPECTIVE

## Medical

- DOCTOR - Primary neurologist
- dentist
- ortho surgeon
- Kidney specialist
- urologist
- Hanger orthotics
- ENT audiologist
- Gastro I. gyne

testing/diagnostics:  
MRI, EEGS, Xrays,  
blood draws, vegal stimulator

non-disabled children, school, teachers, family, friends, job, coworkers



# Idea of Sameness

*Findings suggest that parents who use Parent to Parent for non-emergency help benefit from contacts with other parents by:*

- Feeling better able to cope with their child and family situation,*
- Feeling better able to view their family and personal circumstances in a more positive light, and*
- Helping other parents make progress on goals that are important to them.*



# Parent Training and Information for Special Education

- Early Intervention and School-aged Special Education
- Information dissemination
- Training
- Consultation
- IEP Partners



# Health Care Information

- Eligibility, Services and Systems Navigation
  - Division of Developmental Disabilities
  - Arizona Long Term Care System
  - Children's Rehabilitative Services
  - Behavioral Health
  - Social Security Administration
  - Legal Options at the age of Majority
  - And more ...



# NICU Family Outreach

- Manual
- Referral



# Physician Training

- Resident Physician Training
- Dental
- Nursing

“It's great to know a service that can act as a central hub for my patients”

– Resident Physician

*Pediatricians should encourage and facilitate peer-to-peer support and networking, particularly with children and families of similar cultural and linguistic backgrounds or with the same type of medical condition*



# Parent Panels

- Pre-service
  - Teachers
  - Related Service Providers
  - Counselors
  - Behavioral Health Providers



*Q: What needs to happen ... in order to make more progress in family involvement policy?*

*A: One of the most important, and most challenging, tasks is getting schools of education to transform their way of training teachers and administrators in a way that includes family involvement – Arnold Fege*

# Parent Perspective for Professionals

- *Professionals were viewed by a majority of these parents as important sources of support*
- *Although professionals can, and do, offer many important services, their language, viewpoint, and day to day experience is simply very different from that of a family member*
- *Professionals might benefit from understanding that they do not know the 24-hour reality of parenting a child with a disability*
- *Parent to Parent should be considered by policy makers and funders as a component of an array of family supports for families of children with disability*

# Parent Leadership (full circle)

- Training
  - Accountability
  - Ethics
  - Confidentiality
  - Mentoring
  - Telling your story
- Mentor
- Parent Perspective / Family Voice
- Legislative Advocacy
- **More than Half** of our current staff started as a **Parent Leader** for the organization
- **80%** of the Management Team at Raising Special Kids started as **Parent Leaders**



# Relevant Research

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