



Overview of Florida and Virgin Islands Deaf-Blind Collaborative

Presenters

Pam Kissoondyal, Family Engagement Coordinator

Emily Taylor-Snell, Project Coordinator



FAVI-DBC Goals for Today

- Overview of FAVI-DBC Project and Services
- Who are the children and youth who are considered Deaf-Blind?
- What is an Intervener?
- Highlight Upcoming Events
- Spotlight Resources and Family Supports
- How to get more information and services

FAVIDBC Core Team



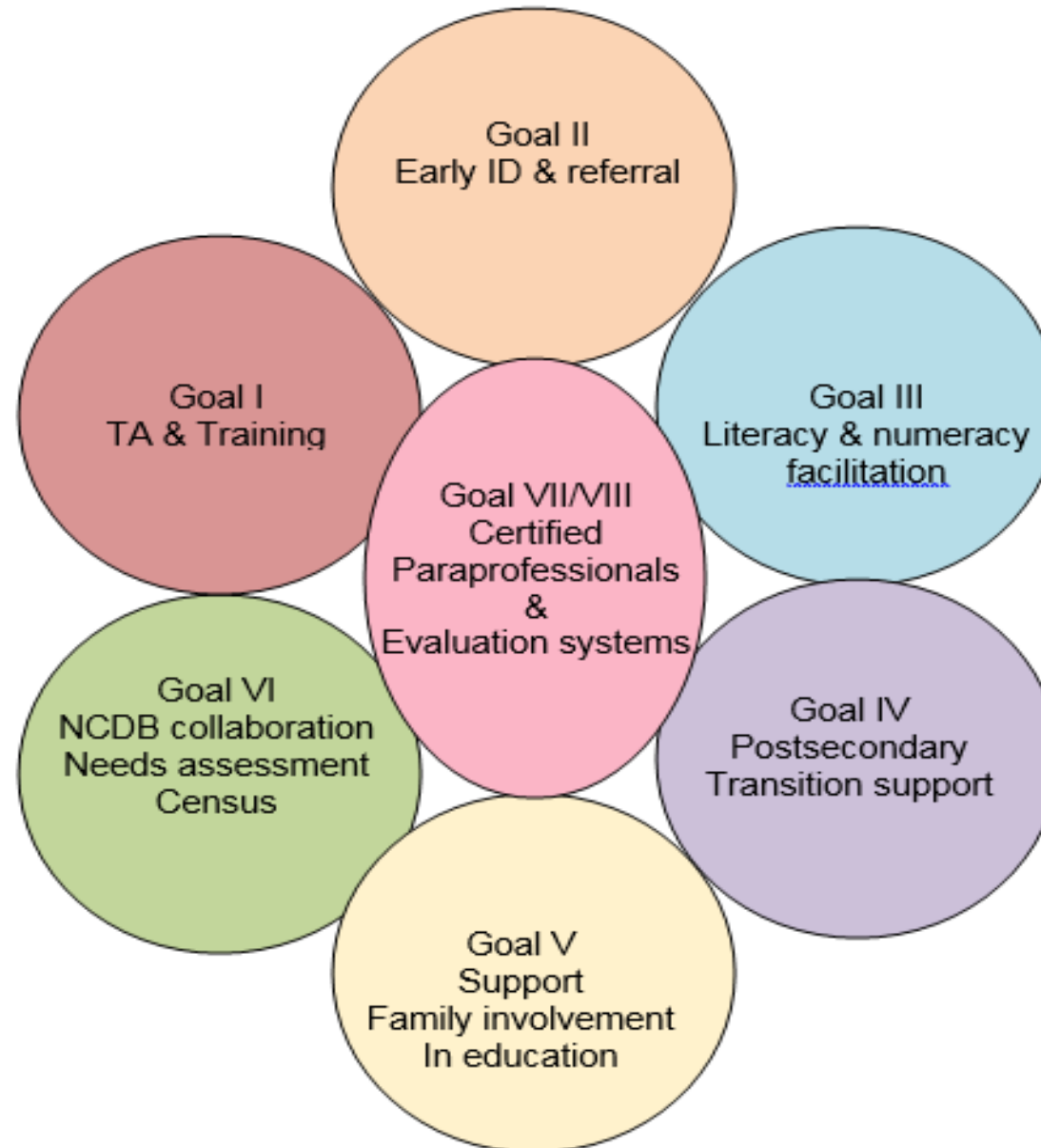
- Regina Bussing, MD, MSHS, Project Director
- Emily Taylor-Snell, MEd, Project Coordinator
- Pam Kissoondyal, Family Engagement Coordinator
- Michelle Pearson, MA, Technical Assistance Specialist
- Shelly Voelker, EdD, EdS, MEd, Family and Information Specialist



Florida and Virgin Islands – Deaf-Blind Collaborative

- *Funded* by the US Department of Education, Office of Special Education Programs as a Technical Assistance and Dissemination Grant 2018 - 2023
- *Housed* at the University of Florida, in Gainesville and serves Florida & Virgin Islands
- *Serves* families and service providers of children and young adults who are deaf-blind ages birth – 21 years of age
- *Provides* information, training, consultation and collaboration-- **FREE** of charge!!!

Eight FAVI-DBC Goals





FAVIDBC Required Grant Priorities

- Deliver Technical Assistance and training necessary to **improve youth outcomes**
- Increase **early identification and referral**
- Facilitate **literacy** and **numeracy**
- Support for **postsecondary transition**
- Increase family support to facilitate **involvement in education**
- Collaborate with NCDB on **needs assessment** and **census**
- Increase number of **certified paraprofessionals** (interveners)



Who are children who are considered
Deaf-Blind?



Deaf-Blind Youth are **all** UNIQUE!





FAVI-DBC 2018 Census Data
(more on this topic next session)

2018 Age Distribution (597 FL Children reported)

- **Graduates (ages 18+) = 146** (includes 16 aged out)
- **Transition-aged (14-17) = 122**
- **Part C (ages 0-3) = 23** (includes 8 aged out of Pt C)
- **Other School-Aged (ages 4-13) = 306**



2018 Census Count: 597 Children Reported

Main Causes of DB in Florida

- No Determination of Etiology 217
- Complications of Prematurity 58

Hereditary/Chromosomal (n = 219)

- CHARGE syndrome 59
- Trisomy syndromes 28 Down syndrome (Trisomy 21) 17
- Usher syndrome(s) 21
- “Other” hereditary/chromosomal 94





National Rates of Additional Disabilities for Children with DB

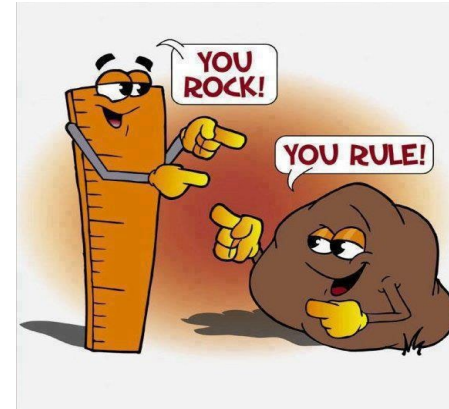
- 66% Cognitive disability
- 57% Physical disability
- 38% Complex health care needs
- 9% Behavior challenges
- 30% Other



DB Federal Definition age 3- 21 years

- ***“Deaf blindness means concomitant hearing and vision impairments, the combination of which **causes such severe communication and other developmental and educational needs** that they cannot be accommodated in special education programs solely for children with deafness or children with blindness”. (IDEA, 2004)***

Florida DOE DB Rule Revision



- ▶ Change in selecting Dual Sensory Impaired on December 1 Count eligibility
- ▶ In past, students have been identified as being blind/visually impaired as primary and deaf/hard of hearing as secondary (or vice versa)
- ▶ Change: If have a combination of vision and hearing loss, identify as **Deaf-Blind** as primary, recognizing it as a single disability.



NEWS FLASH!!



- Students can be reported under a variety of categories on the State December 1 count
- **AND**
- Be reported as Deaf-Blind on the National DB Census if they have BOTH vision and hearing loss and other disabilities



What Are Potential Impacts of Dual Sensory Loss?



“Blindness separates a person from things, but deafness separates him from people.”

- Making sense of the world
- Developing concepts
- Learning to communicate
- Orientation: Where am I?
- Mobility: How do I move around?
- Inclusion in family and community
- Transition from service and educational systems

Helen Keller

Definition and Role of an Intervener

An Intervener can be an allowable IDEA Related Service for youth who are Deaf-Blind.



An intervener is defined as an individual who:

- Works consistently one-on-one with a student who is DeafBlind.
- Has training and specialized skills related to DeafBlindness (Alsop, Blaha, and Kloos, 2000).



The Role of the Intervener is to:

- Facilitate access to environmental information usually gained through vision and hearing, but which is unavailable or incomplete to the individual who is deafblind.
- Facilitate the development and/or use of receptive and expressive communication skills by the individual who is DeafBlind.
- Develop and maintain a trusting, interactive relationship that can promote social and emotional well-being (Alsop, et al, 2000).

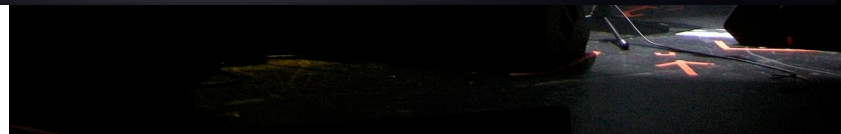
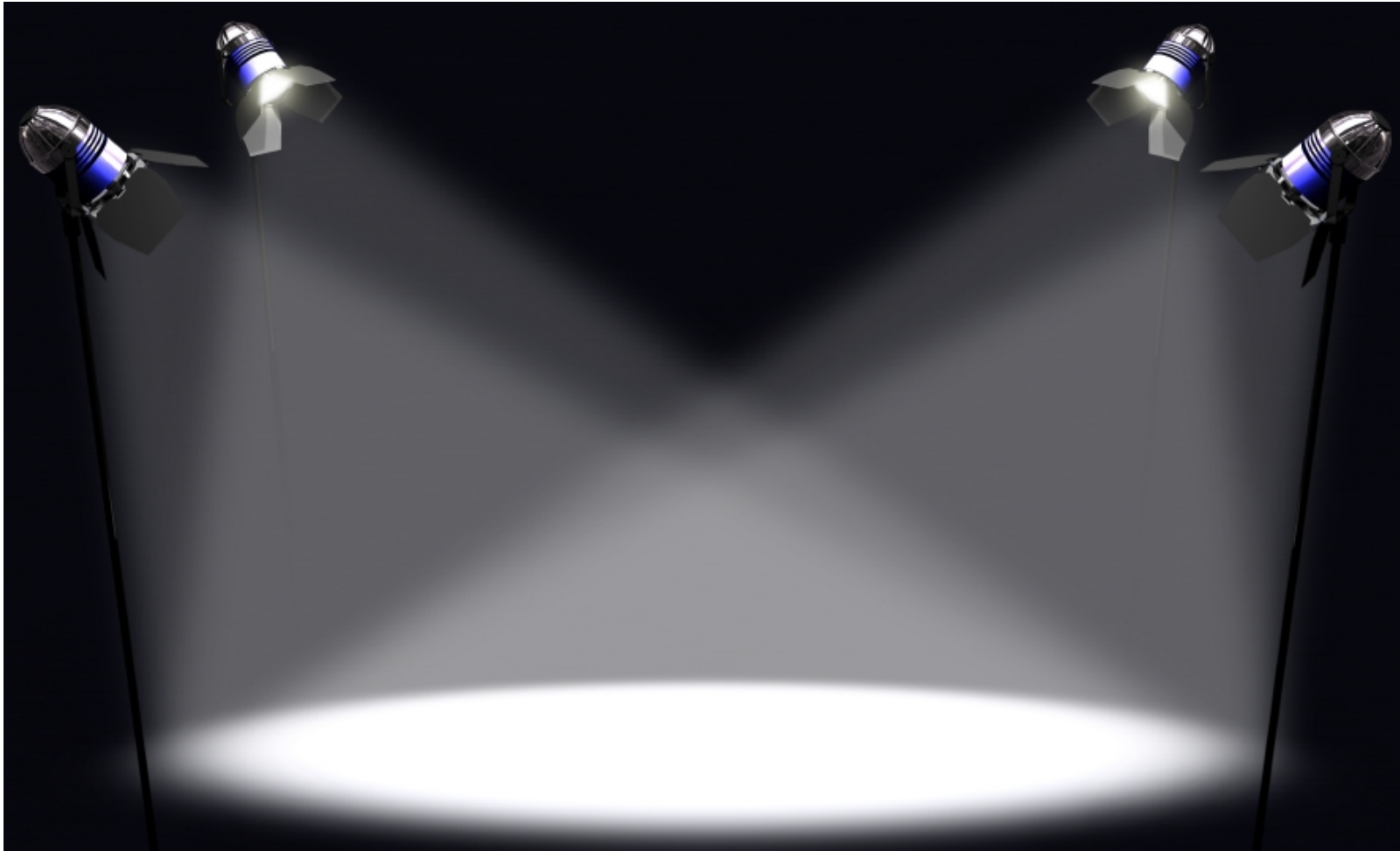


Resources to Support Intervener Services

1. Ruth Ryder US Dept. of Ed OSEP Letter naming “Intervener” as an allowable related service under IDEA
2. CEC Specialty Set: Special Education Paraeducator Intervener for Individuals with DeafBlindness (PDBI) Competency List
3. NCDB Technical Assistance and Training for Open Hands, Open Access (OHOA) online modules (www.nationaldb.org)
4. Utah State University Intervener Certification Courses
www.online.usu.edu/intervener
5. Resources for families, districts and interveners to determine need for intervener, videos and national information www.intervener.org
6. Intervenors who have completed training can apply for certification through National Center for Paraeducators Marilyn Likens Marilyn@nrcpara.org



Highlights of FAVIDBC Services and Supports





Onsite Technical Assistance Visits





Connecting to Literacy Resources

- 1) National Center on Deaf-Blindness Website with an assessment checklist, resources, videos, samples www.literacy.nationaldb.org
- 2) Design to Learn Materials by Phil Schweigert and Charity Rowland
www.designtolearn.com
- 3) Perkins Paths to Literacy program
www.pathstoliteracy.org/overview-multiple-disabilities-and-deafblindness



Customized Training and Presentations





SE Transition Institute





SE Multi-state DB Transition Institute

- Annual Transition Institute for youth 14 and older and families
- July 11 – 14, 2019 in Raleigh, NC, TH – Sun
- Teach about Self-determination and Transition Planning
- Develop DB Mentors and feature DB Role Models
- Opportunities for SSP's, Interpreters, TVI's, VR and DBS Staff
- Collaboration with 12 DB Projects; Locations vary annually

National Deaf-Blind Equipment Distribution Program - NDBEDB

The goal of NDBEDP is to ensure that every person with combined hearing and vision loss has access to modern telecommunication tools and the training necessary to use them.

FAVIDBC collaborated on 25 cases to help get technology and training. PLEASE SHARE!



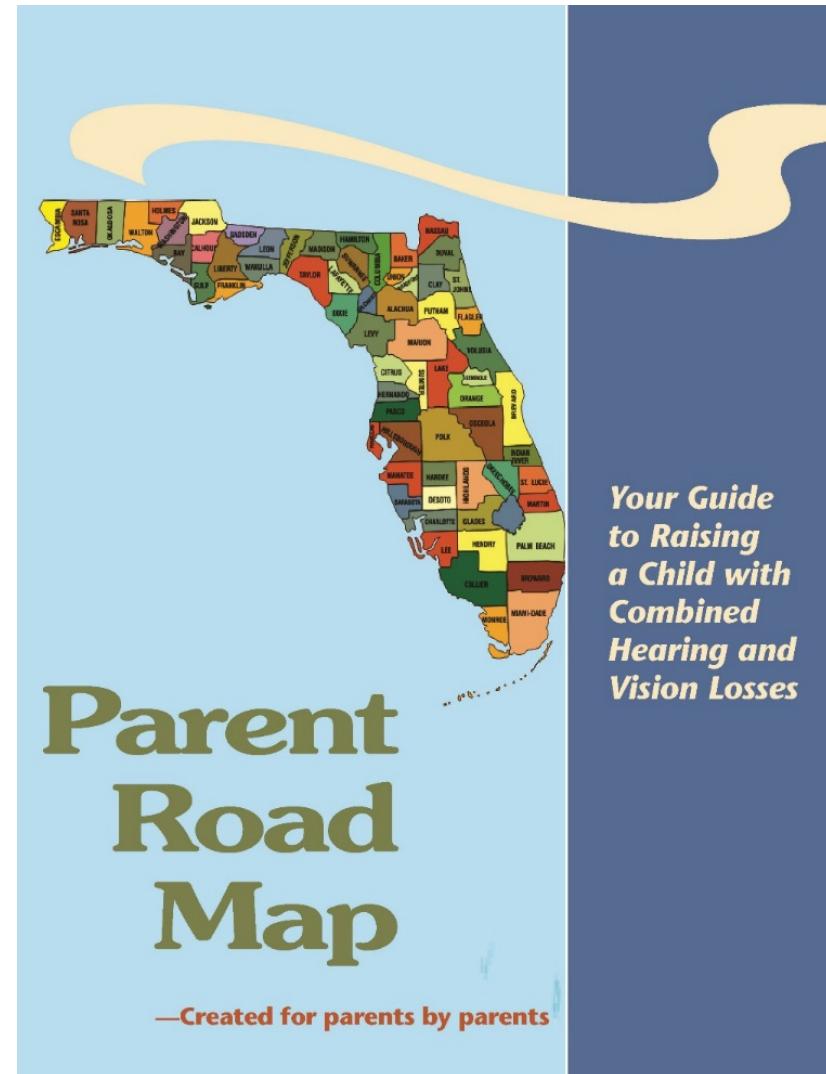
www.iCanConnect.org

Cory Parker, HKNC Rep
cory.parker@hknc.org

NEW!

Florida's Parent Road Map Volume 2

www.deafblind.ufl.edu





SPANISH CONFERENCE CALLS FOR FAMILIES

Peer support through facilitated conversations is a way to allow parents and family members of individuals with deaf-blindness to express their challenges and successes.

TWO times the family support by phone per month - all free

Spanish-speaking families of individuals who are deaf-blind, now have two options to participate in monthly conference calls for discussing issues that may arise and for supporting each other in Spanish.

Both national calls are facilitated by parents, giving everyone an opportunity to share their story and receive support, information, and resources. Family members may join both or either call.

Every SECOND Tuesday
September 2018 — July 2019
at 9PM ET / 6PM PT

Join NFADB / CDBS for friendly and confidential calls for Spanish-speaking family members of individuals who are deafblind. Every other month, these calls will also have a speaker on topics of interest. Myrna Medina will facilitate these calls. To participate in the NFADB / CDBS calls, please call Myrna Medina at 951-785-7898 or email myrnam@sfsu.edu to get call details

Every THIRD Tuesday
September 2018 — May 2019
at Noon ET / 9AM PT

Join the Family to Family Community (F2FC) calls for families who speak Spanish. These calls will be more structured. Families must enroll before the end of September and will commit to joining for the entire school year. These calls will have two facilitators and the "Charting The Life Course" materials will be shared to guide the discussions.

Please contact Silvia Verga at 718-997-4855 or email Silvia.Verga@qc.cuny.edu to enroll and get call details.

We look forward to your participation to benefit your children and the rest of the family!



The National Family Association
for Deaf-Blind

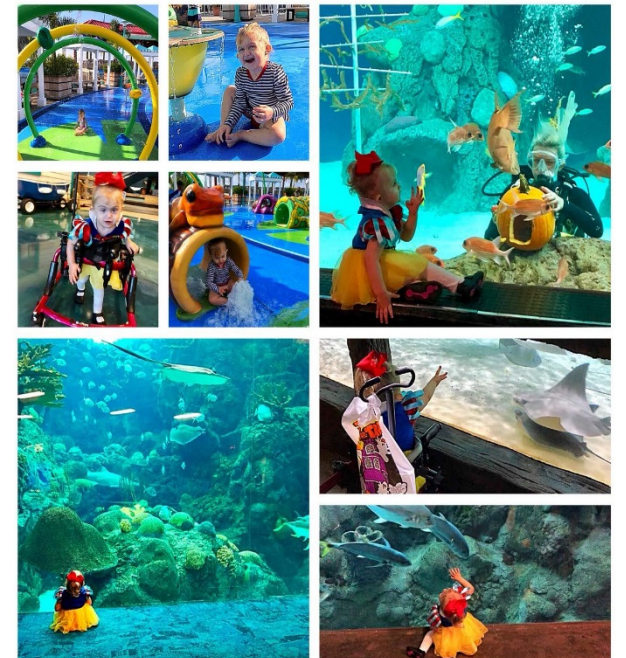
These calls are offered in partnership with NCDB



CDBS is funded under a grant from the U.S. Department of Education #H326T130031. Although project staff will moderate on one set of calls and may take part in discussions, the content of these calls does not necessarily represent the policy of CDBS, or the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer: Jo Ann McCann.

Family Engagement Materials

- **For Families** section of the NCDB website – has resources that can be of immediate assistance to families with connecting to the DeafBlind network
<https://nationaldb.org/families>
- **Families Matter Stories** – stories about families across the nation who have children with DeafBlindness
<https://nationaldb.org/families/familiesmatterstories>



Family Engagement Materials

- **Friday Family Fun Facts** – posted every Friday on NCDB's Facebook and Twitter. A recent post had 64,442 views!
<https://nationaldb.org/pages/show/dbfamilyfunfacts>
- **Family Engagement Initiative** space on the NCDB website – we post monthly forums with updates on what's happening in the network and ways to engage <https://nationaldb.org/groups/page/10/family-engagement>





14th International CHARGE Syndrome Conference
Dallas, Texas • August 2-5, 2019

Our next conference will be taking place August 2-5, 2019 in Dallas, Texas at the stunning Hilton Anatole hotel. Conference registration will open around March 1, 2019.



CHARGE Syndrome Webinars



- **2018-19 Webinar Wednesday Series** – posted on the Charge Syndrome site. January 16 – Impact of a Child with Complex Needs on the Family and the Importance of Self-Care 8-9:30 p.m. EST **(all topics are archived)**
- <https://www.chargesyndrome.org/for-families/resources/webinars/>

Florida & Virgin Islands Deaf-Blind COLLABORATIVE



Family Café is an annual Statewide Disability Conference.

Family Café conference has more than 100 1 hour sessions. You can choose to attend the sessions that are most important to you and your family. This is the 20th year! The best part is getting an opportunity to connect with other families and services that may be beneficial to you and your family.

Florida & Virgin Islands Deaf-Blind Collaborative (FAVI-DBC) has limited scholarships available for families interested in attending. Contact Pam K. for more information.

Pam Kissoondyal
FAVI-DBC Family Engagement Coordinator
Call/Text: 352-672-4598
Office: 352-273-7529
Toll-free: 800-667-4052

FAMILY CAFÉ CONFERENCE

JUNE 7-9, 2019

HYATT REGENCY ORLANDO

9801 INTERNATIONAL DRIVE ORLANDO, FL 32819

Support participation in Family Cafe





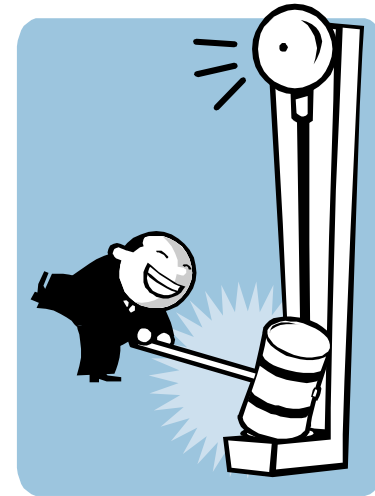
The Sky's the Limit!!

With the right:

- supports
- education and training
- opportunities
- hard work

a person who is deaf-blind is limited only by funding and the attitudes of others.

Be a Supporter!





Stay Connected

- Florida and Virgin Islands DB Collaborative
- University of Florida
- 1600 SW Archer Rd., P.O. Box 100234
- Gainesville, FL 32610

- Email:  info@deafblind.ufl.edu
- Phone: 352-273-7530 or 800-667-4052
- Website: www.deafblind.ufl.edu

