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Severe Combined Immunodeficiency (SCID) Telehealth for American Indians and Alaska Natives

White Paper



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Abstract

The addition of severe combined immunodeficiency (SCID) to the national Recommended Uniform Screening Panel for newborns in 2010 has increased the number of infants diagnosed with and treated for SCID. This number includes a higher proportion of infants among the Athabascan-speaking American Indian and Alaska Native population. However, proper early diagnosis and treatment mean that more children with SCID require ongoing care in tribal areas far from SCID specialists. Telehealth may help bridge the gap between American Indian and Alaska Native SCID families and their SCID providers. This white paper examines the existing landscape of telehealth use among American Indian and Alaska Native populations, identifies lessons learned from existing programs, and explores opportunities to use these lessons to address the needs of American Indian and Alaska Native children born with SCID. We found key factors affecting the implementation of telehealth at the patient, organizational, and environmental levels that are specific to the needs of American Indian and Alaska Native children born with SCID and their families. Considering these factors affecting the implementation of telehealth, we propose opportunities for improving telehealth practices (e.g., telehealth procedures, staffing for auxiliary and supportive services, and access to telehealth devices) and policies (e.g., access and payment) to better support these patients and their families.

Introduction

Severe combined immunodeficiency (SCID) is a rare disorder, with only about 76 children (1 in 58,000 live births) diagnosed each year in the United States (Immune Deficiency Foundation, n.d.). However, the Athabascan-speaking American Indian and Alaska Native population, including the Navajo and Apache, has a higher incidence than the general U.S. population (1 in 2,000 live births) (Uong & Jain, 2014). Beginning in 2010, SCID was added to the national Recommended Uniform Screening Panel for newborns, which has aided in early identification to support management of SCID. This is important because if not accurately diagnosed and treated, SCID leaves infants at high risk of life-threatening infections because they have few or no immune cells (Kwan et al., 2014). Because SCID is such a rare disorder, few providers are experts in the disease, and they are often located a significant distance from where American Indian and Alaska Native populations live. Treatment for SCID requires an interdisciplinary care team with members who may not be co-located. Telehealth may help bridge the gap between American Indian and Alaska Native SCID families and their SCID providers. This white paper will detail the existing landscape of telehealth use among American Indian and Alaska Native populations, identify lessons learned from existing programs, and explore opportunities to use these lessons to address the needs of children born with SCID.

Health Disparities Among American Indian and Alaska Native Populations

Since the first contact of non-native populations with American Indian and Alaska Native populations in the United States, disparities have existed between the groups in their health, social determinants of health (SDOH), and access to health care. American Indians and Alaska Natives in the U.S. Indian Health Service (IHS) area are more likely than people of all other races in the United States to die from common chronic conditions such as diabetes or liver disease (IHS, 2019). American Indians and Alaska Natives also have an increased risk of experiencing or witnessing violent or traumatic events, which has resulted in high-risk health behaviors including alcohol and drug use and suicide attempts among American Indian and Alaska Native youth (Gone & Trimble, 2012; Sarche & Spicer, 2008).

American Indian and Alaska Native Definition

It is important to note that the use of the term "American Indian and Alaska Native" represents a diverse set of over 500 federally recognized tribes in the United States. Each tribe has its own unique history and culture. However, for most data collection in the United States, these tribes are combined under the term "American Indian and Alaska Native." Therefore, we use this term throughout this paper, while also recognizing specific tribal information where possible.

Many American Indians and Alaska Natives experience disparities in SDOH. More than a quarter of American Indian and Alaska Native children and families live in poverty, which is

more than double the rate in the U.S. general population (Sarche & Spicer, 2008). A study by the U.S. Department of Housing and Urban Development of American Indian and Alaska Native housing needs found that physical housing problems (such as lack of electricity or plumbing or failing roofing) for households in tribal areas remain much more severe than those for households in other areas of the United States (Pindus et al., 2017).

Transportation problems were indicated as a substantial reason for unmet medical or dental needs (Flores & Tomany-Korman, 2008). This lack of resources impacts the ability of American Indians and Alaska Natives to obtain care and maintain their health.

Further compounding these disparities are the challenges American Indians and Alaska Natives face in accessing health care to meet their needs. According to data from the National Survey of Children’s Health, American Indian and Alaska Native children had the highest adjusted odds of any racial or ethnic group of children to lack health and dental insurance. The survey also indicated that American Indian and Alaska Native children had four times the odds of white children of having no usual source of medical care (Flores & Tomany-Korman, 2008). Although the disparities affecting American Indian and Alaska Native populations are overwhelming, advances in health technology, including the rapid expansion of telehealth technologies, offer opportunities to improve health and access to health care for this population.

Telehealth as an Opportunity to Address Disparities

Telehealth uses technology to promote communication. Telehealth is used for direct patient care and provider-to-provider communication. Direct patient care can be technology enabled when providers and patients or caregivers are not able to meet in person, including in situations such as COVID-19 closures and lack of available providers in a specific area. Telehealth is also used for consultations between providers, such as a specialist providing information to a family physician.

Telehealth Definition

For the purposes of this paper, the term “telehealth” is being used to encompass multiple modes of technology-enabled communication about health, including two-way communications between providers or between patients and providers, the use of remote patient monitoring devices, and the use of mobile health technologies.

The four basic modes of telehealth, as defined by the Office of the Assistant Secretary for Planning and Evaluation in 2016, are shown in **Table 1**. Telehealth encompasses several types of care including speaking with a doctor over live video or phone, direct communication between patients and providers, direct electronic communication between providers, and the use of medical devices to transmit health information.

Table 1. Modes of Telehealth

Mode	Description
Live Video (Synchronous)	Live, two-way interaction between a person (patient, caregiver, or provider) and a provider using audiovisual telecommunication technology. For example, a patient having a video visit with their primary care provider to discuss an infection. In this example, the patient and the provider are meeting with each other at the same time, often referred to as "live" or "synchronous."
Store and Forward (Asynchronous)	Transmission of videos and digital images such as X-rays and photos through a secure electronic communication system. For example, a radiologist sending their interpretation of a patient's X-ray results to the patient's primary care physician. Because of the lag, or delay, between the time an image is sent and when it is interpreted, store and forward is often referred to as "asynchronous."
Remote Patient Monitoring	Collection of personal health and medical data from an individual in one location, then transmitting those data to a provider in a different location. For example, a patient with a continuous glucose monitor that sends blood sugar readings to their endocrinologist.
Mobile Health	The use of mobile technologies such as smartphone apps and texting to foster health and well-being. For example, programs that send targeted text messages aimed at encouraging healthy behaviors, send alerts about disease outbreaks, or remind patients to adhere to specific care regimens.

Source: Office of the Assistant Secretary for Planning and Evaluation, 2016.

Telehealth was first used as a method to deliver care to American Indian and Alaska Native communities in the 1970s (Carroll & Horton, 2013). The use of telehealth has been shown to address several barriers faced by American Indian and Alaska Native communities that result in disparities. Distance between American Indian and Alaska Native communities and health care facilities, particularly those providing specialty care, are often vast, resulting in costs to patients in the forms of travel and time away from employment (Kruse et al., 2016). Telehealth use can help reduce these costs and increase access to care by eliminating the need for extensive travel to receive health care. The implementation of telehealth has also been shown to improve the health outcomes of American Indian and Alaska Native populations by increasing access to specialist care and educational and support services (Kruse et al., 2016). The use of telehealth has reduced long wait times to receive these types of supports (Weissman et al., 2018).

Methods

To understand the potential for the use of telehealth to support American Indian and Alaska Native SCID populations, two methods were used:

1. A review of peer-reviewed and gray literature was conducted to identify articles related to telehealth, American Indian and Alaska Native populations, and SCID.

2. Semi-structured interviews were conducted with providers and caregivers of American Indian and Alaska Native SCID patients who had used telehealth to support delivery of services.

During the semi-structured interviews, feedback was obtained about interviewees' use of telehealth and any changes due to the COVID-19 public health emergency (PHE). The identified full-text articles and interview transcripts were reviewed by subject matter experts, and relevant information about the telehealth implementation barriers and facilitators was extracted. The findings of this analysis are presented in the Results section.

Results

Examples of Telehealth Use in American Indian and Alaska Native Populations

Telehealth has been used in American Indian and Alaska Native populations to address acute care and chronic disease management. Over the past 40 years, there are several examples of the use of telehealth with this population. In this section, we will highlight three recent examples of these programs:

- **Chronic disease management.** In 2011, the Care Beyond Walls and Wires project began delivery of telehealth services to individuals in remote areas, including American Indians and Alaska Natives suffering from heart failure. Patients were given equipment to remotely monitor their condition and access to smartphones to interact with their care team. Patients showed decreases in hospitalization and health care utilization related to the use of telehealth (Riley et al., 2015).
- **Cancer.** In 2006, the Native People for Cancer Control Telehealth Network was launched to provide support groups, educational presentations, case conferences, and telepsychiatry to clinical sites serving Washington and Alaska tribal populations (Doorenbos et al., 2011). Participants in the support groups indicated high levels of satisfaction with telehealth facilitation that allowed them to connect with other patients experiencing the same issues regardless of distance (Doorenbos et al., 2010).
- **Ophthalmology.** In 2009, Alberta, Canada, opened a set of community tele-ophthalmology clinics to provide eye-screening services for Aboriginal Canadians with diabetes. Opening services in community locations reduced financial and geographic barriers, and specific social and cultural concerns were addressed by hiring Aboriginal nurses and incorporating traditional ceremonies at the locations (Arora et al., 2013).

American Indian and Alaska Native–focused telehealth programs can provide us with a better understanding of the factors affecting the implementation and use of telehealth to serve these populations in the future. In addition, interviews with patients, caregivers, and providers about the use of telehealth during the COVID-19 PHE to treat American Indian and Alaska Native SCID patients can highlight additional implementation factors. This section identifies factors affecting implementation and use of telehealth with American Indian and Alaska Native populations at the patient, organizational, and environmental levels.

Factors Influencing Telehealth Adoption in Tribal Communities

Patient-Level Factors

Access to Reliable Devices and Broadband

Telehealth visits typically require access to telecommunication-enabled devices and a broadband network. Individuals living on reservations or in rural areas may have limited access to telecommunication-enabled devices such as smartphones, tablets, or computers. Additionally, some tribal individuals may live in areas without broadband service or with inconsistent service. Lack of access to devices or internet can serve as a barrier to telehealth for a patient.

Access to Reliable Devices and Broadband

"I mean, tele-health is great, but on the reservation, it is hard to get the access to it for families that live in rural areas and having to drive. Some families don't even have vehicles. So it's really tough for them to get around."

—SCID Caregiver

In addition, there may not be access to technical support. During telehealth visits, various technical glitches may arise. Common glitches include insufficient audio input or output and freezing or unclear videos. Glitches can arise because of problems with the device itself or a poor internet connection. Glitches may cause frustration for patients and providers alike and may negatively affect their telehealth experience (Patrick-Miller et al., 2015).

Digital Literacy

For some individuals, telecommunication devices may not be part of everyday life, and the devices used for telehealth may be unfamiliar. As a result, these individuals may have more trouble participating in telehealth compared with those who use these devices regularly. Discomfort with technology may make a patient less likely to agree to telehealth services in lieu of in-person care. If patients do participate in telehealth, their experience may be affected due to technology use challenges (Brooks et al., 2012). Challenges with technology may also exacerbate existing communication barriers for telehealth patients.

Some individuals may have difficulty reading text on a screen or experience language barriers when communicating with their provider via telehealth. Having access to information in written and spoken formats with the help of an interpreter or native-language provider can improve the patient experience (Arora et al., 2013). Telehealth programs may also rely on email communication with patients for tasks like scheduling appointments or sharing laboratory results. Patients who do not normally use email may have difficulty communicating with their provider and getting the information they need to receive care virtually (Doorenbos et al., 2011).

Patient Preferences

As with any population, some American Indian and Alaska Native individuals may prefer in-person treatment to telehealth (Doorenbos et al., 2011). Patients and caregivers may feel they cannot form a personal connection with their provider via telecommunication. Additionally, patients may feel uneasy about their care if their provider cannot perform visual or physical examinations in person (Hiratsuka et al., 2013). As a result, patients and providers who prefer in-person care may have more difficulty forming a patient-provider relationship when receiving care virtually.

Patient Preferences

"I know I prefer one room doctor. That way I feel more comfortable having my grandson being examined versus being a Zoom and telehealth call."

—SCID Caregiver

Geography and Access to Transportation

Individuals in tribal communities may need to travel long distances to see a health care provider in person. This is particularly true for specialists with experience with rare diseases such as SCID. Having access to health care services via telehealth from their home or at a nearby location, such as a community health center, may increase patients' likelihood of seeking care and reduce missed appointments (Arora et al., 2013). For patients receiving telehealth from a community health center or other local facility with internet service, the distance from their home to the facility is a crucial factor. If patients must travel a long distance or have limited access to transportation, they may be less likely to participate in telehealth, even if the local facility is more convenient than a larger medical center (Arora et al., 2013).

Geography and Access to Transportation

"So telehealth has really like opened doors to let them see them without having to like fly him emergency over there. Oh, we need to lay eyes on him right now. You know, it's been a huge help."

—SCID Caregiver

Trust and Access to Culturally Competent Providers and Resources

Some American Indian and Alaska Native individuals may lack trust in non-tribal institutions, such as health care, because of past harm or lack of familiarity (Arora et al., 2013). Mistrust of non-tribal medical providers may make a patient less likely to participate in telehealth or more likely to have negative experiences. Medical care is best delivered when the provider is familiar with and responsive to the patient's cultural practices and beliefs. American Indian and Alaska Native individuals may be more likely to attend telehealth appointments if they have access to a culturally competent provider (Arora et al., 2013). Patients may feel that they should be able to discuss their needs or concerns with their provider without the constraints of

Trust and Access to Culturally Competent Providers and Resources

"For the Native American populations, I encountered by telehealth, I know them already. I've met them before. If I were to be talking to someone new, I don't know whether that would be a problem."

—SCID Provider

time. Having ample time allocated for telehealth visits can ensure that the patient's cultural practices are fully considered and that they can reach a mutual understanding of their care with the provider. The ability to share clear, thorough verbal communication is critical in telehealth because non-verbal cues such as body language may be more difficult to perceive virtually (Hiratsuka et al., 2013; Mahon, 2020). Additional time may also be helpful to address unexpected technical issues if they arise. In addition to medical care, American Indian and Alaska Native individuals receiving telehealth may benefit from support groups with other tribal community members undergoing similar treatment (Doorenbos et al., 2010).

Input from Stakeholders on SCID-Specific Factors

During the COVID-19 PHE, many services were provided via telehealth to American Indian and Alaska Native SCID patients across conditions, including SCID. During interviews with SCID providers and caregivers, similar factors affecting implementation and use of telehealth were identified. As in the literature, they reported technical glitches during telehealth visits and had questions about the process of reconnecting to complete visits. Providers and caregivers also noted concerns about the impact of not being in person on the quality of care provided. Specific examples given were the lack of ability to adequately evaluate rashes over video, assess dental health, or measure patients' weight and height.

The SCID providers and caregivers had previously established in-person relationships before the use of telehealth, which limited some of the concerns noted in the literature about a lack of trust between patients/caregivers and providers and relationship building. The SCID providers also had considerable experience working with the American Indian and Alaska Native SCID population, including annual visits to the reservation each summer before the COVID-19 PHE. With respect to culturally competent care, providers and caregivers noted a lack of broad discussion of these considerations. Because of the COVID-19 PHE and lack of access to other tribal members, there were also limited opportunities to include tribal traditions and ceremonies in medical care that had an in-person component.

Organizational-Level Factors

In addition to factors that any telehealth program may need to consider, many factors may be unique when providing telehealth care for distinct populations, such as American Indians, Alaska Natives, or SCID patients and caregivers, that will also need to be addressed. This section describes organizational factors that are pertinent to implementing telehealth programs in general and factors that may be unique for special populations.

Organizational Costs and Benefits

Costs to start or expand a telehealth program vary based on the specific telehealth services provided. Startup cost examples include facility costs, such as construction or renovation of the space that will be used for telehealth visits, purchasing devices, and upgrading internet connectivity. These costs may serve as barriers to entry for practices when considering telehealth. Recurring costs include staffing and human resources costs and technology costs such as software licensing and annual software upgrades.

Identifying the patient population and payer mix can help when identifying potential financial benefits. For example, those who receive care through IHS may have different telehealth benefits than those who have Medicaid or private insurance as primary coverage. Other organizational benefits can include a reduction in patients who are lost to follow-up, an increase in the number of appointments, and reduced travel time for providers. In addition, there may be workforce development and staff mix opportunities.

Telehealth Program Costs
Facility costs (Mateo et al., 2019)
▪ Construction, renovation, or repair of space that will be used for telehealth visits
▪ Utilities
Staffing costs
▪ Salaries
Equipment costs
▪ Furniture and fixtures
Technology costs
▪ Computers, cameras, phone service, internet, and videoconferencing equipment
▪ Software licensing and yearly upgrades (Rappaport et al., 2018)

Strategy

As health care providers look for opportunities to address disparities in access to quality health care for American Indian and Alaska Native populations, telehealth can play a key role in their strategy. Revisions may need to be made to existing strategic plans for health care providers treating American Indian and Alaska Native populations that identify opportunities to enhance and improve service delivery using telehealth. Facilities may select virtual services based on a select patient population, such as tribal populations, those with rare diseases such as SCID, or those who have geographic barriers to care. Considerations in strategic planning include the overall mission; revenue; and provider, patient, and family satisfaction (Hays et al., 2014). A strategic plan can also help prioritize resource allocation for efforts such as telehealth program development. Other factors to include in a strategic plan will be unique to the goals and objectives of the facility and the patient population being served.

Partnerships

Rural community-based health facilities provide an opportunity for American Indian and Alaska Native patients to receive health care in their communities, but they may lack specialty treatment resources or technology. For that reason, many rural community-based health facilities have benefited from being part of a larger telehealth network or having a partnership with a larger health system. Partnering with telehealth networks such as Project

ECHO could provide an opportunity for provider-to-provider education on the treatment of conditions requiring specialty training or care. Partnering with a larger health system may allow provision of direct specialty services to patients over telehealth or assistance to rural community-based partners in telehealth program development, implementation, and monitoring activities. Partnering with and receiving support from an existing telehealth network and health system partners increase the ability of rural community-based health facilities to serve patients, such as those with SCID, who require specialized expertise (Morenz et al., 2019).

Telehealth Champions

When beginning or expanding a telehealth program, it will be beneficial to have telehealth champions who will earnestly promote and support the program.

Clinical and administrative champions help facilitate buy-in among facility staff. An administrative champion may be someone in a leadership position, such as SCID specialist or SCID provider, who can instill confidence in a specialty program. Champions

garner excitement among providers, set expectations for the benefits of telehealth for providers and patients, and implement continuous improvements to the program.

Administrative champions may also be able to make decisions on allocating funding to support a SCID telehealth program. The clinical champion can garner provider buy-in, communicate goals with staff, and help counter resistance to change (Brooks et al., 2012).

This staff member may have a special interest in SCID patients or may be enthusiastic about increasing access to services and providers for the SCID population using telehealth.

Administrative and clinical telehealth champions can support the telehealth program throughout the process of planning, implementation, and continuous improvement.

Telehealth Champions

“Zoom, you know, you can still get a lot accomplished, and you can still interact and answer questions. And I haven’t really seen any deterioration in our management or in our ability to make assessments or that it’s somehow adversely affected.”

—SCID Provider

Staffing Considerations

Identifying key staff and defining roles and responsibilities can ensure that all staff understand their contribution to the telehealth program. This is especially important because on-site staff will work closely with off-site providers to ensure that encounters are safe and productive for the tribal community.

When coordinating services with off-site providers, the program may want to establish an agreement regarding resources that each site may contribute to the program or the responsibilities of each site. For example, the on-site health center staff may schedule SCID patients, whereas the off-site provider may contribute telehealth equipment to the program.

Costs related to staffing structure may vary based on the program's needs. A SCID telehealth program may need personnel with differing credentials or experience, such as nurses, physicians, or medical assistants, who specialize in SCID care or treatment. Furthermore, contracts or job-specific responsibilities need to be taken into cost considerations. Special assignments or duties, such as caring for SCID patients or emergency assignments on short notice, may command higher rates.

To ensure successful telehealth encounters, staff should undergo proper training that covers topics unique to providing telehealth for tribal communities or rare conditions, such as SCID. Telehealth is heavily dependent on technology, and technical issues may cause complications during an encounter. Having technical support staff on standby during encounters can reduce the burden of technical issues, should they arise. Key components of staff training should include technology-specific challenges such as how to access the technology and how to navigate issues that may arise during the use of the technology such as inability to connect, audiovisual disruptions, or disconnection during service. In addition, establishing protocols for using telephone communication as a backup plan can mitigate the effects of technical issues (Doorenbos et al., 2011; Goss et al., 2017).

Culturally Competent Providers and Staff

Having culturally competent providers and staff is essential. One effective way of addressing cultural competency among providers is to actively recruit providers or staff who are members of the community being served. Seeing members of their community represented when they seek care can provide patients with a sense of trust. These providers and staff are also uniquely familiar with the local beliefs, traditions, and language of the patients they serve and can share their knowledge of how to incorporate these into the delivery of care. This is especially important for tribal communities where mistrust in the health care system

Staffing Considerations

- Determine what on- and off-site support is needed to carry out telehealth services (Swift et al., 2016).
- Identify costs related to staffing structure.
- Outline responsibilities in a way that is understandable to staff (can be incorporated into a training manual or existing policies and procedures).
- Create a reporting structure for each role if different from what already exists (Woods et al., 2019).
- Identify any potential workforce gaps (e.g., number of staff, technical expertise).

may result from historical trauma. If recruiting community members is not possible, then providing training for providers and staff can help offer culturally competent care (Arora et al., 2013; Brooks et al., 2013; Goss et al., 2017). For in-person care, local community clinics are better positioned to provide culturally competent care by accessing the providers and staff in their community. However, by using telehealth, larger urban hospitals providing specialty care may be able to partner with local community clinics for provider-to-provider consultation on culturally competent care for shared patients, ensuring that patients' beliefs, traditions, and language can be respected in their care plan.

Physical Space Considerations

The physical space in which the patient and provider are located can establish the patient's confidence and enhance the quality of the visit (Heath, 2020). There are several privacy and confidentiality considerations to take when providing telehealth services. Many facilities are tight on space; thus, multiple people share an office. If it is not possible to change infrastructure, headphones can be used during the telehealth appointment to preserve confidentiality (Kaftarian, 2019). Lighting can also affect the quality of the telehealth visit. Lighting in the physical space should be sufficient but not produce a glare or make it challenging to see (Heath, 2020; James, 2016). Facilities may not have access to light sources that reduce shadows and allow for natural clarity. Reducing the amount of background noise can also increase the quality of the visit. Although a room might be shared with other patients or providers, background noise should be limited (Heath, 2020), so all parties can be adequately heard. This is especially important for tribal communities with a rich oral tradition. Noise reductions in microphones or headphones may be necessary to ensure clear audio and conversations. One operational solution may be to stagger scheduling of telehealth appointments to reduce noise. The space needs to allow sufficient room for any necessary telehealth equipment while also allowing the patient to sit comfortably at an appropriate distance from the monitor or camera (Maunder et al., 2018). In rural or tribal areas, there may be a need for interpreters or inclusion of tribal elders. If in-person services are required, ensure sufficient space or workstations for the interpreter and the patient.

Physical Space Considerations

- Privacy and confidentiality
- Quality lighting
- Background noise
- Sufficient size
- Interpreters

Physical Space Considerations

"If somebody is worried about a kid's rash, well, that's really hard to take a look at in a tele-health visit. So I often end up saying, look take the kids to the window after we're finished here in that light of day, take the best picture you can on your iPhone and then email it because when they try to hold up something kind of a jiggly iPad, it's just in the dark, you know."
—SCID Provider

Workflow Changes

Telehealth is a different mode of care that involves changes to administrative or clinical workflows that are new to providers and that include a variety of stakeholders. Items to

update include scheduling, workflows, and contingency plans. Creating a scheduling framework can include developing a regular schedule of clinical services, such as block scheduling that reserves chunks of time for unforeseen circumstances (Batastini et al., 2020). Designating staff to oversee scheduling and coordination and using a common scheduling system at both facilities involved in care can reduce administrative burden by updating both schedules simultaneously. Details of the workflow will have to be adapted based on the needs of the provider site and the health facility. **Table 2** lists a few basic workflow elements that can be considered.

Table 2. Administrative and Clinical Workflow Elements

Administrative Workflow Elements	Clinical Workflow Elements
<ul style="list-style-type: none"> ▪ Creating procedures for initiating telehealth referrals ▪ Communicating new referrals with the provider site ▪ Scheduling the telehealth appointment ▪ Determining how providers will access the information needed before each telehealth visit ▪ Determining how to support patients with disabilities such as hearing loss or visual impairments ▪ Determining how to support caregivers who are assisting patients during the telehealth visit ▪ Ensuring access to technical support at the patient and provider sites 	<ul style="list-style-type: none"> ▪ Connecting features of the telehealth devices ▪ Deciding where to place the camera, screen, and speakers or headphones ▪ Recording encounters, if applicable ▪ Conducting operational checks with the provider and interpreter (if applicable) before an encounter ▪ Verifying that patients' equipment is working ▪ Asking whether patients have the privacy they need ▪ Keeping the visit as much like an in-person visit as possible using friendly body language and eye contact

Source: Health Resources and Services Administration, n.d.; Mateo et al., 2019.

Input from Stakeholders on SCID-Specific Factors

During interviews with SCID providers and caregivers, a handful of organizational factors affecting implementation and use of telehealth were identified, which complemented what was found in the literature. Physical space was most frequently noted as a challenge by providers and caregivers. Managing the physical space and environment of providers in their offices and caregivers and patients during telehealth visits was especially a challenge because many SCID patients participating in telehealth are infants, toddlers, or young children. This led to issues with background noise and other distractions. In addition, lighting was a challenge when trying to have young children be still enough to assess conditions such as rashes. However, providers also mentioned that they appreciated being able to see the home environment of patients and their families and to see the number of people in the home.

Resources for auxiliary and supportive services were also noted as organizational factors affecting telehealth use by SCID providers and caregivers. SCID providers and caregivers noted that the community health center on the Navajo reservation was a source of support for issues that could not be resolved by telehealth alone, including blood draws or in-person examinations. Caregivers also identified a need to access auxiliary and supportive services via telehealth when dealing with a chronic condition such as SCID. Caregivers noted that telehealth was more difficult to access for issues outside of the immediate scope of dealing with the patient’s SCID diagnosis. They identified a need for auxiliary and supportive services to be added to telehealth including mental health supports or social work supports for the patient, caregiver, and family.

Environment-Level Factors

Broadband Access

Access to broadband is a precursor to telehealth. Limited access to broadband is an issue facing many who need to access telehealth services. In the Federal Communications Commission’s (FCC’s) most recent Broadband Deployment Report, it was estimated that over 18 million Americans do not have access to a broadband network (FCC, 2020). This lack of access is more pronounced in tribal reservation communities. Reservation communities have inadequate structure or resources for regular internet or telephone; as of 2018, between 58% and 88% of people living in the Navajo Nation reported lack of access to broadband (Kruse et al., 2016). Individuals living in areas without broadband may face significant barriers to receiving care via telehealth.

Broadband Access

“So obviously we have to have internet for school and telehealth, but it is really hard when that’s a hundred dollars bill a month that I definitely don’t have all the time. So that’s definitely hard.”
—SCID Caregiver

Telehealth Laws and Regulations

Telehealth laws and regulations related to licensing, credentialing, and reimbursement also affect the availability of telehealth services in tribal communities. The ability to practice medicine in person or remotely is based on the state in which a provider is licensed and credentialed. For rare conditions, patients may need to receive care from specialty providers located in a different state. For example, Navajo SCID patients and caregivers may reside on the Navajo reservation in Arizona, New Mexico, and Utah, whereas the closest SCID specialists are in California. For a provider in one state to care for a patient via telehealth in another state, the provider would need to obtain a license and credential in the other state or provide services only to patients living in states that are part of the Interstate Medical Licensure Compact (<https://www.imlcc.org/>). These requirements can limit the ability of providers to interact with patients and caregivers via telehealth (Office of the National Coordinator for Health Information Technology, n.d.).

In addition, parity in payment for telehealth differs by state. In some states, providers of telehealth services must be reimbursed at the same rate as providers of in-person services. In states where this is not the case, providers may be less inclined to offer telehealth services if they do not receive sufficient reimbursement (Hays et al., 2014). As a result, patients may have limited access to telehealth depending on their insurance coverage.

Input from Stakeholders on SCID-Specific Factors

SCID providers and caregivers echoed the concerns raised in the literature about limited connectivity on tribal reservations. SCID caregivers noted that during COVID-19, some broadband access points were added on tribal reservations at community centers to provide access for students accessing school online. However, accessing those resources still required transportation to get to the broadband access points. In addition, the points did not necessarily offer privacy sufficient for a health care visit. Other caregivers who reside in areas where broadband is available struggled with the costs to obtain and maintain access to support telehealth and school for their children. It is also possible that we may have missed issues experienced by American Indian and Alaska Native SCID patients and caregivers residing in areas with extremely limited connectivity because we were unable to gain a larger sample of caregivers. Alternative methods of data collection may need to be considered in the future to capture the perspectives of tribal populations living on reservations.

Currently, all newborns in the United States are screened for SCID. For families whose child is diagnosed with SCID, services like genetic counseling, childcare, and social services are important as they pursue treatment. However, there is a general shortage of services, which is exacerbated in rural communities. Environmental factors are even more pronounced when working with American Indian and Alaska Native SCID patients and caregivers. Consistent with the literature, providers and caregivers noted that housing conditions (including proper ventilation and running water) are especially critical in reducing the risk of infection. In some cases, SCID patients may not be able to return home after treatments, such as bone marrow transplants, that involve ongoing immune system impacts until appropriate housing is obtained.

Considerations for Practice and Policy

Based on the review of the landscape of telehealth use among American Indian and Alaska Native populations and feedback from SCID providers and caregivers, many opportunities exist to use telehealth to address the needs of American Indian and Alaska Native children born with SCID and their families. The benefits of telehealth are predicated on addressing patient- and organizational-level considerations and developing practices and policies to better support these patients and families. What follows is a summary of considerations for telehealth practice and policy to support American Indian and Alaska Native SCID families.

Considerations for Practice

Telehealth Procedures

As noted in the literature and in interviews with SCID providers and caregivers, telehealth is an option that addresses geographic and transportation barriers due to the distance between providers with expertise in SCID and American Indian and Alaska Native SCID patients. However, SCID providers and caregivers clearly identified that the use of telehealth comes with challenges that need to be addressed related to the use of technology by patients and caregivers from their homes. These challenges include technology-specific issues such as how to access the technology and how to navigate problems that may arise during the use of the technology such as inability to connect, audiovisual disruptions, or disconnection during service. Some of these challenges are related to preparing the physical space to minimize distractions, ensure privacy and confidentiality, and provide appropriate lighting to support the visit. These issues require developing new or modifying existing procedures that address these telehealth-specific issues.

When developing telehealth procedures, providers should also look for opportunities to incorporate discussions of cultural considerations. Identifying and addressing cultural considerations that may affect the treatment and well-being of patients and caregivers was infrequently addressed in telehealth and in-person service delivery according to interviews with SCID providers and caregivers. Developing new or modifying existing telehealth practices and procedures provides an opportunity to specifically address when and how to incorporate a discussion with patients and caregivers about their cultural needs. In many cases, local providers can also be an important part of addressing cultural needs because they are embedded within the community.

Staffing for Auxiliary and Supportive Services

As providers consider the needs of patients and their caregivers, they should consider whether they need additional auxiliary and supportive services such as mental health, social work, or social service supports. Caregiving has been shown to result in chronic stress that may also affect the caregiver's physical health (Schulz & Sherwood, 2008). Siblings may also have mental health needs associated with having a chronically ill sibling that need to be addressed (Sharpe & Rossiter, 2002). These mental health needs can be addressed by mental health services provided via telehealth, which has consistently been shown to be as effective and comparable with in-person care. During telehealth visits, providers may be able to interact with family members whom they may not see during an in-person visit. Providers should consider using this opportunity to screen caregivers and siblings for mental health needs and be prepared to make referrals to appropriate mental health telehealth services (Hilty et al., 2013). Often affecting the mental health needs of American Indian and Alaska Native SCID families is their need for financial and housing social service supports. American Indian and Alaska Native SCID caregivers stated that these supports were readily

available and accessible during in-person treatment, but once they returned home, those supports were not always readily available. Telehealth may provide an opportunity for the social workers supporting American Indian and Alaska Native SCID families to continue this support once they return home.

Access to the Internet and Internet-Enabled Devices

Providers and caregivers of SCID patients noted challenges when using technology to evaluate patients. Specific examples given were the lack of ability to adequately evaluate rashes over video, assess dental health, or measure patients' weight and height, particularly when bandwidth was poor. However, technologies exist that could better support evaluation of these issues via telehealth. For example, evaluating rashes and assessing dental health may be supported by higher-resolution cell phone cameras. Weight may be addressed by providing scales that can transmit data directly to providers, whereas height may be addressed using a non-technical solution such as a tape measure. Home-use blood pressure cuffs and wearable devices are available to supplement telehealth. Providers should consider whether a model like the Care Beyond Walls and Wires project, which provided backpacks containing supplies to monitor heart failure, may be an option for SCID patients and caregivers.

Considerations for Policy

Access to Care

Community health centers can be a tool for providing high-quality telehealth care to tribal patients. Prioritizing recruitment of tribal providers at community health centers would have positive benefits for the overall telehealth program. Additionally, establishing educational programs for local and native individuals to complete medical training can promote a culturally competent clinical workforce.

SCID is a rare disease, and few providers specialize in SCID treatment. These providers often practice at larger urban hospitals that are located far from American Indian and Alaska Native communities. Although some treatments, such as hematopoietic stem cell transplants, can only be done in person, follow-up and monitoring care may be possible via telehealth. For this to be successful and scalable, standardized protocols and training programs for remote SCID treatment may be necessary. Urban hospitals may also benefit from strengthening partnerships with providers proximal to the community to facilitate disease monitoring, such as routine blood draws for white blood cell counts. Although these partnerships exist to some extent, local providers often lack sufficient technology to run tests like white blood cell counts and must express ship blood samples to a larger facility in the area. This process can be expensive and increase the risk of compromising the sample before analysis. Collaboration with SCID specialists at distant urban hospitals is key;

however, these providers may face regulatory barriers when practicing telehealth across state lines.

SCID patients in the American Indian and Alaska Native communities commonly seek care in other states, where providers specialize in the most effective treatments. Traveling to these visits can be burdensome to the patient and their family due to the associated time, costs, and risk of infection. Offering treatments and consultations via telehealth can dramatically increase access to high-quality care for tribal SCID patients. Currently, only some states allow telehealth providers to deliver care to patients across state lines. Because of COVID-19, the Centers for Medicare & Medicaid Services (CMS) allowed providers to practice interstate telehealth without additional licensure, but only for services related to COVID-19 relief (CMS, 2021). Furthermore, for this waiver to apply, the state must have an additional waiver in place for its state-level licensure regulations. Currently, 41 states have waivers in place, but many of these are temporary (Federation of State Medical Boards, 2021). Expanded medical licensure laws that allow interstate telehealth treatment for SCID can ensure that these patients have access to the proper providers for their treatment. This is especially important in states like Arizona, New Mexico, and Nevada, where many SCID patients live, and California, where SCID providers reside. The Interstate Medical Licensure Compact has spearheaded this effort; however, neither California nor New Mexico currently participate. Although complicated licensure laws influence SCID patients' access to medical care, access to non-medical services should be considered as well.

For families whose child is diagnosed with SCID, services like genetic counseling, childcare, and social services will be important as they pursue treatment. Housing is especially important—SCID patients are at increased risk of infection and need electricity, proper ventilation, and plumbing to mitigate this risk. Expanding coordination and coverage of these services will ensure that all SCID patients and their families have their non-medical needs addressed and can focus on seeking the best-quality medical care.

Access to the Internet and Internet-Enabled Devices

American Indians and Alaska Natives, including SCID patients, may also face greater barriers to accessing technology needed to participate in telehealth. Grants to supply devices and expand broadband networks to these communities can improve access to care via telehealth. Necessary devices include a telecommunication device (e.g., tablet) and any remote monitoring devices needed for the patient's care (e.g., remote blood pressure cuff). Devices must also be easy to use and high quality to ensure sufficient internet connection, audio, and visual quality. Technology provision policies should consider how practices can utilize and distribute devices, as described in the Access to Reliable Devices and Broadband section.

Payment

As telehealth expands because of COVID-19, health insurance providers or payers are continuously updating their payment policies for telehealth to include new services, provider types, and geographies that can be reimbursed. CMS recently extended the use of some telehealth service codes permanently or beyond COVID-19. Permanent adoption of additional temporary telehealth service provisions will ensure that providers can continue to treat patients virtually and expand access to care. Additionally, unclear billing policies and limited reimbursement serve as potential barriers for providers to treat patients with SCID via telehealth. It is important that payers clarify how SCID services should be billed as policies rapidly change. Additionally, policies such as payment parity for telehealth would ensure that providers can receive sufficient reimbursement for their telehealth services. This is important for public health insurance programs and private payers.

Monetary incentives for clinicians providing telehealth could be considered as a strategy to increase the number of American Indian and Alaska Native or local community members on staff at health centers or hospitals that serve these populations. Incentives can be geared toward the provider to garner interest in a clinical career or toward the medical facility to stimulate recruitment. As medical facilities aim to recruit more telehealth providers, they must also consider the technical infrastructure needed to provide telehealth services and the associated startup costs (as outlined in the Organization-Level Factors section). Monetary incentives at the facility level may also help health centers and hospitals cover various startup costs and encourage more medical facilities to expand their services to include telehealth.

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