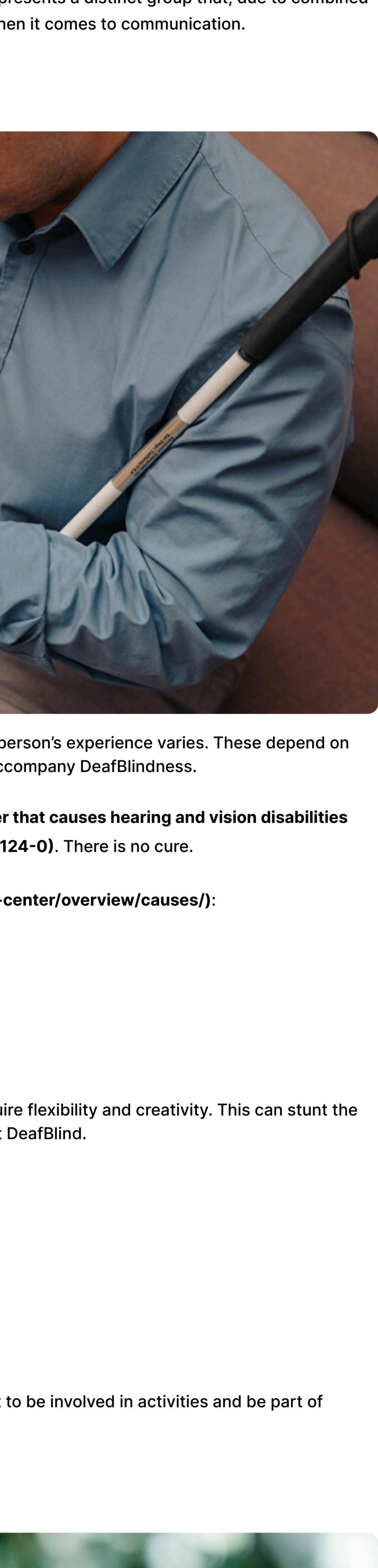


## The DeafBlind Community and Telecommunications Access

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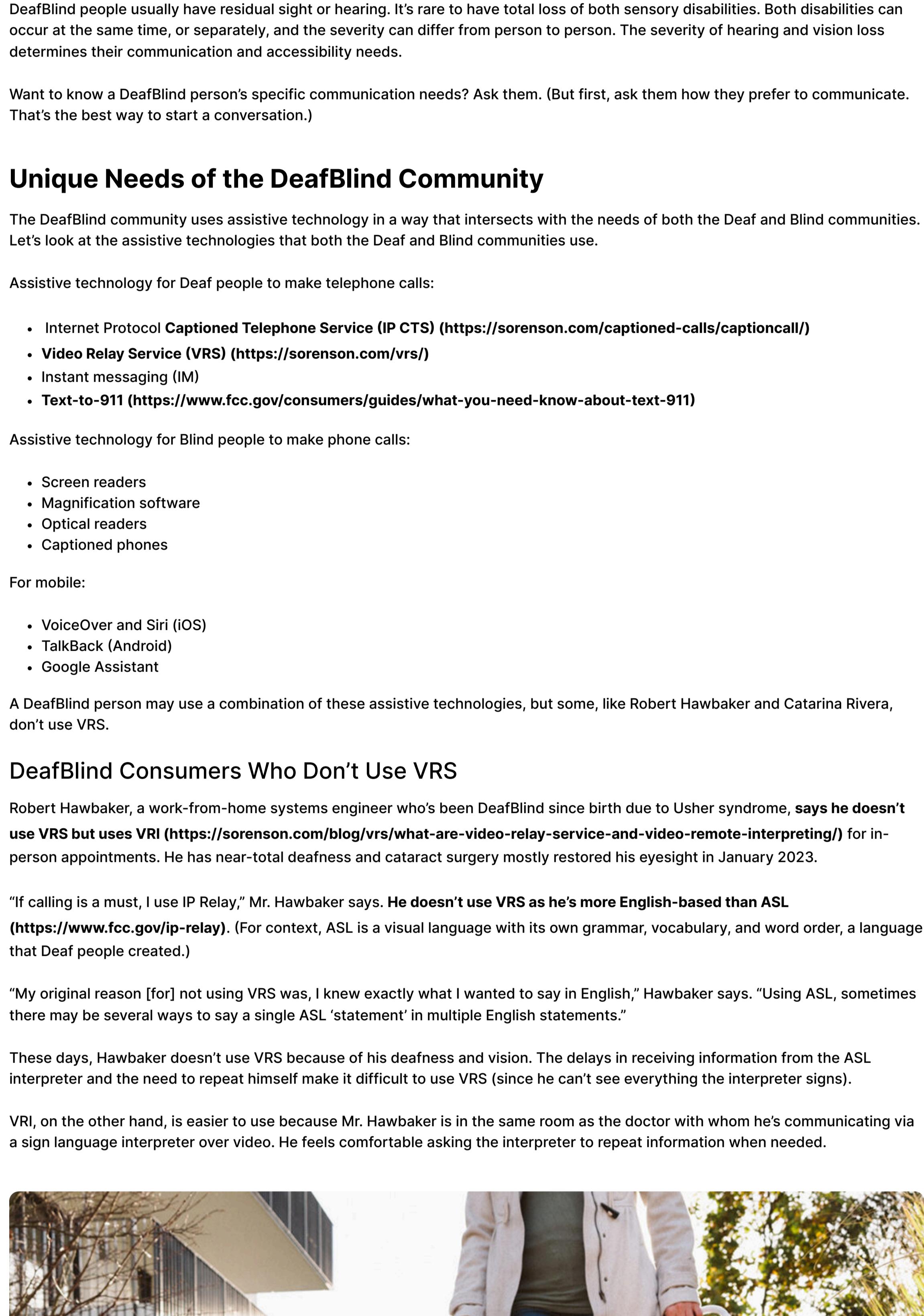
# The DeafBlind Community and Telecommunications Access



Communication is fundamental to human interaction and belonging. Without it, we would end up confused, frustrated, and lonely.

In the U.S., there are approximately 50,000 people who are DeafBlind. (https://www.loc.gov/nls/services-and-resources/informational-publications/deafblindness/) The DeafBlind community represents a distinct group that, due to combined hearing and vision loss, presents with a unique set of challenges and experiences when it comes to communication.

### DeafBlindness Causes



Although DeafBlindness is a combination of hearing and vision loss, each DeafBlind person's experience varies. These depend on the cause and severity of hearing and vision loss. In many cases, other disabilities accompany DeafBlindness.

One of the main causes of DeafBlindness is Usher syndrome, a rare genetic disorder that causes hearing and vision disabilities (https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0124-0). There is no cure.

Some common causes of DeafBlindness include (https://www.nationaldb.org/info-center/overview/causes/):

- Hereditary disorders: Usher syndrome, CHARGE Syndrome, Down syndrome
- Prenatal complications: hydrocephaly, microcephaly, cytomegalovirus
- Postnatal complications: meningitis, brain injury

### A Tenuous Social Connection

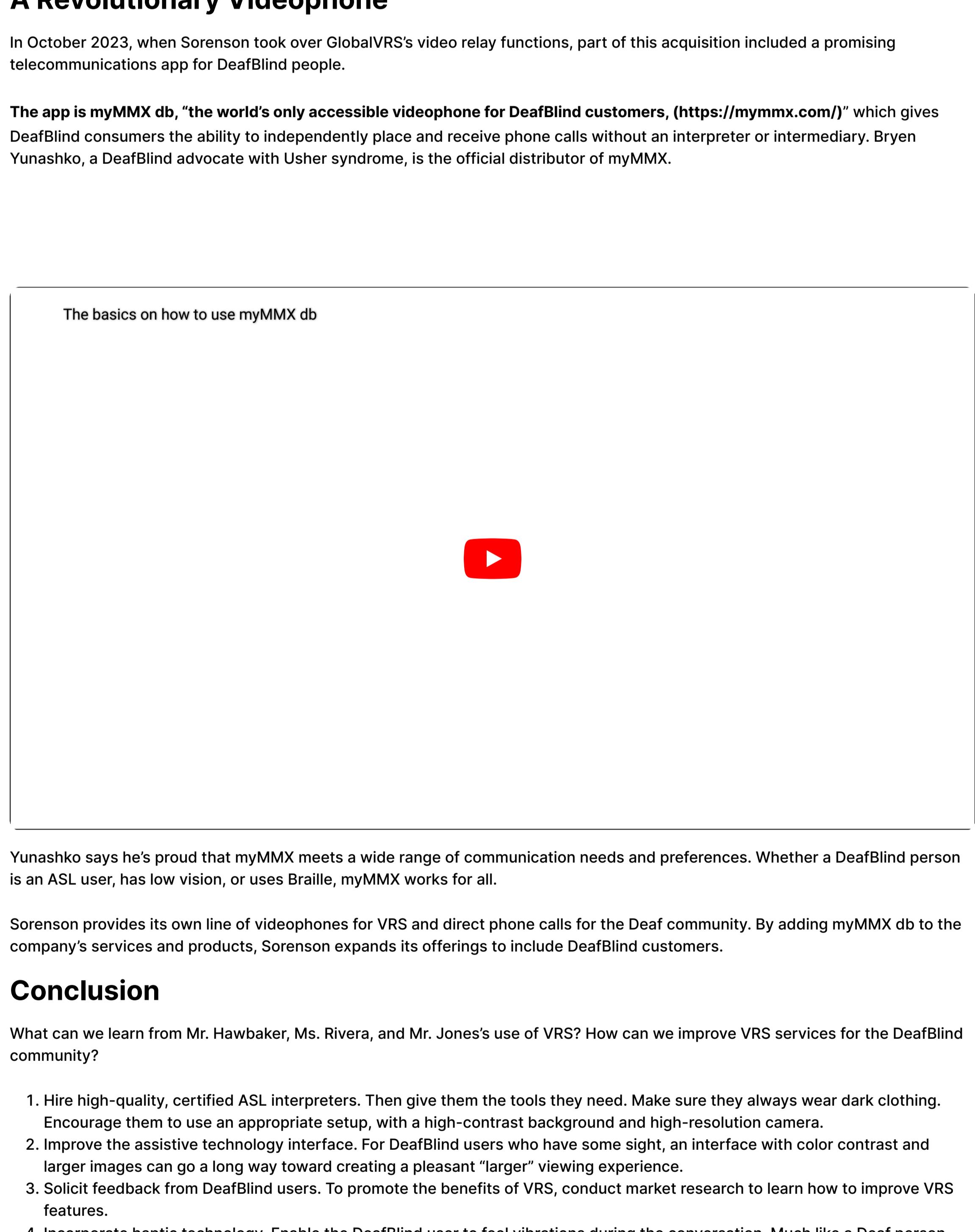
Like the Deaf and Blind communities, communication with DeafBlind people can require flexibility and creativity. This can stunt the development of strong social skills and the ability to interact with others who are not DeafBlind.

Some ways that poor social connections can affect a DeafBlind person's livelihood (https://academic.oup.com/dsdc/article/18/4/446/560048):

- Higher rates of anxiety and depression
- Avoiding people outside of their family
- Social isolation
- Low self-confidence
- Non-DeafBlind peers often overlook and ignore them

The desire for human connection and independence remains. DeafBlind people want to be involved in activities and be part of society, and also have relationships with their peers.

### Understanding the DeafBlind Community



It's important to remember that one DeafBlind person does not represent the entire DeafBlind community, just as one Deaf or Blind person does not represent their respective community. Each DeafBlind person has their own unique experience related to communication.

DeafBlind people usually have residual sight or hearing. It's rare to have total loss of both sensory disabilities. Both disabilities can occur at the same time, or separately, and the severity can differ from person to person. The severity of hearing and vision loss determines their communication and accessibility needs.

Want to know a DeafBlind person's specific communication needs? Ask them. (But first, ask them how they prefer to communicate. That's the best way to start a conversation.)

### Unique Needs of the DeafBlind Community

The DeafBlind community uses assistive technology in a way that intersects with the needs of both the Deaf and Blind communities. Let's look at the assistive technologies that both the Deaf and Blind communities use.

Assistive technology for Deaf people to make telephone calls:

- Internet Protocol Captioned Telephone Service (IP CTS) (https://sorenson.com/captioned-calls/captioncall/)
- Video Relay Service (VRS) (https://sorenson.com/vrs/)
- Instant messaging (IM)
- Text-to-911 (https://www.fcc.gov/consumers/guides/what-you-need-know-about-text-911)

Assistive technology for Blind people to make phone calls:

- Screen readers
- Magnification software
- Optical readers
- Captioned phones

For mobile:

- VoiceOver and Siri (iOS)
- TalkBack (Android)
- Google Assistant

A DeafBlind person may use a combination of these assistive technologies, but some, like Robert Hawbaker and Catarina Rivera, don't use VRS.

### DeafBlind Consumers Who Don't Use VRS

Robert Hawbaker, a work-from-home systems engineer who's been DeafBlind since birth due to Usher syndrome, says he doesn't use VRS but uses VRI (https://sorenson.com/blog/vrs/what-are-video-relay-service-and-video-remote-interpreting/) for in-person appointments. He has near-total deafness and cataract surgery mostly restored his eyesight in January 2023.

"If calling is a must, I use IP Relay," Mr. Hawbaker says. He doesn't use VRS as he's more English-based than ASL (https://www.fcc.gov/ip-relay). (For context, ASL is a visual language with its own grammar, vocabulary, and word order, a language that Deaf people created.)

"My original reason [for] not using VRS was, I knew exactly what I wanted to say in English," Hawbaker says. "Using ASL, sometimes there may be several ways to say a single ASL 'statement' in multiple English statements."

These days, Hawbaker doesn't use VRS because of his deafness and vision. The delays in receiving information from the ASL interpreter and the need to repeat himself make it difficult to use VRS (since he can't see everything the interpreter signs).

VRI, on the other hand, is easier to use because Mr. Hawbaker is in the same room as the doctor with whom he's communicating via a sign language interpreter over video. He feels comfortable asking the interpreter to repeat information when needed.



On the other hand, Catarina Rivera, a light-skinned Latinx woman with dark brown hair, "doesn't like to make and receive phone calls in ASL. Therefore, she does not use VRS. Instead, she relies on other free telecommunication tools to make and receive phone calls. She also does not use VRS because she has low vision, or uses Braille, and myMMX db for all."

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