

A group of six women, likely Indigenous, are standing in a desert landscape. They are wearing traditional, dark-colored dresses with intricate patterns and accessories like necklaces and belts. The background shows a vast, open landscape under a clear sky.

Frameworks for Engaging Communities in Research to Inform Practice and Polity

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<https://www.indigenousgoddessgang.com/thru-indigenous-lens/cara-romero>

OVERVIEW

- CBPR Core Principles
- Reflexive Praxis – “Community”
- CBPR Principles and Ethics Issues
- rETHICS Study and Indigenous Ethics Principles





Floyd H. McCall, Getty Images

CORE PRINCIPLES

- It is participatory.
- It is cooperative, engaging community members and researchers in a joint, equitable process.
- It is a co-learning process.
- It involves systems development and local community capacity building.
- It is an empowering process through which participants can increase control over their lives.
- It achieves a balance between research and action.

Wallerstein, N., Duran, B., Oetzel, J., & Minkler, M. (2018). *Community-based participatory research for health* (3rd ed.). Newark: Wiley.



American Indian Women: Th...
nativeamericannetroots.net



Photos of Native Americ...
huffpost.com



Influential Native American Women ...
biography.com



Native American women go missing at ...
inlander.com



American indian girl ...
pinterest.com



Influential Native America...
biography.com



Beautiful Native Ameri...
thehypertexts.com



Reflexive Praxis – “COMMUNITY”

Two distinct, yet coexisting, modern worlds – the *systems world* of legal, economic, and political systems and the *life world* of families and cultural traditions, in which individuals reproduce their identities and knowledge.

- Wallerstein & Duran (2018) on Habermas (1987)

CBPR PRINCIPLES AND ETHICS

- Recognize community as a unit of identity → How does the community define itself?
- Build on strengths and resources within the community → What are community priorities?
- Facilitate collaborative, equitable partnerships in all research phases and involves an empowering and power-sharing process that attends to social inequalities → What does equity look like?
- Promote co-learning and capacity building among all partners → How does the community see capacity?
- Integrate and achieve a balance between research and action for the mutual benefit of all partners → How does community view benefits?

CBPR PRINCIPLES AND ETHICS

Emphasize public health problems of local relevance and ecological perspectives that attend to the multiple determinants of health and disease



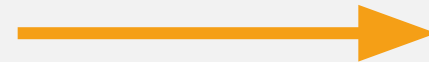
How does community define relevance?

Involve systems development through a cyclical and iterative process



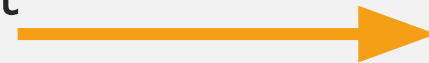
What norms does community have regarding engagement?

Disseminate findings and knowledge gained to all partners and involve all partners in the dissemination process



What are community practices for dissemination?

Invest in a long-term process and commitment to sustainability



What burden does this research pose for the community?

Address issues of race, ethnicity, racism, and social class and embrace “cultural humility”



How can we integrate a cultural lens?

rETHICS Study

Randomized controlled trial exploring effectiveness of a culturally-grounded human subjects training curriculum in AIAN communities.

- Includes AIAN ethical principles and applications.
- Provides AIAN research context for understanding ethics issues.
- Tested among national sample of AIAN community members with the culturally grounded curriculum ($n = 244$) with a standard nationally used online curriculum ($n = 246$).

rETHICS Study

The goal of this research was to use CBPR principles to clarify Indigenous research perspectives that support research within Indigenous communities that:

- Recognizes the autonomy and rights of communities to engage in, govern, and consent to research;
- Ensures the research results in benefits; and
- Ensures equal access for Indigenous communities to those benefits tailored to community needs.

Community Expert Panel (n=12)



Antony Stately, PhD
(Ojibwe/Oneida)



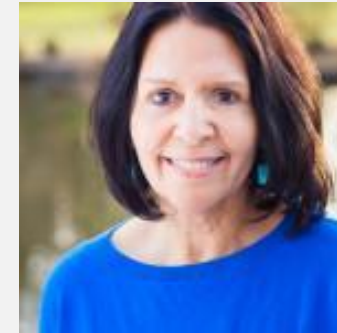
Travis L. Lane
(Navajo/
Southern Ute)



Emily White Hat, JD
(Sicangu Lakota)



Vanessa Hiratsuka, PhD
(Navajo/
Winnemem Wintu)



Dr. Brenda Dial
Deese (Lumbee)



Lucy Smartlowit Briggs
(Yakama)



Beverly Patchell, PhD
(Cherokee/Creek)



Billie Jo Kipp, Ph.D.
(Blackfeet)



CeCe Big Crow
(Oglala Lakota)



Lynnette Jordan
(Ojibwe & Colville)



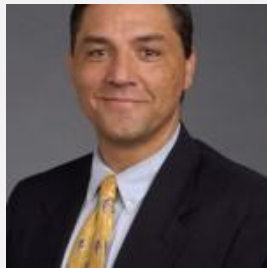
Sandra Stroud
(Choctaw)



Amanda Gaston, MAT
(Zuni Pueblo)

Scientific Expert Panel (n=14)

Indigenous scholars & allies



Dr. Ronny Bell
(Lumbee)



Rodney C. Haring,
PhD (Seneca)



Melissa L. Walls
(Anishinabe)



Dr. Lee Anne
Nichols (Cherokee)



Ms. Angal (MPH,
CIP)



Julie E. Lucero
Ph.D., MPH



Nicolette
Teufel-Shone
Ph.D.
U Arizona



Scarlett Hopkins,
RN, MA



Jada L. Brooks, PhD,
MSPH, RN (Lumbee)



Dr. Julie Baldwin,
(Cherokee)



Dr. Irene
Vernon
(Apache)



Dr. Annie Belcourt
University of Montana
(Mandan / Hidatsa)



Tassy Parker, PhD,
RN, (Seneca)



Daniel Dickerson, D.O.,
M.P.H. (Inupiaq)

Policy/IRB member Expert Panel (n=5)

Tribal IRB administrators & policy experts



Francine C. Gachupin, PhD,
MPH,
(Pueblo of Jemez)



Stephanie Craig Rushing,
PhD, MPH



Dr. Malia Villegas
(Native Village of Afognak)



Donald Warne, MD,
MPH (Lakota)



Dr. Gary Ferguson
Alaska Native Tribal Health
Consortium



William L. ("Bill")
Freeman, MD,
MPH

Research in the United States

- The Code of Federal Regulations codifies the Ethical Principles of the Belmont Report
- Rules & regulation for IRB
 - Defines “Research” with “Human Subjects”
 - Details
 - Informed consent and autonomy
 - Privacy and confidentiality
 - Assessing risks and benefits
- Protects specific groups, such as pregnant women, human fetuses, and neonates, prisoners, and children.

Indigenous Ethics Model

Curriculum discussions held with American Indian and Alaska Native community members, researchers, and ethics experts.

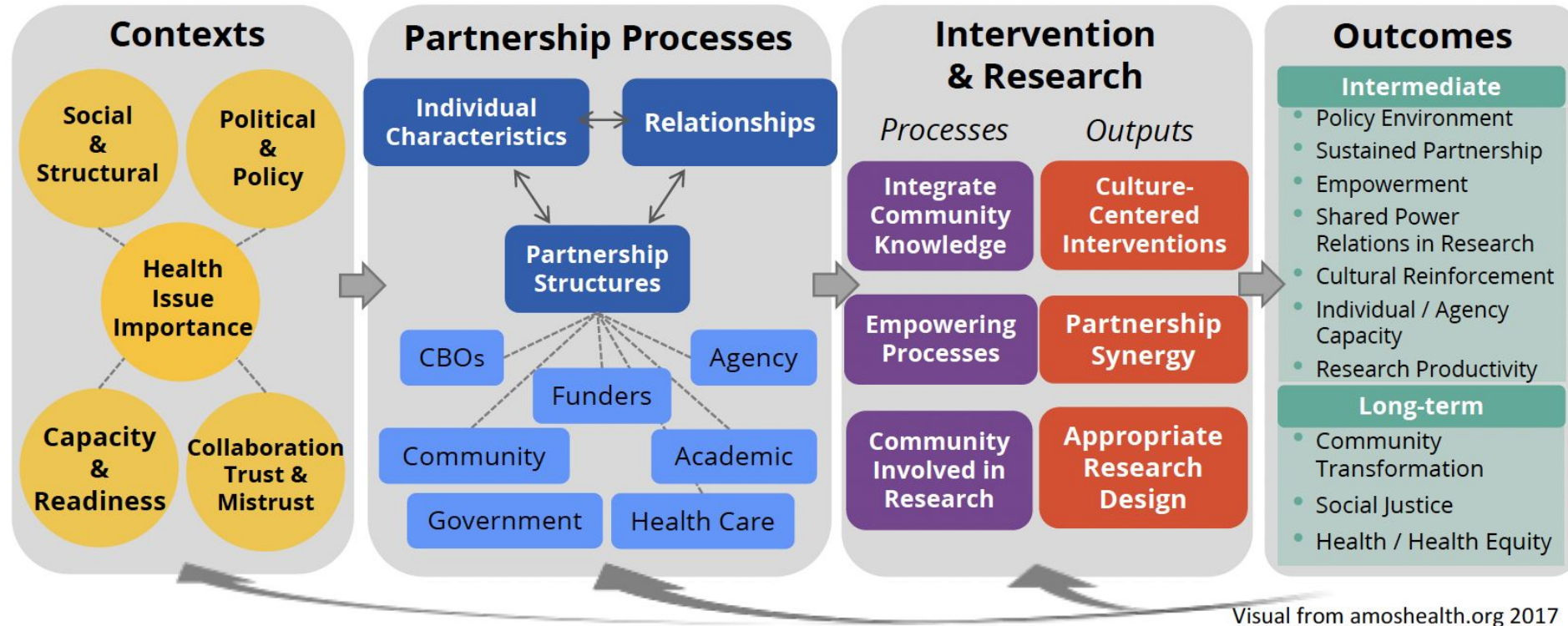
Major themes emerged from qualitative analysis.

Themes confirmed through cognitive debriefing interviews with community participants.



CBPR Conceptual Model

Adapted from Wallerstein et al, 2008 & Wallerstein and Duran, 2010, <https://cpr.unm.edu/research-projects/cbpr-project/cbpr-model.html>



Visual from amoshealth.org 2017

Contexts	Partnership Processes	Intervention & Research	Outcomes
<ul style="list-style-type: none"> • Social-Structural: Social-Economic Status, Place, History, Environment, Community Safety, Institutional Racism, Culture, Role of Education and Research Institutions • Political & Policy: National / Local Governance/ Stewardship Approvals of Research; Policy & Funding Trends • Health Issue: Perceived Severity by Partners • Collaboration: Historic Trust/Mistrust between Partners • Capacity: Community History of Organizing / Academic Capacity/ Partnership Capacity 	<p>Partnership Structures:</p> <ul style="list-style-type: none"> • Diversity: Who is involved • Complexity • Formal Agreements • Control of Resources • % Dollars to Community • CBPR Principles • Partnership Values • Bridging Social Capital • Time in Partnership <p>Individual Characteristics:</p> <ul style="list-style-type: none"> • Motivation to Participate • Cultural Identities/Humility • Personal Beliefs/Values • Spirituality • Reputation of P.I. <p>Relationships:</p> <ul style="list-style-type: none"> • Safety / Respect / Trust • Influence / Voice • Flexibility • Dialogue and Listening / Mutual Learning • Conflict Management • Leadership • Self & Collective Reflection/ Reflexivity • Resource Management • Participatory Decision-Making • Task Roles Recognized <p>Commitment to Collective Empowerment</p>	<ul style="list-style-type: none"> • Processes that honor community and cultural knowledge & voice, fit local settings, and use both academic & community language lead to Culture-Centered Interventions • Empowering Co-Learning Processes lead to Partnership Synergy • Community Members Involved in Research/Evaluation Design that Reflects Community Priorities • Bidirectional Translation, Implementation, Dissemination 	<p>Intermediate System & Capacity Outcomes</p> <ul style="list-style-type: none"> • Policy Environment: University & Community Changes • Sustainable Partnerships and Projects • Empowerment - Multi-Level • Shared Power Relations in Research / Knowledge Democracy • Cultural Reinforcement / Revitalization • Growth in Individual Partner & Agency Capacities • Research Productivity: Research Outcomes, Papers, Grant Applications & Awards <p>Long-Term Outcomes: Social Justice</p> <ul style="list-style-type: none"> • Community / Social Transformation: Policies & Conditions • Improved Health / Health Equity

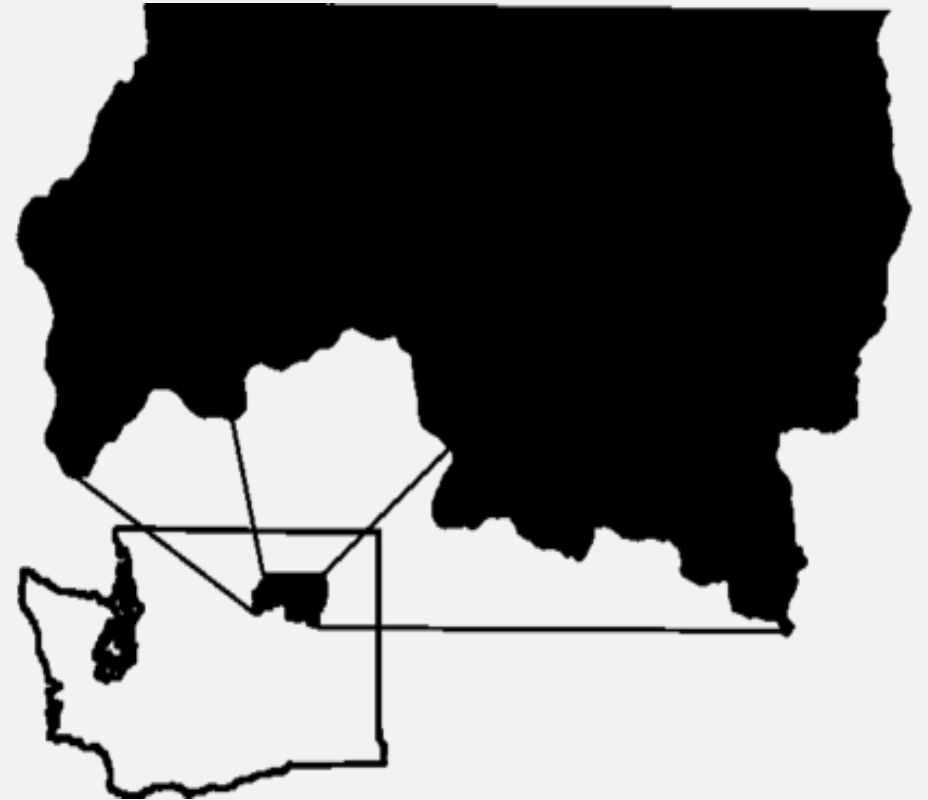


STIM A SPU'US: WHAT'S IN YOUR HEART?

Cultural Adaptation of Attachment Vitamins, a trauma-informed, evidence-based parenting intervention

The Confederated Tribe of the Colville Reservation

- Established by Presidential Executive Order (1872)
- 1.4 mil acres located in North Central Washington
 - Originally twice as large as today
- Diversity of natural resources: standing timber, streams, rivers, lakes, minerals, native plants and wildlife
- Governed by the 14 member Colville Business Council

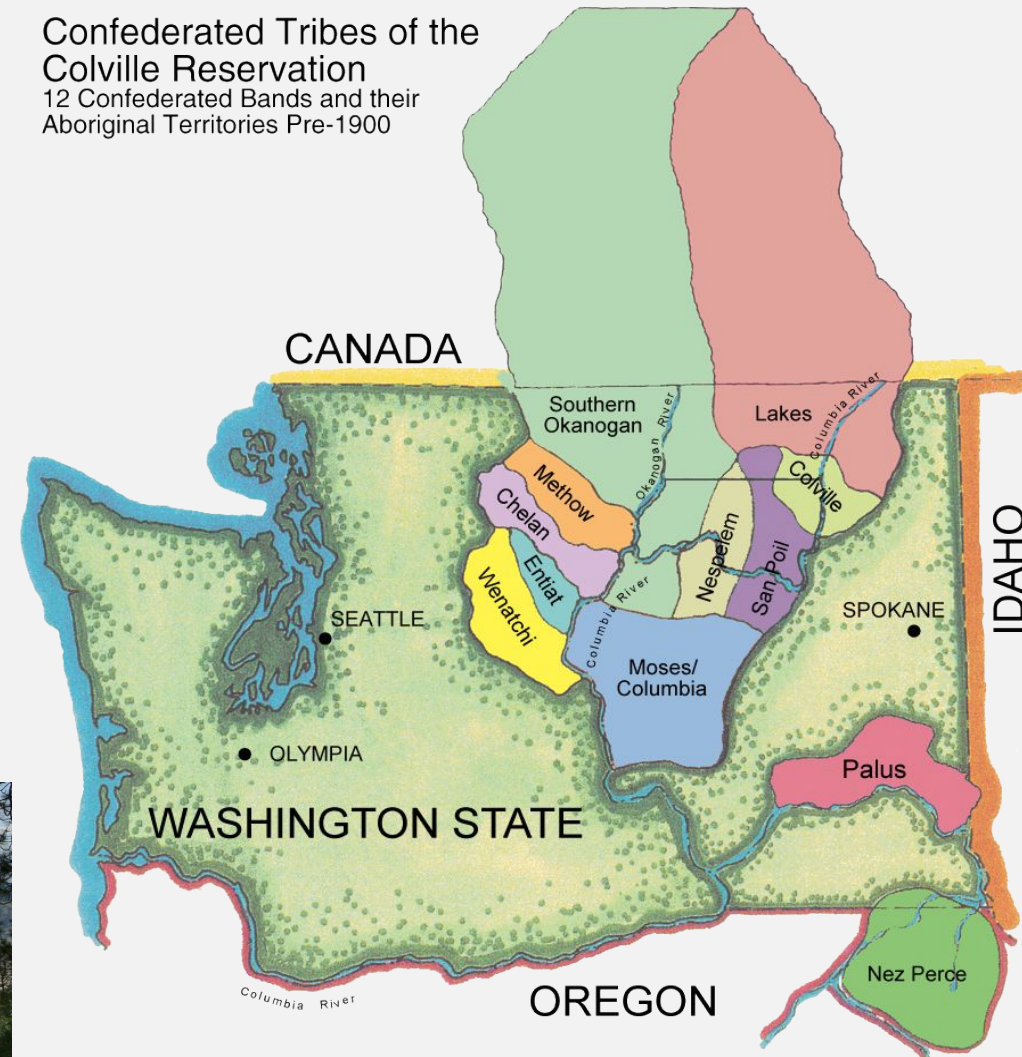


The Confederated Tribe of the Colville Reservation

- Prior to colonization in mid 1850s, ancestors of the 12 aboriginal tribes were nomadic, following the seasons and sources of food
- The aboriginal territories were grouped primarily around waterways: Columbia, Sanpoil, Okanogan, Snake, and Wallowa Rivers



Confederated Tribes of the Colville Reservation
12 Confederated Bands and their
Aboriginal Territories Pre-1900



Today: Over 9,365 members of the 12 Tribes

nsełxćin		uknaqín	Okanogan	Seeing over the top
	mætɬ^wu	Methow	Blunt hills around a valley	
	snʔáyckst	Lakes	Speckled fish	
	sǎ^wyʔitp	Colville	Sharp, pointed trees	
	nspilm	Nespelem	Prairie	
	sənpʔ^wilx	San Poil	Grey mist as far as one can see	
nxaʔamxćin	škwáxćənəx^w	Moses-Columbia	People living on the bank	
	šnpəšq^wáwšəx^w	Wenatchi	People in the between	
	šntiyátk^wəx^w	Entiat	Grass in the water	
	ščəlámxəx^w	Chelan	Deep water	
nimipu	wałwáma	Nez Perce	Joseph Band, Wallowa People	
	palúšpam	Palouse	Palus People	



Image of dancers at powwow owned by Alvina Marris

Colville Community COVID Study Purpose and Method

To evaluate the impacts of the COVID-19 pandemic on Colville Tribal community members in the following areas:

- Access to and comfort/familiarity with telehealth
- Mental and behavioral health
- COVID vaccine use and hesitancy
- Online education for caregivers of school-aged children
- Sources of stress and resources for coping

Stratified random sample of 2000 enrolled Tribal members 18 or older living on or near the reservation based on the Tribal enrollment list of 4062 names with stratification:

- Proportionally across 4 districts (Inchelium: 16%, Keller: 6%, Nespelem: 38%, Omak: 40%)
- Evenly across 4 age groups (18-30, 31-45, 46-60, 61+)

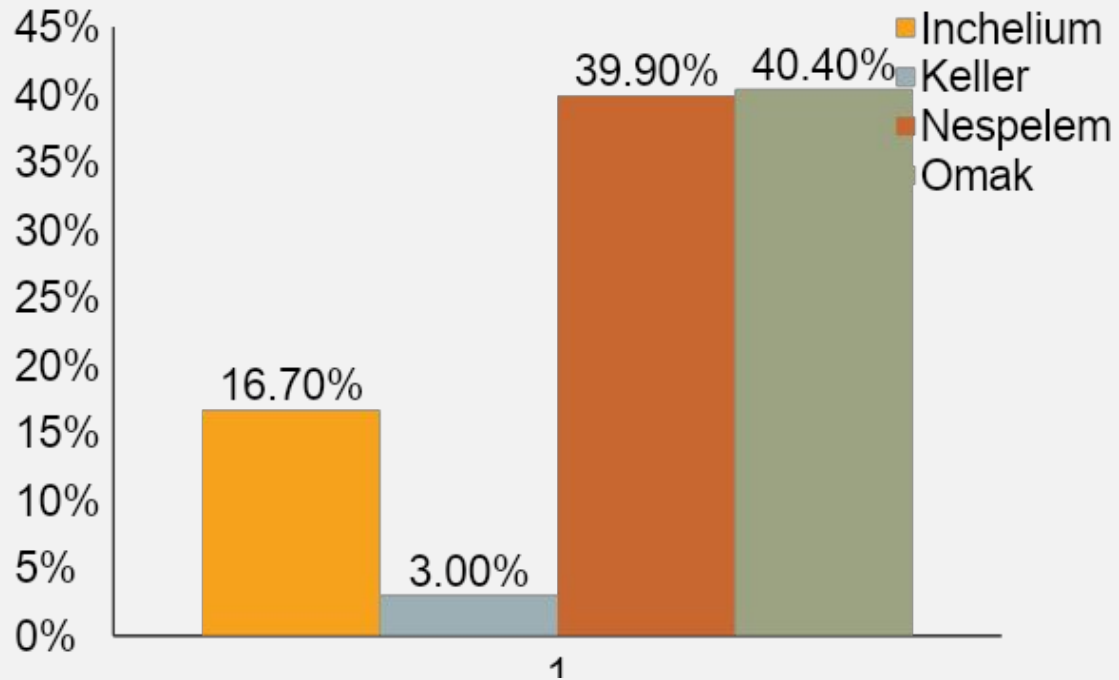
Surveys mailed early November 2021, returned via self-addressed stamped return envelopes by December 15 (three postcard reminders sent)

Two hundred sixty four surveys were returned / reported undeliverable

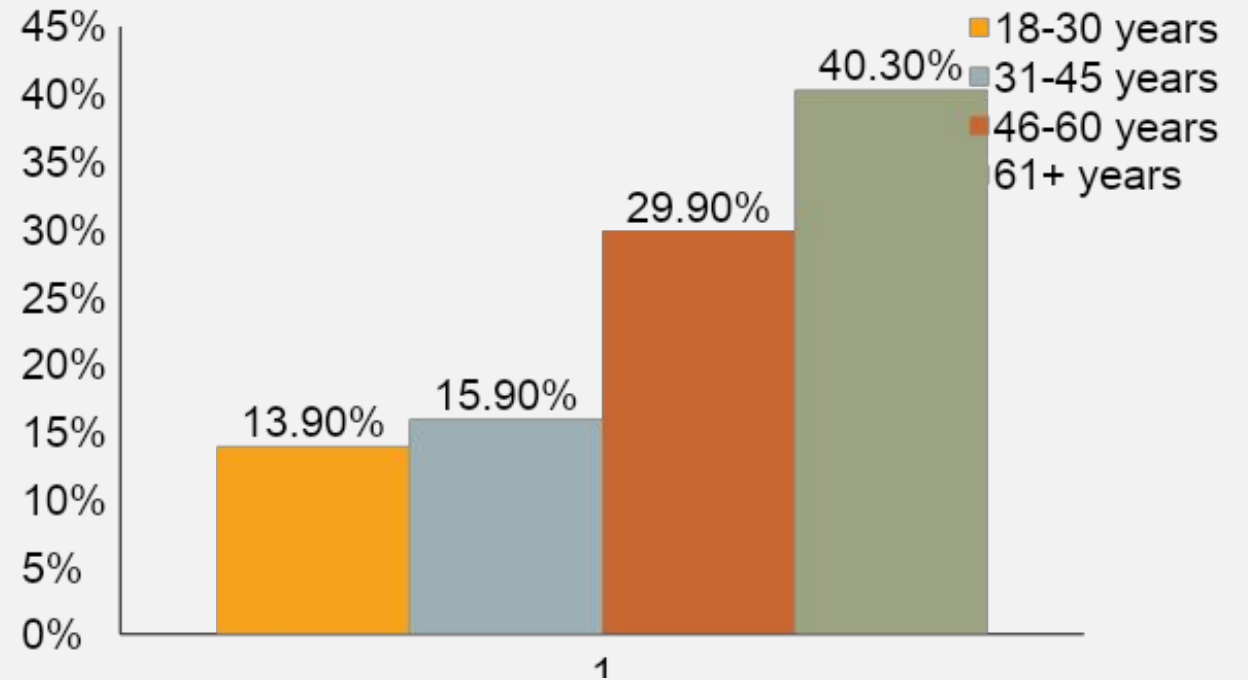
Basic demographics

203 people returned completed surveys, 65.8% female (34.2% male)

Districts



Age Groups



TOP SOURCES OF STRESS



Financial concerns



Physical health



COVID safety



Family sick with COVID



Housing concerns

TOP ACTIVITIES TO COPE WITH STRESS



Being in nature



Connection with family



Exercise



Spiritual / ceremonial practices

38% of people access traditional medicine when ill or healing

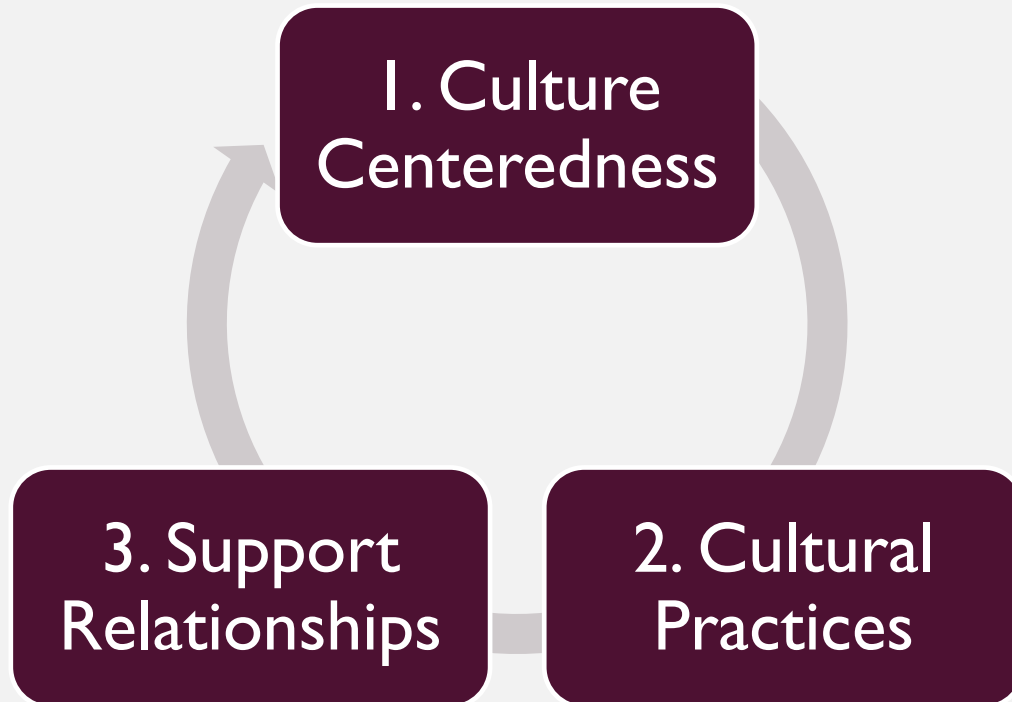
CULTURALLY-ADAPTED PARENTING PROGRAM

- Group program for caregivers of young children
- 6 weekly meetings facilitated by two trained community members
- Core elements of every meeting:
 - Psychoeducational curriculum
 - Reflective discussion among caregivers
 - Sharing Moments of Connection
 - Parenting Journey
 - Storytime



Image of infant owned by Alvina Marris

PRIVILEGING COMMUNITY STRENGTHS AS A SOURCE OF RESILIENCE



1. Identify and integrate tribal traditions, knowledge systems, and norms
2. Rebuild and revitalize “praxis” within and with community
3. Own roles and power in strengthening family connectedness

Results: Intergenerational strengths

My mom talks about that nurturing she got from her grandma, and every time she talks about it I can see in her eyes, I can feel that sweet gentleness of my great grandma and it makes me feel like a little tiny baby [protected and loved] - Language Expert

I remember more my great-grandmother and grandparents being there for me, as being these caring, nurturing individuals... And then when my sister... when there was a deep illness, I saw a lot of that care really double upon the child - Elder

Results: Traditional lifeways

When they [grandparents] take you out in the mountains and they want you to follow them and they wanna teach you why this is growing that way and why you pick this on that season and stuff like that. And culturally speaking, that's a part of parenting that, grandparents and mothers and fathers... we used to come to the country and up in the mountains for weeks at a time and pick huckleberries and things because that's what you're supposed to do. That's just what we knew to do. - Elder

I think keeping my kids in tune with a lot of the culture and values that I was raised with by my parent, my mom, and my grandparents, is kinda what I try to instill in my children, because it's part of who we are as a people. It's important to keep those cultures alive by teaching my kids those. - Caregiver

Results: Desire to gain traditional knowledge

So we weren't raised culturally, like, traditionally, but I do have some aspects of that of being around my grandparents up here. So I know about what to do during a funeral and stuff like that, but not, not fully cultural. And I feel now that I'm an adult and have children of my own, I wish I did know that because culture is a lot for our members and we just don't have the resources. Like, we do and we don't. - Caregiver

If I could do it, I would put my whole heart into our culture 'cause it does make it feel like I'm missing out to not know the culture and I wasn't raised and I cannot speak any type of Salish anything, and it sucks because I can't teach my children that. - Caregiver

stim' aspu?ús - What's in Your Heart? Curriculum

- The trauma-informed curriculum was based on Attachment Vitamins, an existing parenting intervention
- The curriculum focuses on supporting attachment and parenting skill development.
- The curriculum was redesigned to include Colville cultural values and knowledge, and was reduced to six sessions.

stim aspu?ús Sessions

1. Attachment
2. Temperament
3. Parents as a Secure Base
4. Becoming a Partner with Your Child
5. Toxic Stress and Trauma
6. Strength and Resilience



Session 3

Page 8

Using the HONOR Approach to Parenting Young Children

We know our children represent the future, and we value and respect the gifts they bring to us.

Use the word HONOR to think about what our kids might need from us:

- H Hungry:** the need for food ("Are they hungry right now? When was the last time they ate?")
- O Overwhelmed:** the need for calm ("Is it really loud or have they been really busy? Are they a child who needs some down time to relax?")
- N Need for Connection or Affection:** the need for your presence ("Have we been spending a lot of time apart? Are they afraid of losing me or losing my love?")
- O Options for Power:** the need to be acknowledged and heard by you ("Are they feeling overwhelmed or overstimulated? Do they need a break or some quiet time?")
- R Rest and Reset:** the need for sleep ("Did they take a nap today? Have they been getting to bed at a good time?")

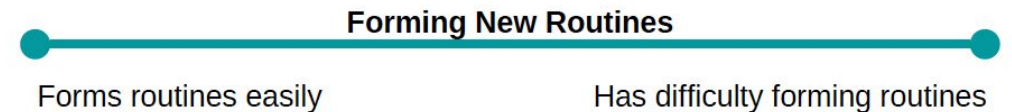
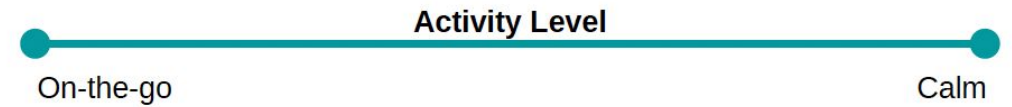
Temperament

- This worksheet and book excerpt demonstrates the Indigenized approach to examining child temperament with parents.
- In the Parenting Journey, we include reflection on “How are you going to represent your family in your journey?”

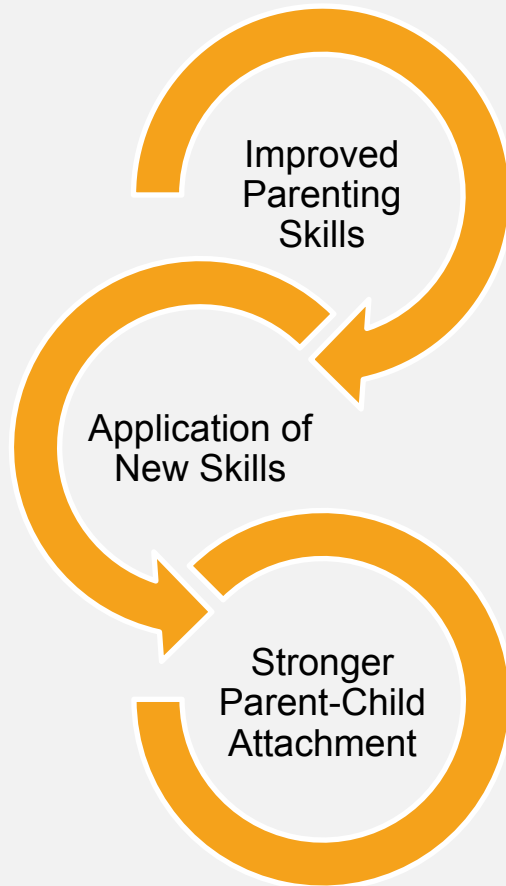


Cawt, or "Way of Being" Child Temperament Worksheet

Part I. Mark where on the line you think your child's temperament is.
After making a mark, think of an example.



Mapping Skills to Behaviors



Using the HONOR Approach to Parenting Young Children

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- R** **Rest and Reset:** the need for sleep ("Did they take a nap today? Have they been getting to bed at a good time?")

stim' aspu?ús - Cultural Handouts

- In addition to the weekly sessions, we provide cultural materials designed to support cultural and community connectedness.

S U S T A I N A B L E G A T H E R I N G

(CO- sk'wík'włtałq - Strawberry



Wild strawberries must be enjoyed when they are picked.

Never put it in plastic.

You can harvest the leaves for tea, dry in a paper sack, or air dry in small tied bunches.

Where to find Strawberries -
near Moses Mountain.

Introduce yourself.

Say a prayer.

Let the plant know what you're using it for.

Put tobacco and other offerings you may have at the
base of the plant.

Spread the gathering out over time.

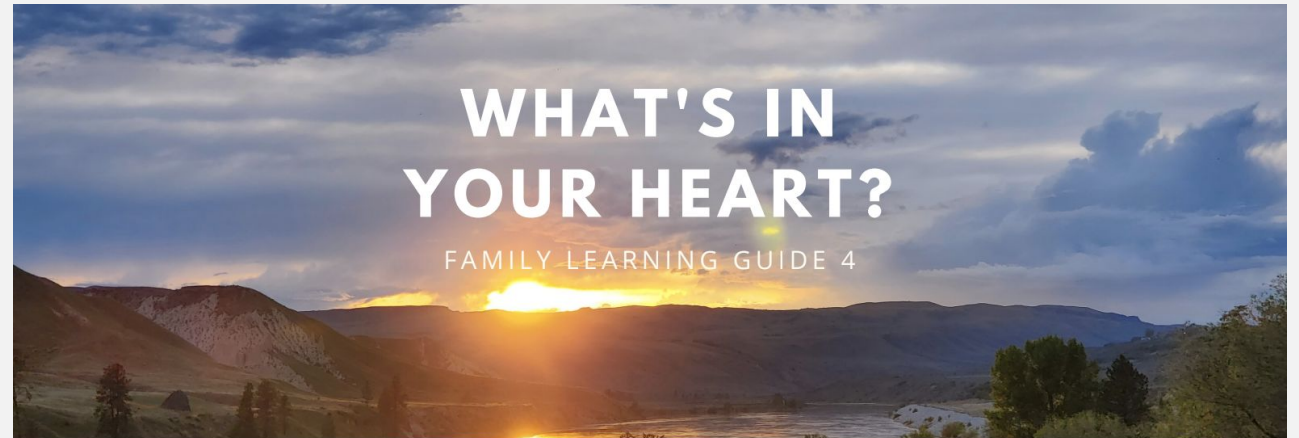
Don't deplete one area; gather from several locations.

only do gathering while the sun is in the sky

(CO- šmink - To Love

stim' aspu?ús

Cultural Handouts



WHAT'S IN YOUR HEART?

FAMILY LEARNING GUIDE 4

WILD ROSE GATHERING

Wild rose can be found in the lower lands near bodies of water and in the mountains closer to creeks.

The flowers can be picked when in full bloom during the summer and the stalks can be gathered year round.

REMINDERS

- Take only what you need- save some for others
- Bring an offering for what you take
- Remind children how to gather responsibly
- Individuals who are mourning area advised to not gather
- Women who are menstruating are also advised not to gather

TRY THESE WORDS

- Wild Rose- sk'kw'witp
- To grow- cplal
- To smell- surh
- To play- ?ickn



Guiding values and goals

- Caregivers in community with one another
 - Group format
 - Facilitation by trained community members
- Multigenerational healing
 - Sensitivity to differences in awareness of historical trauma
 - Sensitivity to differences in knowledge of traditional practices
- Long-term sustainability
 - Where the program “lives” and what that means

KEY TAKEAWAYS

- Understanding the theory underlying the CBPR approach informs interpretation and application of CBPR in our praxis can help support decision making on research ethics.
- Definitions matter – “community” has a unique meaning depending on the community in question and the manner in which they choose to participate, which has implications for ethical issues related to the research.
- CBPR principles can help guide the relationships we develop in CBPR-informed research, yet require iterative thought, discussion, and planning to fully apply, and this includes ethical decision making.

MAACAGÍRAAC



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