

DEAF-PLUS

Supporting Families When Hearing Loss is Not the Only Consideration

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“DEAF-PLUS”



What does Deaf-plus mean to you?



“DEAF PLUS”

refers to

children or persons who have a hearing loss in addition to other conditions that affect them medically, physically, emotionally, educationally or socially.



Among children with hearing loss, what percent also have other significant medical, physical, emotional, or educational socially concerns?





Among children with hearing loss, what percent also have other significant medical, physical, emotional, or educational socially concerns?

50+%



The “Plus” in Deaf Plus....

- Visual Impairment/ Deaf-blindness
- Developmental/cognitive/intellectual delay
- Orthopedic/physical impairment
- Specific learning disability
- Autism
- Syndrome Related
- Emotional/behavioral
- Traumatic brain injury
- Other health impairments

Emotional

- States of grief
- Chronic grief
- “...constantly waiting for other shoe to drop”
- Denial: continual loss
- Physical/emotional exhaustion
- Cultural/religious values
- Privilege and burden of being the “experts”



Medical



- Life and death situations
 - *“My child won’t die from being deaf..but may die from....”*
- Chronic medical conditions/diagnoses
- Other medical conditions masking hearing loss
- Everyday medical care/interventions

Social

- Isolation
- Often limited support
- Peers
- Siblings
- Relationship/marital strain
- Identification with Deaf culture



Financial

- Healthcare costs
- Loss of job for caretaker
- Educational needs



Educational/Service Delivery



- Appropriate programs
- Qualified personnel
- Diagnostic delays
- Service Coordination
- Identification/eligibility
- Communication
- Parents as experts

- Deaf students with multiple disabilities have the educational needs of deaf students plus the educational needs associated with one or more additional disabilities. In addition, the interaction of the disabilities creates educational needs that are not characteristic of any single disability (Jones, 1984).

In other words...

Deaf + 2nd disability \neq 100 + 100 = 200

Deaf + 2nd disability = 100 * 100 = 10,000

Deaf + 2 add'l disabilities = 100 * 100 * 100 = 1,000,000

Needs Of Parents

- Information/Resources
- Safe Place
- Advocacy
- Parent network of support
- Help in managing multiple service providers
- Person centered planning/Mapping



SAFE PLACE

- “for our son that is at home with family”
- “Thank God for CAP, a 1:1 state funded assistant with intensive goal-based program of home and community supports. This program is a life saver for us.”
- “When I go to family weekends, my child is among the “normal” for a change!”

INFORMATION/RESOURCES

“NC DB summer program has been a vital educational resources for me. David would not be reading and writing now if we hadn’t had the ability to learn from faculty at the UNC Center for Literacy and Disability. This information totally changed David’s life and helped us find his potential.”

ADVOCACY

“I have found as our son has gotten older that I am “wearier” at advocating and have needed more encouragement from others to remind me that I can “finish this race.” I also feel challenged at walking the line between allowing him to become more independent while still ensuring that his needs get met.”

PARENT NETWORK OF SUPPORT

“Belonging to the deaf-blind group is a wonderful thing. We have met other families who can help with problems we encounter.”

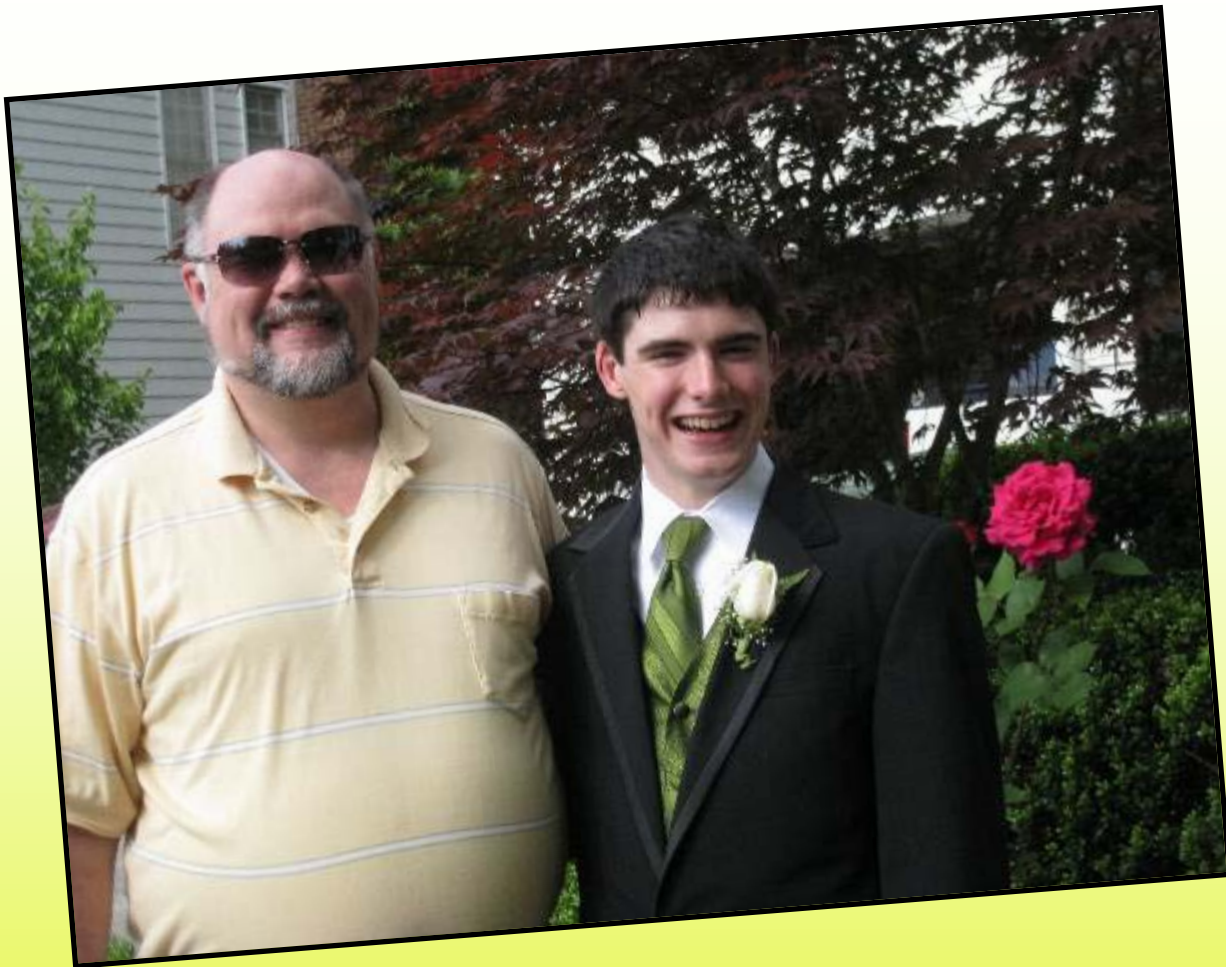
“I was connected with parents with similar challenges right away. When we get together, I feel like I’ve come home where people speak my language.”

SERVICE MANAGEMENT

- “I was so worried when we had to move into "pre-school" and that it would take forever to "break in" a new teacher and therapists!!! But once again, Gateway Education Ctr. has come through and we couldn't be happier!!! Drake's new teacher not only has over 20 years experience, she also use to work at the school for the deaf AND has a special needs child of her own!!! Ann and **all the therapists work well together and I love their communication with each other and with us!** I for see a long and loving relationship building as I write!!!”

PERSON CENTERED PLANNING

- Person centered planning involves bringing together the child, family and friends, and professionals to participate in a series of meetings to learn as much as possible about the child and to plan for positive and functional outcomes for the child (Jones, Jones, Ewing, 2006).

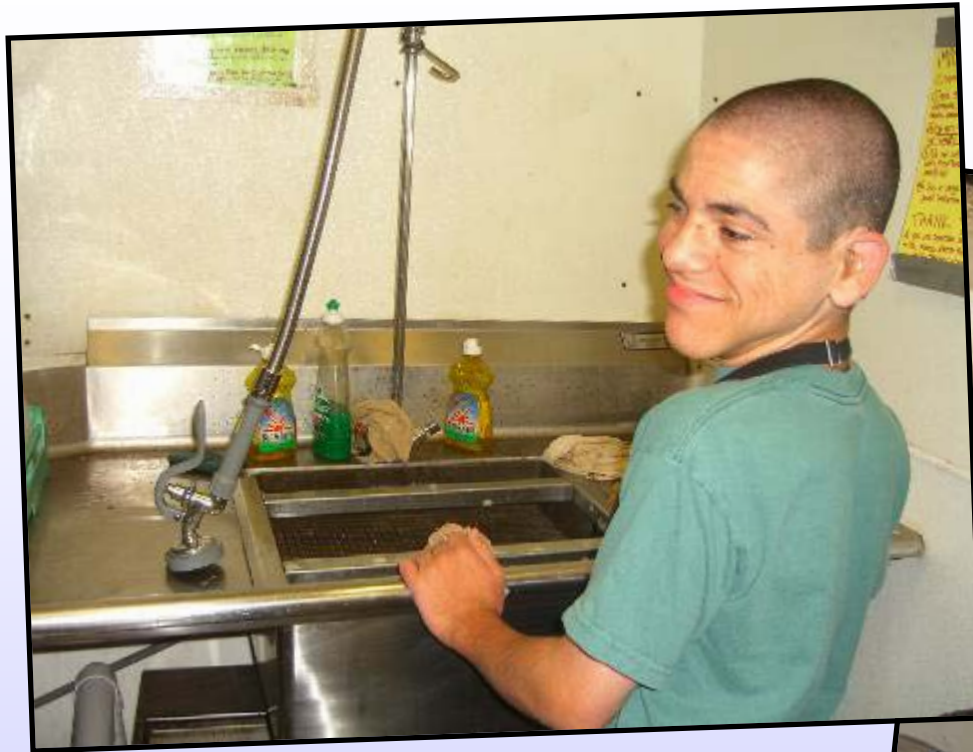


Nathan's Story

Nathan Goes to the Prom!

Malik's Story





David's Story



Drake's Story



Shelby's Story

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REFERENCES

- Perigoe, C. (editor) (2004). Multiple Challenges, Multiple solutions: Children with Hearing Loss and Special Needs. *The Volta Review*, 104, (5).
- Gallaudet Research Institute (2006-2007). Regional and National Summary Report Data form the 2006-2007 Annual Survey of Deaf and Hard of Hearing Children and Youth. Washington D.C.: GRI, Gallaudet University.
- Jones, T. & Jones, J. (2003)(2006). Educating Young Children with Multiple Disabilities. In Bodner-Johnson & M. Sass-Lehrer (Eds.), *The Young Deaf of Hard of Hearing Child* (pp. 297-329). Baltimore: Brookes Publishing Co.
- Luterman, D. (2004). Counseling Families of Children with Hearing Loss and Special Needs. *The Volta Review*, 104(4) (pp.215-220).



Concluding Words of Wisdom

“Let your kids show you who they are and follow their lead—even when it feels like you will never know where they are going...”

THANK YOU!

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