

School Age Kids with Usher Syndrome

Video description: Kevin (a male with short brown hair and grey collared shirt) sits in front of a dark blue background, looks into the camera and signs.

TRANSCRIPT: Hi! Today's topic is education. K-12 years are important! Kids with Usher syndrome may go to schools for the deaf, others may be mainstreamed. It often depends on what's available where you live. Unfortunately, a high percentage of kids with Usher syndrome are overlooked. They may not yet be identified as having Usher. In previous videos, we described how vision loss may not be recognized until the teen years when children start to have difficulty seeing at night or when peripheral vision loss becomes noticeable. This often happens between middle school and high school. Up until then, there are often no signs of RP so Usher syndrome goes undetected. Once it's identified, support services can begin. These may include close vision interpreters who sign in smaller signing space for RP, braille training, orientation and mobility, or cane, training, services from a teacher of the deaf (TOD) and a teacher of the blind and visually impaired (TVI). Let me explain what each does. A TOD is specifically trained to work with deaf students whether they communicate in ASL or use speech. TVIs work with children with various visual conditions. Typically, TODs and TVIs work separately. There is often no middle ground which is exactly what a student with Usher needs! The ideal situation would be for the TOD and TVI to work as a team and coordinate services for the child. Sadly, there are still areas around the country where services are lacking for kids with Usher. Schools may not be able to find teachers who sign, or have training in other critical areas. They're trying their best to provide services. We want you all to be aware of state projects for deaf-blind children. These are federally funded grants. Each state has a person whose job is outreach, and to provide technical support. That can include providing resources, information on best practices, or even training to the staff as to how to work with students with Usher syndrome. To find your state project, go to: <https://nationaldb.org/members/list?type=State+Project> and click on your state. Make sure your child with Usher syndrome - or you, if you're self-advocating - are getting the educational services you deserve.