



Meeting the Needs of Proficient Communicators

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While the majority of the children and youth served by the state deaf-blind projects are emerging communicators, there is a growing number who are “proficient communicators” being served in general education classrooms. Part 1 of this session will address the identification of proficient communicators and resources and strategies for proficient communicators who are congenitally deaf-blind. Part II will address proficient communicators with Usher syndrome.

KEY POINTS

Who are proficient communicators?

1. Use formal language.
2. Take regular state tests with or without accommodations.
3. Most do not have an intellectual disability.
4. Accomplished in the use of a large array of technology.

Have a variety of different etiologies. **Most are congenitally Deafblind** however students with **Usher syndrome are part of this group as well**. Both congenital proficient communicators and those with Usher syndrome are under identified and underserved.

The type of technical assistance (TA) including specific strategies and resources needed by this population differs significantly from emerging communicators. Unlike emerging communicators, however, the resources and strategies for congenital proficient communicators are lacking in our field.

There are a few areas of need that have been identified for congenital proficient communicators:

1. Concept Development
2. Modifying curricular content
3. Comprehension
4. Individual/Group work
5. Homework
6. Technology needs
7. Stress

8. "Behavior"/Distress
9. Social Skills
10. Self-Advocacy
11. Transition
12. The need for additional resources, training and/or staff

[Protactile communication with Orion Withrow](#), congenitally deafblind young man

In addition, students with Usher syndrome need:

- a. Information about Usher syndrome
- b. Strategies to manage as vision changes
- c. Universal accessibility to educational materials
- d. Accessible distance education platforms
- e. Self-advocacy skills and tools
- f. Research driven guidance on: O&M, braille, communication choices
- g. Mentors/role models
- h. Opportunities to meet others with Usher syndrome

RESOURCES ON USHER SYNDROME

For Students

- [Ethan and Gavin talk about Usher Syndrome](#)
- [Ava's Cheat Sheet Template and Samples](#)
- [Student Led IEPs](#)
- USC - Just for Young Adults blog by Megan Lengel ["Seeing is Believing: My College Experience with Usher 1B"](#)
- [First ever video series about Usher syndrome in ASL](#)
- HKNC Video: [Advocacy in the DeafBlind World– Ryan Odland, HKNC](#)
- [USHthis Summer Camp for Youth with Usher Syndrome, ages 11-17](#)
- [USHthis Summer Camp Counselor opportunities, ages 18-24](#)
- [USHangouts – 1 day camp for all kids attending the USC conference](#)
- Facebook group – [Young Adults Living with Usher Syndrome, 18-28](#)

For Parents

- [Usher Syndrome Coalition](#)
 - [Annual USH Connections Conference](#)
 - [USH Trust international registry](#) – register and connect families
 - [Global Usher Syndrome Awareness Day](#) – 3rd Saturday of September

- [USH Ambassadors – building the Usher community, one state at a time](#)
- Blogs on parenting a child with Usher – [Mark Dunning](#) and [Lanya McKittrick](#)
- Webinar – [Educational Considerations for Students with Usher Syndrome](#)
NCDB/Usher Syndrome Coalition/ Patti McGowan/Carly Fredericks
- [Ava's Voice:](#)
 - [The Diagnosis of Usher Syndrome](#) – interview of kids with Usher and their parents
 - [discUSH Family Weekend](#) - family get-away to meet other USH families
- [National Family Association for Deaf-Blind:](#) empowering the voices of families with individuals who are deaf-blind and advocating for their unique needs
- [F2FC](#) – monthly calls for families of kids with Usher syndrome
- Facebook groups – Usher Moms, Moms of Adult Children with Usher Syndrome, Usher Syndrome Parents
- Article - [Denied an IEP or 504 Because Grades are Good](#)
- [iCanConnect](#) – National Deaf-Blind Equipment Distribution Program

For Practitioners

- Webinar - [Starting a National Dialogue on Finding Children with Usher Syndrome](#)
NCDB/Usher Syndrome Coalition/Carly Fredericks/Patti McGowan
- [Video - Meet Ava Bullis as She Transitions to a New School](#)
- HKNC - online offerings
 - [Information](#) about topics such as [Haptics](#) and [ProTactile](#)
 - [Free online courses](#) through December 31

Distance Learning Resources

- HKNC Zoom video conferencing guidelines - [Accessibility Practices for People Who Are Deaf-Blind](#)
- NCDB [Distance Learning for Proficient Communicators](#)

Guidance from the Usher community

- [Artist Tim Chambers, The USH View](#) – What do those with RP really see? Tim is a world class artist/painter with Usher 2A who paints what he sees.
- [Professionals Serving DeafBlind Consumers](#) (PSDBC Google forum) Information on the evolving culture, values and issues
- [Blind but Not Blind](#) – JennyLynn Dietrich, DeafBlind adult on autonomy
- [Haptics Demonstration videos](#)
- [Protactile ASL – A New Language for the DeafBlind](#)