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Practice Summary & Implementation
Guidance**

Virtual Support for Families of Children who are Deaf or Hard of Hearing (DHH) During the COVID-19 Pandemic

Supporting and empowering parents of Deaf/Hard of Hearing children in a virtual world.



Location

Arizona



Topic Area

Telehealth/Emergency Preparedness



Setting

Home-based



Population Focus

CYSHCN



NPM

NA



Date Added

July 2021

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Section 1: Practice Summary

PRACTICE DESCRIPTION

When the COVID 19 pandemic hit in March, with a statewide shut down and virtual only services, Arizona Hands & Voices (AZHV) quickly transformed their operations to provide families with one-to-one and group support from teachers of the Deaf and Hard of Hearing (DHH), Deaf mentors and DHH Guides by adapting their Guide By Your Side (GBYS) Program for a virtual setting. AZHV wanted to ensure that while we were no longer in person, we could still provide opportunities for families to continue to be supported, educated, and empowered in an unbiased manner on their journey raising their DHH children. Guides supported families with the use of new technology as they engaged in telehealth and online learning with their children and provided critical peer support and guidance to parents. For many parents of DHH children, their child may be the first DHH person they have interacted with. Connecting parents with parent and DHH adult guides provides critical support to these families. This support has been especially critical throughout the pandemic, as families were isolated and faced with new challenges in accessing care and support, and for families living in remote or rural communities.

CORE COMPONENTS & PRACTICE ACTIVITIES

The goal of virtual support is to create opportunities for families of children who are deaf/hard of hearing to be supported, educated, and empowered in an unbiased manner. Events were created to listen to and support parents as they shared their concerns and frustrations brought on by the COVID-19 shutdown. Topic focused events are developed upon assessments of family needs. Events include topics such as Audiology presentation on technology, Speech and Language Pathologist presenting on language development at home, mental health presentation, panels of DHH Adults and/or young adults and teens, as well as Literacy Family Fun hours (Storybeatz). These events also offer the ability to connect with other parents and DHH adults to share lived experience.

Core Components & Practice Activities

Core Component	Activities	Operational Details
Education/Support	What's Up Wednesday	<ul style="list-style-type: none">• At least once monthly, topic focused events held.• Guides determine topic based on current needs of families• Presenters secured as needed



		<ul style="list-style-type: none"> • American Sign Language interpreters (ASL), Spanish, and captions secured as needed. • Streamed live to Facebook and recorded for upload to YouTube
Education/Resources	Virtual Family Camp	<ul style="list-style-type: none"> • One day camp with various sessions for parents and children. • Presenters and participants secured to provide information and resources to families as well as share lived experiences. • Camp packages sent prior to event containing materials and resources relevant to the agenda created. • American Sign Language interpreters (ASL), Spanish, and captions secured
Literacy Development	Storybeatz	<ul style="list-style-type: none"> • Once monthly event led by Parent Guide includes storytime, music time and bubble time • Story is read while offering suggestions on placement, language development tips, and increased eye contact while fostering literacy skills. • Also included is music time and bubble time to aid in increasing vocabulary, improve literacy and numeracy, as well as sensory development and memory skills. • American Sign Language interpreters (ASL), Spanish, and captions secured as needed. • Streamed live to Facebook and recorded for upload to YouTube with permission of participants or advanced notice
Family Support	Guide By Your Side	<ul style="list-style-type: none"> • Unbiased support provided to families from Guides in a one-on-one capacity and/or group as needed. • Information and resources shared with families in a timely manner. • Guides ensure families are aware of virtual events and camp. • Technical support provided by Guides as needed to ensure full participation



HEALTH EQUITY

Arizona has significant areas of the state, both tribal lands and rural/remote areas where families have difficulty accessing quality services. COVID-19 has exacerbated those issues where not only are they coping with their usual barriers but now services are virtual and even less accessible. The populations impacted by this project are primarily those rural, remote, and tribal communities. These are the families with the most difficulty accessing services under the best of circumstances and would be entirely excluded without technology assistance.

Additionally, more than 90% of deaf and hard of hearing children are born to hearing parents. This makes services provided by AZHV and its partners critical for these families to receive knowledge and peer support. The Parent Guides are the main support for families in their quest to transition to telehealth services and are in regular contact with families to provide support and connect them to resources. They provide technical assistance as families navigate telehealth and emotional and educational peer support and are advocates for their families and communities. For many parents of DHH children, their child may be the first DHH person they meet. Connecting with Parent Guides parents with shared experiences and Guides provides critical support to these families. This support has been especially critical throughout the pandemic, as families were isolated and faced with new challenges in accessing care and support, and for families living in remote or rural communities. They are also central to quality improvement efforts in continually assessing the changing needs of the population and the extent to which our efforts are successful.

The virtual adaptation has allowed Spanish-speaking and Arabic-speaking families to have access to the bilingual Guides living elsewhere in the state, eliminating barriers of distance or language to receive support services. Additionally, AZHV ensures that American Sign Language (ASL) interpreting and live captions are available for virtual meetings as well as Spanish interpreters as needed, so families can fully participate in the programming and set an example for what accessibility and access should look like for children.

EVIDENCE OF EFFECTIVENESS

AZHV received 21 responses from 28 families that attended the virtual family camp. Of the 21 responses received, 95.2% of the families said they would attend a similar event again. When asked about the length of the camp 66.7% said the length was just right, while 33.3% stated it was too long. Adjustments to the length of a future camp will be taken into consideration.

Comments made included:

- “young adult panel gave me a better perspective, understanding, and hope...”
- “LOVED hearing from the deaf young adults!”
- “My son absolutely loved story time hour!”
- “really a great day!! thanks so much!!”
- “it was amazing!!!! thank so very much.”
- “FAAAAANNNNNNTASTIC! Cheryl (I think was her name?) did a PHENOMENAL job on the family fun time!”



Several more comments included to say, “amazing day”. When asked which session was their favorite 76.2% chose the Literacy/Family Fun. Due to this overwhelming response a monthly event titled “Storybeatz” in which a new book is read each month with the tips and suggestions to develop literacy skills with it was born. Also now occurring is a What’s Up Wednesday “Ask a DHH Guide” for parents to connect with DHH adults and discuss various topics. AZHV will continue to host at least once monthly “What’s Up Wednesday” events to ensure families in all areas of the state continue to have access to information and resources that may be pertinent to them.

Many of AZHV virtual events are held via zoom are recorded and/or streamed live to AZHV Facebook page. They are then uploaded to AZHV YouTube channel which allows for Guides to provide links of either YouTube or Facebook videos to families who may find the information beneficial.

Through Facebook Live videos such as What’s Up Wednesday “Stop CMV Arizona”, reached as many as 1,476 people with more than 887 views and over 300 engagements. Similarly, a “Stop CMV Arizona” was streamed in Spanish that reached 662 people with 387 video views and more than 100 engagements. AZHV will continue to utilize these social media platforms to reach families and continue sharing the links as needed.

Section 2: Implementation Guidance

STAKEHOLDER EMPOWERMENT & COLLABORATION

This project is a collaborative effort between the EAR Foundation of Arizona (EFAz), the Arizona State Schools for the Deaf and the Blind, (ASDB-Part C provider) and AZHV to help identify families and ensure that they have access to a variety of support mechanisms. These continued efforts have strengthened relationships between AZHV and ASDB in the solidarity and support provided to families. Joint collaborations for various events presented to families allowed families the space to feel safe and trust the support from multiple entities.

Not only are parents with lived experiences involved in the identification of issues, and the strategic planning, but they are also intrinsic to the solutions being offered including parent education and peer to peer support. Parent Guides have led the way in planning, adapting, and implementing programming throughout the pandemic, ensuring that parents with lived experience are co-creating the solutions. Parent Guides also connect with families regularly to ensure they understand their changing needs and are able to offer support and resources that are relevant and inform quality improvement efforts. Additionally, families were surveyed following the family camp to help Guides strengthen and continue virtual offerings in the future.

REPLICATION

Hands & Voices Guide By Your Side™ is a replicable family support program that embodies the mission and vision of Hands & Voices™, which is to provide unbiased support to families with



children who are deaf or hard of hearing. Guide By Your Side (GBYS) does this through specially trained parents of children who are deaf or hard of hearing. These parents work as “Guides” directly with families who have just learned of their child’s hearing condition, or who have older children and are in need of the unique support that comes from someone else who has walked this path him/herself and can share from direct experience and wisdom. GBYS programs can also include an option for Deaf/Hard of Hearing Guides (DHH Guides) who are deaf or hard of hearing adults and specially trained to provide support to families.

INTERNAL CAPACITY

These virtual events started with weekly zoom meetings that became “What’s Up Wednesday” with open agenda for families to join AZHV and the GBYS team to discuss their concerns and frustrations that emerged because of the COVID-19 shutdown. From these events the team listened and learned what the needs of the families were and began moving these events to topic focused to meet those needs. Other events such as the camp and monthly literacy event were born of those successful moments. Guides provide one on one support to families and take note of ongoing needs of families to determine resources and information to be provided. Potential presenters and panel participants are identified and invited as needed. Coordinator and Guides with technical experience run the zoom events while streaming live to Facebook and recording to upload to YouTube. This allows for those unable to attend at the time of events to continue to reap the benefits of the information presented by sharing links to the streaming and/or the YouTube recordings. Within our staff we have several bilingual Guides to include Arabic speaking, Spanish speaking, and fluency in ASL giving us the ability to reach families statewide utilizing the virtual platform.

PRACTICE TIMELINE

The Storybeatz literacy and What’s Up Wednesday events are one hour long while the family camp is a one-day event which can be adjusted to fit the agenda of presenters and activities. Individual and group support are dependent on the needs of the families.

LESSONS LEARNED

When we first began What’s Up Wednesday events, they were launched twice daily with one in the morning and one in the evening. After several weeks we eliminated the morning event as the evening tended to gain more engagement and participation. These events continued weekly until we noticed once again the decline in participation and determined that we would move to at least once monthly. Making these changes has allowed for better preparation and advanced marketing to get the info out to families of upcoming events so they can plan accordingly for participation.

We continuously looked for ways to ensure we were reaching as many families as possible and examined the streaming capabilities through zoom and realized the potential of the reach in this method. We educated ourselves on the logistics of streaming and later began recording to then be uploaded to our YouTube page. This created the opportunity for newly enrolled families or families that missed an event to receive a link from their Guide or explore our Facebook and YouTube page for events related to their needs.



Prior to camp, packages were sent in Spanish and English to families containing materials and resources needed for participation. Also included were instructions on how to setup and utilize devices for successful engagement and participation especially for those utilizing Spanish speaking interpreters and ASL interpreters. We learned that some families need verbal instructions with a walk through of setting up and understanding the logistics of connecting virtually. This is done by connecting with Guides to offer support and guidance. Future camp events will include a follow up call to those that register to go over any questions they may have for engaging on the day of event. Instructions are also provided at beginning of each event as needed for accessibility purposes.

NEXT STEPS

AZHV is committed to continue providing virtual support as it has eliminated the barrier of reaching families in the hard-to-reach areas of our state. We will also continue to seek funding and resources to provide these ongoing events as well as a virtual camp annually.

