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## Developing Resources for American Indian/Alaska Native Transgender and Two-Spirit Youth, Their Relatives, and Healthcare Providers

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### Abstract

American Indian and Alaska Native (AI/AN) youth disproportionately face barriers accessing healthcare, including lack of access to culturally-specific resources. This paper details the creation of a culturally-specific Toolkit for AI/AN transgender and Two-Spirit youth, their relatives, and their healthcare providers across the United States (U.S.). The Toolkit aims to (1) deliver culturally-grounded resources to youth with diverse gender identities, (2) provide resources for families, and (3) increase healthcare provider awareness. A culturally-appropriate Toolkit, “Celebrating Our Magic”, was created from continual engagement with community partners over a six-month period to address identified needs. The Toolkit has been shared regionally with partners who helped with its creation and nationally with Indian Health Service (IHS), Tribal, and Urban clinics serving AI/AN youth. This Toolkit creation process could be applied to manuals or guides for work in other underserved communities.

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In 1990, American Indian and Alaska Native (AI/AN) activists created the term Two-Spirit to promote transcendence beyond a colonized categorization of binary gender and sexuality. Two-Spirit encompasses multiple aspects of identity—sexuality, gender, culture, and spirituality—and is used only to describe AI/AN individuals. Because Two-Spirit spans gender and sexuality and incorporates an individual's role in the community, the term Two-Spirit is not equivalent to the term transgender. Many Two-Spirit individuals have historically been respected by their communities as leaders, medicine people, and Holy people (1, 2). Despite this reverence, settler colonialism and the United States (U.S.) boarding school era systematically removed acceptance from Native communities and instilled a restrictive gender-binary environment where transgender and Two-Spirit individuals were unable to express themselves openly (3–5). These difficulties were compounded by historical and intergenerational trauma already present among AI/AN communities. Because traumas impacted spiritual, mental, and physical realms, health has been negatively impacted (6–13).

Among AI/AN transgender and Two-Spirit youth, health disparities are increased compared to their AI/AN cisgender peers (14, 15). With regard to physical health, rates of disease and substance use are increased due to lack of access to care and high levels of discrimination (16). This subset of youth also face higher levels of psychosocial distress including bullying, violence, family rejection, and homelessness, and are at increased risk for experiencing anxiety, depression, suicidal ideation, and suicide completion (15, 17).

Transgender and Two-Spirit youth who are supported by their healthcare providers and their families have levels of anxiety and depression similar to their cisgender siblings and peers (18, 19). They are also more likely to have positive adult health outcomes such as self-esteem, social support, and better general health, and are less likely to experience depression, substance abuse, and suicidal ideation (18, 20). Access to culturally-relevant resources may help youth receive the support they need, enable healthcare providers and families to provide this support, and improve mental and physical health outcomes. Unfortunately, AI/AN transgender and Two-Spirit youth, their relatives, and their healthcare providers often lack access to such resources.

In this paper, we discuss the community-engaged development of a culturally-specific Toolkit for AI/AN transgender and Two-Spirit youth, their relatives, and their healthcare providers across the U.S. The main objectives of the “Celebrating Our Magic” Toolkit are to (1) deliver culturally-grounded resources to youth with diverse gender identity, including those who are exploring their gender identity and/or are interested in gender-affirming medical interventions (e.g., gender-affirming hormone therapy), (2) provide resources and support for their families, and (3) increase healthcare provider awareness of characteristics unique to caring for AI/AN transgender and Two-Spirit youth (21). By illuminating this process, we hope to offer a framework that can be applied to develop resource guides for work in other underserved communities.

## Community-Based Resource Development

This paper details the Toolkit creation process using a Community-Based Participatory Research (CBPR) framework, including understanding community contexts, developing partnerships, Toolkit creation, and dissemination of the finalized Toolkit (22). This process occurred over a six-month period, as illustrated in Table 1.

We conceptualized this project as quality improvement, rather than research, and all community discussions and partnerships were voluntary; thus, we did not seek IRB approval. Any stories or responses shared by community members were paraphrased and deidentified, allowing partners to remain anonymous.

### Partnership development

Project teams at Seattle Children’s Hospital (SCH) Center for Diversity and Health Equity (CDHE) and the Northwest Portland Area Indian Health Board (NPAIHB) were primarily responsible for facilitating Toolkit development. Members at CDHE and NPAIHB were already working on projects related to AI/AN gender identity and collaborated to reach the common goal of increasing culturally-relevant care for transgender and Two-Spirit youth.

The first author (AA) was affiliated with CDHE and assumed the role of project leader, taking responsibility for ensuring that a) Toolkit development was community-driven and b) relationships with partners incorporated mutual respect, understanding, and strong communication.

CDHE and NPAIHB team members identified initial partners from existing contacts among tribal and LGBTQ2S (lesbian, gay, bisexual, transgender, queer/questioning, Two-Spirit) communities. These included tribal community connections (elders and community members; Two-Spirit support organizations; healthcare providers at tribal, urban, and rural health centers), LGBTQ2S community connections (SCH Gender Clinic Community Advisory Board (CAB)); national LGBTQ2S support organizations), and content experts (gender-affirming care; historical trauma; mindfulness). The first author contacted these individuals and set up in-person, phone, or virtual meetings to describe the project and gather early thoughts. Initial partners subsequently provided the CDHE team with contact information or introductions to facilitate connection with additional partners. Youth and family members were identified through referral from a tribal community partner, or self-referred after hearing about the Toolkit project.

Figure 1 provides additional details on teams and community partners. We do not disclose the names of all individuals or organizations involved at the request of community partners to preserve the integrity of partnerships and tribal relationships. While some project team members and community partners do not identify as AI/AN, LGBTQ, or Two-Spirit themselves, their involvement in this project emphasized the importance of allyship in this field of work. Similarly, although SCH and NPAIHB are located in the Pacific Northwest, partnerships included tribal and LGBTQ2S community members from across the U.S. in both rural and urban settings. This allowed many perspectives to be shared and aided in later dissemination across the U.S.

Iterative discussions with partners throughout the six-month process ensured Toolkit development respected the Indigenous context (i.e., Indigenous ways of knowing, historical trauma, and colonization), incorporated partnerships with AI/AN individuals and communities, was culturally relevant for both AI/AN youth and gender non-conforming youth, and produced a sustainable, transformative product (22, 23). All participating partners had the opportunity to provide continuous feedback, from initial writing and revision through dissemination.

### **Understanding community contexts**

Community perspectives regarding needs, strengths, and barriers faced by youth, their relatives, and their healthcare providers were critical. Community partners identified key priorities and gaps in current resources that directed Toolkit creation (see Table 2). For example, they illuminated the need for increased access to resources both in and out of the healthcare setting and emphasized the benefits of re-connection to Native traditions. There was consensus that information about medical interventions for transgender and Two-Spirit youth needed to be shared more widely among AI/AN communities and made culturally-relevant. Gender-affirming care and mental health providers offered critical information to include for all audiences: youth, families, and healthcare providers.

The project leader conducted a review of the existing literature and resources available for AI/AN transgender and Two-Spirit youth to supplement partner discussions. The review demonstrated that culturally-specific information related to gender-affirming care is limited both in printed materials and online. Further, strategies for youth to engage in the larger Native LGBTQ2S community are lacking. Likewise, clinical guidelines regarding best practices for gender-affirming care, though available in the literature, were not tailored for the AI/AN population (24–26). The project leader shared these results with partners, who subsequently decided which findings should be included and prioritized in the Toolkit product.

### **“Celebrating Our Magic” Toolkit creation**

Collaborative content development sessions followed initial communication with partners and consisted of virtual meetings facilitated by the project leader and/or NPAIHB team members. Depending on partner preference, sessions included individuals from single or multiple community organizations. The project teams gathered with healthcare providers from tribal clinics (n=20), SCH Gender Clinic CAB members (n=8), Two-Spirit organizations (n=4), and AI/AN youth and family members (n=25). Content, frequently asked questions, and personal stories were shared during these sessions.

One-on-one sessions were also conducted by the project leader with community partners and content experts if requested. These included discussions with AI/AN youth and their relatives (n=8), LGBTQ2S support group leaders (n=3), and topic specific experts (n=5). Partners agreed on key themes from these discussions, while the project leader took deidentified notes (later shared electronically with the CDHE and NPAIHB teams). Key themes were then placed into a working table of contents that was modified as discussions continued.

Iterative content development sessions allowed for continued feedback on Toolkit content. All partners had the choice to participate in multiple sessions over time and received updates and check-in emails from the project leader. Development sessions continued until saturation in key ideas was reached (i.e., when the majority of partners brought up the same topic or shared similar opinions.)

Toolkit drafting began during month three. The project leader was responsible for consolidating content from community partners and literature review, and ensuring that resources and information included were evidence-based. Feedback from community partners took place through in-person meetings, virtual meetings, or email communication of progress. Partners were asked to critique Toolkit content and to provide feedback regarding remaining gaps. Partners also shared whether they would like to participate in editing the Toolkit at this time and provided suggestions for later dissemination.

Once initial content creation was complete, dedicated copy-editing and graphic design occurred during months four and five. Community partners and content experts had multiple opportunities to review the Toolkit and provide feedback on content, cultural relevance, reading level, visual appeal, and graphic design format. The project lead communicated on a weekly basis with these partners via phone, in-person meetings, or email to review edits and

share back with the CDHE and NPAIHB teams. Partners shared their input verbally and via edits directly on the drafting document. Any disagreements were discussed by multiple topically-relevant partners until an understanding was reached. “Celebrating Our Magic” was finalized by the end of month six and is organized into five main sections: background and overview, youth, families and relatives, healthcare providers, and general resources.

### “Celebrating Our Magic” Toolkit dissemination

During months four and five, team members and partners identified outlets and means of dissemination. Considerations included sharing the resource with youth, relatives, and providers in areas where internet access may be limited or where having a physical copy of the Toolkit may have been unfeasible or unsafe.

Toolkit dissemination took place during month six and onward, starting with oral presentations to community partners (n=16), community members (n=4), and eight national conferences. The project leader and NPAIHB team members facilitated these presentations and worked with local community members to adapt to the specifics of each community. The Toolkit was also posted on the NPAIHB website (<http://www.npaihb.org/2slgbtq/#print>), and linked to by several other partner organizations. This webpage was shared by email via networks of community partners. A print copy was mailed to all partners who assisted with creation and was made available to the public free of charge. There have been print Toolkit request from more than 28 states. CDHE and NPAIHB team members also assisted with manuscript preparation to further disseminate the resource.

## Discussion

This paper details the community-engaged process of creating a Toolkit of resources for AI/AN transgender and Two-Spirit youth, their relatives, and their healthcare providers. “Celebrating Our Magic” was developed using a CBPR approach which ensured that contents were culturally-appropriate, feasible, and sustainable for the intended audience.

The Toolkit creation process revealed a number of lessons. First, community partnership is critical when creating a comprehensive, community-centric resource. Developing strong relationships with partners and creating a product that meets their needs fosters a supportive environment and helps frame the desired product for success. Engaging with partners in continual review through an iterative process helped contents stay true to community needs. Ensuring that these partners represented a diversity of the individuals we were hoping to serve strengthened the Toolkit product.

Second, developing a resource that is generalizable to all individuals within a diverse population is important. We aimed to present information that was applicable to as many youth as possible regardless of tribal affiliation or geographic location. While it was not feasible to account for all the unique aspects and traditions of all tribal communities, we included some tribal-specific information as examples. We also acknowledged that our Toolkit was created as a broad resource that could be further modified for specific communities.

Lastly, creating a comprehensive product requires significant engagement from community members and professionals. The critical need for this resource for the end-users--AI/AN transgender and Two-Spirit youth, their families, and healthcare providers—motivated our team to work quickly, which enabled community members to have a tangible outcome of their participation. Further, Toolkit creation and revision was financially feasible, with the main cost being the time of the first author conducting the literature review, meeting with youth, family, and providers, and drafting and revising the Toolkit itself.

The extensive literature review and content development discussions established that a Toolkit would be useful to address issues surrounding gender and sexuality in AI/AN youth. The paucity of resources addressing the intersection of identities—gender, sexuality, and AI/AN—created an opening for the “Celebrating Our Magic” resource and allowed SCH and NPAIHB to identify areas to focus outreach, research, and programmatic efforts. An online and open-access Toolkit provides youth and their families access to relevant and potentially sensitive information. Medical and mental health resources presented are especially critical for youth living in rural and remote locations. These youth may not have easy access to providers trained in gender-affirming care or specialized gender clinics. Because health providers in these resource-limited settings may also lack access to training regarding identity formation (gender and AI/AN specific), gender-affirming care, and/or standardized medical guidelines for medical transition, the Toolkit can be beneficial for them as well.

### **Limitations and next steps**

We would have liked to include more AI/AN transgender and Two-Spirit youth in content development sessions but were unable to due to restraints in time and requirements for tribal-specific review boards. For future work, we would recommend allowing time to seek specific approvals for this purpose. Despite this, youth who were included in creating this Toolkit shared rich experiences that translated into the stories shared and ultimately made this work possible. Similarly, perspectives from healthcare providers and relatives, although adults, were critically important as this is a resource not only for youth but also for their supports. Future work includes ongoing dissemination as well as a formal evaluation of Toolkit implementation, accessibility, and sustainability across a variety of settings.

### **Conclusions**

Using a community-engaged process, we created a Toolkit to provide AI/AN transgender and Two-Spirit youth, their families, and their healthcare providers with culturally-specific information regarding health and healthcare. Community input continued in an iterative process throughout the Toolkit creation and dissemination phases. The Toolkit aims to increase awareness, medical literacy, and cultural connection among these youth, and to improve their mental health outcomes. The Toolkit creation process allowed partners to prioritize current and future projects on LGBTQ2S efforts, and forge connections with allies and organizations in their communities. Information gathered also spurred the development of research projects and helped to garner support for grants. Additionally, the Toolkit creation process outlined in this article may be adapted for use by specific AI/AN

communities or other underserved minority groups, to modify or develop their own practices regarding gender-affirming care or primary care for LGBTQ2S youth.

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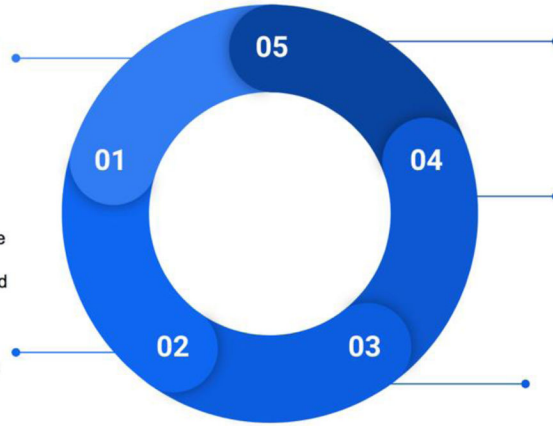
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**Seattle Children's Hospital- Center for Diversity & Health Equity**  
Description: aims to reduce health disparities and improve health outcomes for all patients & families  
Role: Primary team members, including project lead, responsible for creating, disseminating Toolkit; manuscript authors  
Members: identify as AI/AN, LGBTQ2S

**Tribal community connections**  
Description: AI/AN individuals from across the U.S.  
Roles: Identify community needs; serve as community contacts; assist with table of contents development; involved with iterative drafting and revisions; lead community engagement and resource sharing/dissemination  
Members included: reside across rural and urban settings; reservation and non-reservation settings; ages: youth through adults; AI/AN identifying; LGBTQ2S identifying; leaders and members of national Two-Spirit organizations



**Northwest Portland Area Indian Health Board (NPAIHB)**

Description: non-profit, tribal advisory organization that serves federally recognized tribes of Oregon, Washington, and Idaho; tribal epidemiology center  
Role: Key partner in creating, disseminating, and funding Toolkit; manuscript authors  
Participating members: identify as AI/AN, Two-Spirit and LGBTQ2S

**Content experts**

Description: Individuals from across the U.S. with expertise in AI/AN health, gender-affirming care, health promotion, mental health, etc.  
Role: Assist with content development for Toolkit; drafting & revisions  
Participating members: AI/AN, LGBTQ2S

**LGBTQ community connections**

Description: LGBTQ2S individuals from academic centers and communities across the U.S.  
Roles: Assist with content development for Toolkit; involved with draft editing and dissemination  
Members included: youth, adults, physicians, mental health providers, social workers; support group leaders

**Figure 1:**  
Partnership descriptions

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**Table 1:**

Project Timeline diagram

Objective	Jan 2019	Feb 2019	Mar 2019	Apr 2019	May 2019	Jun 2019
<b>INITIAL COMMUNITY ENGAGEMENT</b>						
Literature review	x					
Context gathering	x	x				
Community capacity	x	x				
<b>PARTNERSHIP DEVELOPMENT</b>						
Initial partnership connections	x					
Initial discussions—phone calls, in person meetings, virtual meetings	x	x				
Initial partners reach out to additional community contacts	x	x	x			
Establishing partnership structure	x	x				
Partner empowerment	x	x	x	x	x	x
Maintaining open communication	x	x	x	x	x	x
<b>RESOURCE CREATION</b>						
Collaborative content development sessions		x	x	x	x	x
Table of contents development		x	x			
Feedback from partners	x	x	x	x	x	x
Content creation, initial draft with partners			x	x		
Copy-edit drafting of full Toolkit product				x	x	
Graphic design				x	x	
<b>TOOLKIT DISSEMINATION</b>						
Online and in-print						x
Presentations and conferences to community members and partners						x
Prepare and submit manuscript						x

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**Table 2:**

Gaps in AI/AN gender-affirming care addressed by the Toolkit

<b>Gaps identified by community partners:</b>	<b>Audience:</b>	<b>Section(s):</b>	<b>Toolkit provides:</b>
Information regarding historical Native perspectives on gender difficult to find	Youth Families Healthcare providers	Background & Overview	- Historical context
Lack of role models for AI/AN LGBTQ2S youth	Youth Families Healthcare providers	Background & Overview, Youth	- Stories about historical transgender and Two-Spirit folks  - Presentation of modern-day leaders who are both AI/AN and LGBTQ2S
Paucity of data regarding AI/AN LGBTQ2S health disparities	Youth Families Healthcare providers	Background & Overview	- Selected statistics from relevant studies
Confusion regarding definitions	Youth Families Healthcare providers	Background & Overview	- Definitions  - Guide on how to use pronouns  - Importance of chosen name  - Terms to avoid  - Medical transition information
Stories from AI/AN youth about their gender-affirming journeys	Youth	Youth	- Stories and quotes from transgender and Two-Spirit youth  - Q&A section created with input from AI/AN youth
Lack of resources for scenarios when access to mental health care is limited	Youth Families Healthcare providers	Youth, Families & Relatives, Providers	- Mindfulness and meditation resources for youth without access to mental health care  - Information about the importance of mental health care  - Strategies for finding a mental health provider  - Tips on how to incorporate mental health checks into primary care
Strategies related to community and traditional celebration	Youth, Families	Youth, Families & Relatives	- Resources for local community groups, online forums, national Two-Spirit groups and events  - Strategies for being a youth-advocate  - Discussion of support groups for families
Resilience	Youth, Families	Youth, Families & Relatives	- Mindfulness and meditation resources  - Discussion of how youth can serve as mentors for peers and be leaders in schools  - Parent strategies for fostering resilience (self and in their children)
Lack of provider education regarding gender-affirming care	Healthcare providers	Providers	- Resources for having conversations with youth about gender, pronouns, chosen name  - Creating a welcoming office space  - Tips on becoming an ally/supporter both for AI/AN youth and LGBTQ2S youth  - Training and webinar links

Gaps identified by community partners:	Audience:	Section(s):	Toolkit provides:
			- Information regarding the importance of primary care and sexual health, as well as mental health
Provider acknowledgement of AI/AN history and/or culture	Healthcare providers	Providers	- Reference to tools for cultural competence
Crisis Hotlines	Youth Families Healthcare providers	Multiple sections	- Phone numbers and text message systems for use in emergency scenarios

Note: This is not a comprehensive list of material covered by the Toolkit.

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