



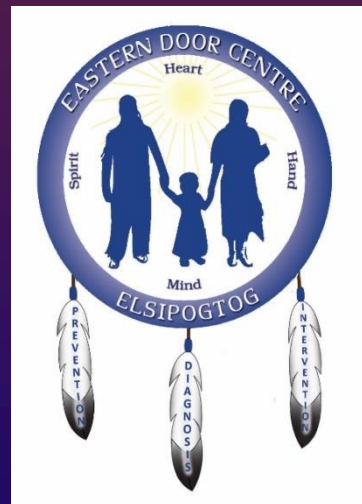
Sleepy Bear Difference Game Cards



Bronson Augustine-Elsipogog Eastern Door Youth

Eastern Door Centre

- ❖ Cards developed as a screening tool for youth sleep problems at the ED Centre



Culturally Safe Services





Eastern Door Centre

- ❖ ED offers multi-disciplinary Elder informed healing services for FASD and related disorders
- ❖ Screening-diagnosis-prevention-intervention
- ❖ Integrates medical + community cultural practices
- ❖ Concept of Two-Eyed-Seeing informs our work



Two-Eyed Seeing

In Two-eyed seeing

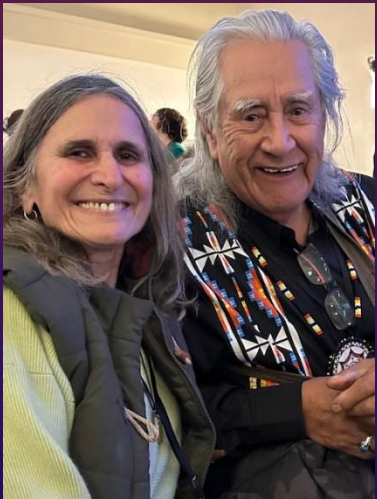
- ❖ One eye looks through a traditional lens
- ❖ One eye looks through a scientific lens

Looking in this way gives more depth in perspective



Mi'gmaq Two Eyed Seeing

- ❖ Two-Eyed Seeing was brought to Eastern Door by Murdena Marshall and her husband Albert



Acknowledge Indigenous Elders: Josie Augustine, Elizabeth Penashue, Noel Milliea Joe John Sanipass, Peter Clement





Sleep Teachings

- ❖ Elders also taught us about the role of sleep in the Wabanaki world and how it connects us to ourselves and to spirit
- ❖ The Sleepy Bear Cards developed from teachings western science as well as Wabanaki Elders

Acknowledge the Youth in Elisipogtog



Kassidy Joseph -- Student at the Elisipogtog School



Medicine Wheel Sleepy Bear Cards

- ❖ Allow us to listen to youth about their sleep
- ❖ Engages youth in the process and helps them have awareness, learn self-advocacy by actively working to improve their sleep
- ❖ Sleep can be affected by elements in multiple domains as it can affect functioning in these domains Mental, Physical, Emotional, Spiritual



Acknowledge Western Sleep Teachings

- ❖ Dr. Osman Ispiraglu invited us to a sleep research symposium
- ❖ Travelled to the community to help us in our work.
- ❖ Collaborated with us on a CIHR grant that resulted for us in development of Sleepy Bear approach.





Western Sleep Science

- ❖ Dr. Chris Loock is a clinician who has supported us by bringing her clinical expertise to the Eastern Door collaborating with us on developing a TES healing model. She is also here today
- ❖ Dr. Ispiraglu is in Europe working with international sleep researchers and will start off by giving some context to the Sleepy Bear approach



Sleepy Bear

Difference
Cards for
Screening,
Self
Assessment

And
Intervention



Sleepy Bear Sleep Screening

- ❖ To Wabanaki Elders sleep is essential to a person's physical health and spiritual well-being.
- ❖ Dreams are a place of quiet
- ❖ Allowing us to hear our own voice as well as that of Creator.
- ❖ Mainstream health professionals and researchers also recognize the relation of sleep to health.
- ❖ From their perspective, sleep is restorative



Sleepy Bear Sleep Screening

- ❖ Sleep is a time when the brain and the body does its clean-up work--repairing, restocking and reorganizing.
- ❖ The quality or architecture of a person's sleep has much to do with whether the process works the way it should.

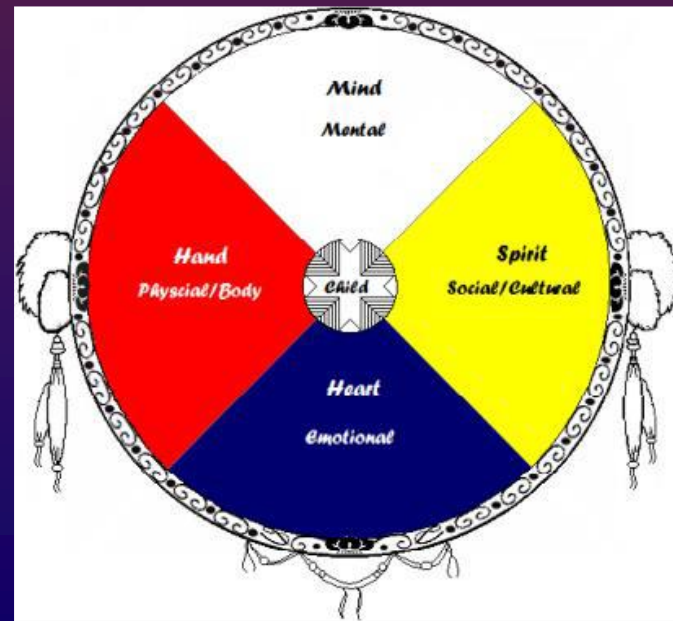


Sleepy Bear Sleep Screening

- ❖ Children with complex neurodevelopmental disorders, C-NDD's, like FASD often have problems getting good quality sleep.
- ❖ PAE gives rise to sleep problems- these in turn can exacerbate CNS dysfunction in other domains
- ❖ Yet sleep is often neglected in our evaluations of FASD

Holistic Approach to Sleep Problems

- ❖ Sleep problems may also be associated or exacerbated by other physical, social and emotional issues





Sleepy Bear Sleep Screening

- ❖ If we look at the sleep disorder in a holistic way
- ❖ An imbalance or dysregulation of an individual's internal or external world
- ❖ We can identify sleep issues and help youth identify their sleep problems
- ❖ To begin the work of resolving them
- ❖ Connect the youth/family to services they require



Shift In Approach

When there is disrupted and restless sleep often during the day the child has:

- ❖ Difficulty regulating emotions and frustrations
- ❖ Difficulty paying attention and remembering
- ❖ Difficulty with judgement and impulsivity
- ❖ Sensitivity to lights, sounds and touch
- ❖ Frequent melt-downs

These have more to do with system imbalance and exhaustion than defiance and disrespect



Typical Approach May Not Work

Often advice given to families is:

- ❖ be stricter, work harder, ‘train’ the child to sleep, take away their ‘sleepy bear’ so they don’t depend on them for comfort and security
- ❖ These approaches can make things worse.
- ❖ Children with FASD do not need more pressure.
- ❖ They need safety, calm and co-regulation



What does help?

We can support sleep by:

- ❖ Creating a sense and feeling of safety at bedtime
- ❖ Staying calm even if the sleep seems broken
- ❖ Reducing sensory overload (noise, light, action)
- ❖ Work with children's sleep patterns –not against them-one child is not be the same as another's
- ❖ Understand that parents rest is important
- ❖ Parents regulation helps their child regulate



They Need More if in Pain

- ❖ If their legs hurt
- ❖ If their tummy's hurt
- ❖ If they can't breathe
- ❖ If they are cold or hungry



Sleepy Bear Sleep Screening

- ❖ Designed to screen for physical, emotional, mental, and social issues affecting sleep and also
- ❖ To engage youth in their own journey to a good night's sleep





Sleepy Bear Cards

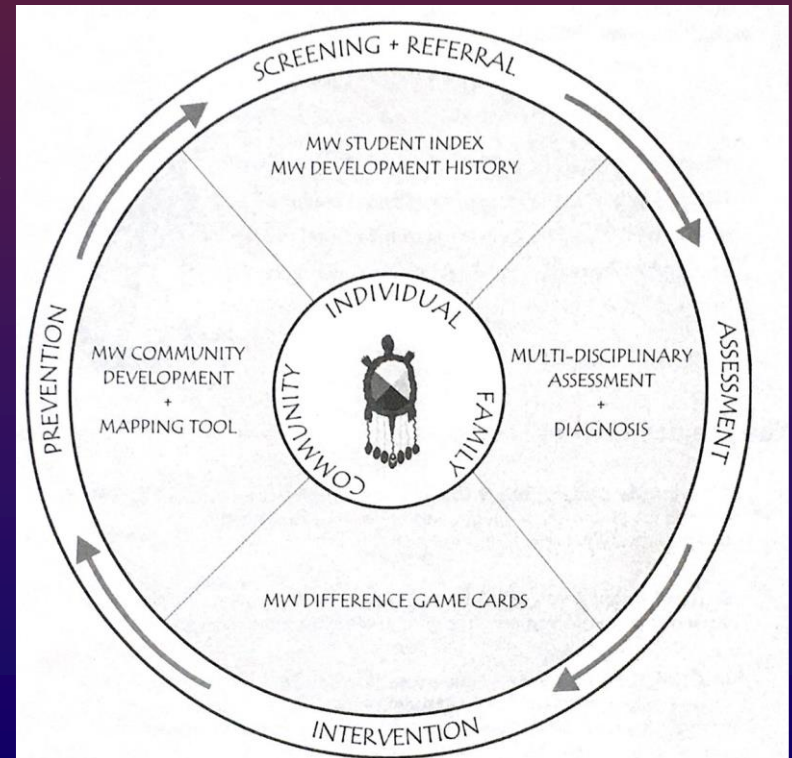
- ❖ Cards and instructions can be downloaded from the Eastern Door website

www.easterndoor.ca

- ❖ Cards can be laminated to create a hard copy
- ❖ Digital version available on the website
- ❖ Helpful working with youth in remote communities as they can be administered digitally

Sleepy Bear Difference Game Cards

- ❖ Can be used independently just for sleep screening
- ❖ Or as part FASD screening and assessment process
- ❖ Suite of Two-Eyed Seeing Tools designed Eastern Door





Sleepy Bear Cards

- ❖ Incorporate the structure of the well-established BEARS pediatric sleep screening framework:
- ❖ Bedtime Issues
- ❖ Excessive daytime sleepiness
- ❖ Awakenings
- ❖ Regularity and duration of sleep
- ❖ Snorning



Sleepy Bear Cards

- ❖ BEARS screening concepts embedded in
- ❖ Narrative-based, visual, culturally familiar format
- ❖ Helps youth tell their sleep stories
- ❖ Including those with cognitive, communication or executive functioning challenges
- ❖ Reflects day and night realities of Indigenous, neuro-diverse and marginalized youth



Sleepy Bear Cards

- ❖ Cards encourage storytelling—from the child's view
- ❖ They respond better than using abstract questions
- ❖ Each card reflects a specific aspect of sleep and sleep disruption that relates to clinical domains
- ❖ It has sensitivity like BEARS screening but each area need more investigation--gentle probing
- ❖ Continuing the sleep conversation which helps with specificity



Sleepy Bear Cards

- ❖ Youth choose the cards that relate to their experience
- ❖ So they are participants rather than subjects of an assessment or objects of a study
- ❖ In telling you why they chose the card it becomes a conversation rather than an interrogation—a collaboration



Sleepy Bear Cards

- ❖ The listening fosters respect and relationship
- ❖ Trust, engagement and safety
- ❖ Sleepy Bear approach is wider than sleep symptoms
- ❖ Explores contexts that can be invisible in usual clinical encounters



Sleep Bear Approach

- ❖ Issues such as inadequate housing, lack of beds or bedding, over-crowding, nighttime noise, fear of violence, inconsistent care-giving, late-night screen-use, food insecurity and emotional distress.
- ❖ The game creates a space for these to be named
- ❖ And framed as contextual realities that shape sleep opportunities and quality
- ❖ Rather than as behavioral or individual or parental failing



Social Determinants of Sleep

- ❖ Cards help clinicians and community workers identify structural and social determinants of sleep
- ❖ These require responses and allow an approach more sensitive than typical ‘sleep hygiene’ advice
- ❖ Aligns with contemporary understanding of sleep in the ICD-11 which introduced a dedicated chapter on sleep-wake disorders



ICD-11 Shift

- ❖ ICD -11 recognizes sleep disorders as distinct primary not just secondary to other disorders
- ❖ Emphasizes dimensional assessment, interaction biological, psychological, environmental factors.
- ❖ ICD-11 framework reinforces importance of comprehensive sleep assessment that considers comorbidity, context and function—daytime and nighttime two halves of one whole
- ❖ Key for clinicians working with youth with FASD



Sleepy Bear Complements ICD-11

- ❖ Practical youth-engaged entry point into assessment
- ❖ Supporting early identification of sleep-related concerns needing further evaluation-ICD criteria
- ❖ Provides a relational front door to evidence based sleep assessment—not a replacement for it
- ❖ Translates diagnostic categories into meaningful lived experience--bridging the gap between classification systems and real world practice



Sleepy Bear and Child Rights

- ❖ Beyond clinical alignment the Sleepy Bear Cards deeply grounded in a children's rights perspective
- ❖ Emerging recognition of a child's right to sleep per United Nations Convention on the rights of child
- ❖ Right to sleep embedded within the rights to health, development, protection and participation.
- ❖ Adequate sleep essential for cognitive development, emotional wellbeing, learning, safety.



Administration of Sleepy Bear Cards

- ❖ Pre-administration — Get written or verbal informed consent from the parent or guardian.
- ❖ Phase One -Initial Sorting of cards 30-45 minutes
- ❖ Phase Two Small Steps Planning --30-45 minutes
- ❖ Small Steps Work — Ongoing
- ❖ Phase Three -Evaluation Progress - 30-45 minutes

Administration

- ❖ Phase One Sleep Story Screening
 - Initial sorting 30-45
 - Setting sleep goals
- ❖ Phase Two Improving Sleep
 - Small Steps Planning 30-45
 - Referrals 15-30
 - Small Steps Work Ongoing
- ❖ Phase Three Evaluation progress 30-45



It Would Make A Difference To My Sleep



1. It didn't take me so long to fall asleep
- 2 My feet didn't move around so much
- 3 I didn't feel so scared and lonely
- 4 My thoughts didn't bother me
- 5 I had my own bed and room
- 6 It wasn't so noisy
- 7 I had more blankets
- 8 I didn't feel so itchy
- 9 I wasn't so hungry
- 11 I didn't cough and sneeze so much
- 13 I had a lock on my door

BEDTIME PROBLEMS

It Would Make A Difference If

14. It wasn't so hard to wake up in the morning

15. I wasn't so tired during the day

16. I didn't feel like sleeping in class or in the car

17. I didn't have to take naps

**EXCESSIVE
DAYTIME
SLEEPINESS**



It Would Make A Difference If:

18. I didn't toss and turn all night

19. I didn't wake up so many times

20 I didn't have such bad dreams

21. It didn't take me so long to get back to sleep

22. I didn't wake up all frightened and scared

23. I didn't sleepwalk

AWAKENINGS



It Would Make A Difference

24. My friends would stop texting me at night

25. I didn't stay up so late with games

26 I didn't sleep so late in the morning

27. Someone would tell me a story every night and tuck me in bed

REGULARITY



It Would Make A Difference If

28. I could breathe better

29. I didn't wake myself up with my snoring

30. Other people would stop making fun of my
snoring

SNORING



Setting the Sleep Goals

Phase One : What Do You Need to Get a Good Night Sleep?

- ❖ Make a copy of the Score Form
- ❖ Bring out the cards and show them to the youth
- ❖ Note that literacy level may be problematical so position yourself where you can read the cards out-loud as the youth is reading them



Sleepy Bear Game Script

While you are showing the cards say something like:

- ❖ *This is a game we call the Sleepy Bear Game.*
- ❖ *Each of the cards says: 'It would make a difference to my sleep if '*
- ❖ *I want to know what you need to get good sleep*
- ❖ *Each card has on it something that might make a difference to help you sleep better.*



How to Use the Cards

- ❖ *There are also 4 wild cards you can use in case you have an idea not listed on the other cards. But you don't have to use them*
- ❖ *Now I would like you to divide the cards into two piles.*
- ❖ *In one pile put the cards that would not make a difference to help you sleep This is the NO pile.*



Phase 1--First Sort

- ❖ *The 2nd pile is for the things that would help.*
- ❖ *This is the YES pile.*

- ❖ *The YES pile is for the things that right now would make a difference to help you sleep*



Phase 1-Engage Youth

- ❖ Engage the youth in dialogue about the cards they've chosen so you can listen to their sleep stories—relate to your own sleep story if you can
- ❖ After the cards are chosen and in the 2 piles, take the NO cards out of the game
- ❖ Keep them in a pile to make note later on the scoring sheet as NO.



Sleepy Bear—Second Sort

- ❖ Continue the sorting process explaining to the youth once again to put the cards that matter in the YES pile and the others in the NO pile
- ❖ Make sure to keep the cards in the second and third sorts in their own piles so that you can enter them on the score sheet



Sleepy Bear Sorts-Top 5

Tell the youth:

- ❖ *Continue sorting until you choose the top 5 most important things that would make a difference to help you sleep better*



The Final Sort—Top Five

Then tell the person youth:

- ❖ *Of the 5 cards you have chosen I would like you to put these in order of importance with #1 as your most important. (They may need help with the concept)*
- ❖ After the youth has selected and handed the cards to you keep track on the Score Form of the top five



Listening to the Sleep Story

- ❖ Score the top 5 cards on the form immediately and score the others when you can do it without disturbing the dialogue
- ❖ Scoring keeps track of all sleep issues identified
- ❖ Allows you to re-visit
- ❖ Any problem identified by the youth can drive the dialogue and inform the sleep narrative resulting in possible referral or intervention



Listening to their Sleep Story

- ❖ If an issue is highly charged for the youth it may take a few sessions for them to discuss with you
- ❖ The idea is to engage the child in their own sleep journey and allow them to tell you their sleep story
- ❖ Remember that their narrative may not match up with their parents



Phase 1-Scoring Summary

Scoring keeps track of all sleep issues identified by the youth

- ❖ 1st Sort-Put an X in either the yes or no column
- ❖ 2nd Sort – Issues that matter a little rank of 7
- ❖ Additional Sorts- Issues matter a lot rank of 6.
- ❖ Final--Top 5 Issues matter most ranked in order



Phase 2-Small Steps

- ❖ Take out the ‘Small Steps’ sheet
- ❖ In Small Steps phase the collaborative work begins
- ❖ Helping youth set goals and improve their sleep
- ❖ In this phase the 5 goals identified in the initial cards-sort broken down into ‘small steps’ that are easier to accomplish
- ❖ Youth can work on more than one goal if practical



Small Steps Form

- ❖ Start slowly –Give as much help as is needed
- ❖ Record the small steps that need to be taken on the ‘Small Steps’ form
- ❖ You should also record who will be responsible for carrying out each of these steps.
- ❖ Youth may require various levels of advocacy



Small Steps-Self Advocacy

- ❖ You are supporting youth in learning how to advocate for themselves
- ❖ How to take their own journey to good nights sleep
- ❖ At first high levels of support
- ❖ Support diminishes as youth learn about their sleep
- ❖ How to accommodate their sleep style
- ❖ Make healthy choices for themselves



Say:

- ❖ *I am here to work with you to help you get what you need to get a good nights sleep*
- ❖ *We can work together to decide small things that can be done right now*
- ❖ *Tell the youth— Small steps can get you where you want to go*
- ❖ *This is where the referrals can come in*



Phase 2-Referrals

- ❖ Referrals are a key part of Small Step process
- ❖ Youth may have identified sleep issues that require a medical sleep assessment or referrals to outreach, counseling, Elders or help from social agencies
- ❖ It is possible to use the cards primarily as a sleep screening tool- leading to referrals and services
- ❖ On the referral form are services tied to youth identified problem sleep areas



Phase 2-Referrals--Small Steps

- ❖ Explain role of each of the referral specialists who might be able to help the youth in improving sleep
- ❖ Ask about sharing information with parents
- ❖ If there is resistance –respect it and take the time to work through it—but don’t give up—build trust
- ❖ Understand issues can be charged in various ways



Reporting vs Referring

- ❖ Difference between reporting and referring
- ❖ If there is a disclosure of abuse you have to report
- ❖ Explain this to the youth from the outset
- ❖ If you do have to report let them know—and also the safety reasons and your concern
- ❖ It doesn't have to erode the relationship if you are honest



Reporting vs Referring

- ❖ An issue such as ‘It would make a difference if I had a lock on my bedroom door’ should be probed
- ❖ Might/might not indicate family violence-abuse
- ❖ If there is disclosure
- ❖ Immediate reporting and make sure to follow-up and continue support if possible



Working Collaboratively

- ❖ Some areas that are not so clear-cut
- ❖ Be aware of structural inequities that can damage or erode relationships
- ❖ Possible to engage youth and family in finding community cultural paths rather than ‘reporting’—housing, food insecurity, cultural counseling



Referral Examples

- ❖ Restlessness- Difficulty keeping feet still –medical referral to assess movement disorders/Iron Deficiency
- ❖ Snoring-medical referral- assessment sleep apnea-c
- ❖ Food insecurity, poor housing or clothing— referrals for advocacy and support
- ❖ Sleep fears/nightmares-counseling, mental health,Elder referrals



Phase Three-How Are We Doing?

- ❖ Use the Goals-Evaluation Form to Evaluate the Process—Make a copy of the form
- ❖ After a few months the person who is setting the goals and the youth worker evaluate their level of satisfaction with the progress being made-each from their perspective .



Say:

- ❖ *Now is the time for us to check out how we both think things are going.*
- ❖ *Are you satisfied with the progress being made? Rate your feelings on a scale of 1 to 5-- with 1 being totally unsatisfied-no progress and 5 being totally satisfied*
- ❖ *I will do the same*



Focus on the Positive

- ❖ This is also the time to discuss differences of opinion. Work on the positive. Praise the small steps that have been accomplished. Decide what other small steps need to be taken.
- ❖ Record the goal, the date set, the date assessed, the small steps that were made and overall satisfaction from each perspective.

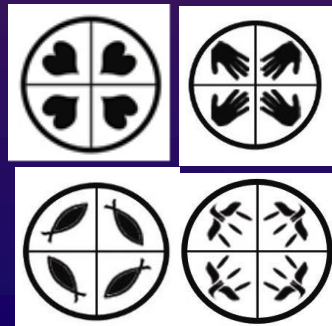
MEDICINE WHEEL DIFFERENCE GAME GOALS-EVALUATION FORM

DATE GOAL SET	GOALS	DATE OF ASSESS- MENT	COMMENTS ON PROGRESS WHAT HAS BEEN DONE? WHO HAS DONE IT?	SATISFACTION WITH PROGRESS TOWARDS GOAL	TYPE OF GOAL SUIT
				PROGRESS: NONE VERY PERSON <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> HELPER <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u>	
				PROGRESS: NONE VERY PERSON <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> HELPER <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u>	
				PROGRESS: NONE VERY PERSON <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> HELPER <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u>	
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				PROGRESS: NONE VERY PERSON <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u> HELPER <u>1</u> <u>2</u> <u>3</u> <u>4</u> <u>5</u>	
				PROGRESS: NONE VERY	



Wela'lieg—Thanks

- ❖ We are grateful for the work of all those who came before us and also for those who will come after to adapt these tools or develop new ones that are culturally safe and work to empower FN people.

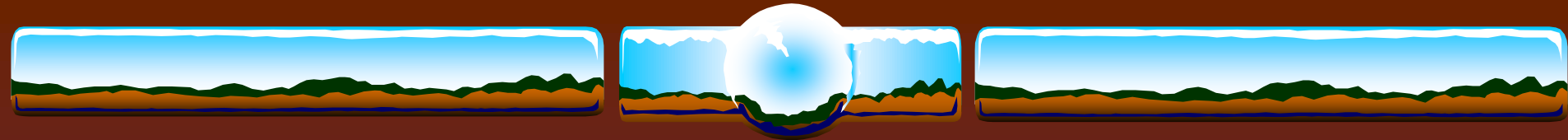


HEART: HAND: MIND: SPIRIT

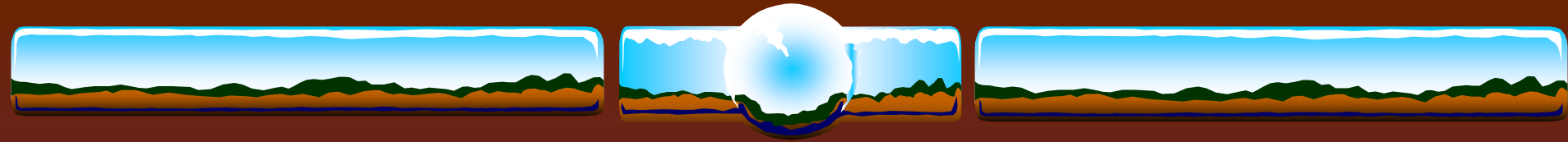


Trying Out the Cards

- ❖ Divide into pairs-decide on roles
- ❖ Start playing the game
- ❖ Working with each other to screen for sleep issues
- ❖ Listening to each others sleep stories



- ❖ Elder Marshal teaches that sleep is a sacred time
- ❖ Supporting good sleep helps to restore balance
- ❖ For the child, the family and the community.
- ❖ Approach sleep support with gentleness not force
- ❖ Honour safety rhythm, and relationship
- ❖ Recognize dreaming as part of a child's overall wellness and help the child to understand their dreams are there to help them not hurt them



❖ Western interventions alone are often insufficient without this broader understanding



North
Prevent-Reduce PAE
 Awareness, Education
 Improve Determinants Health
 Reduce cultural risk

Direction Inside
 Connection-Self

Direction Above
 Connection Creator

West
Prevent-Reduce
Generational FASD
 Youth FASD having baby FASD
 Mother having another baby
 PAE



East
Reduce Effects PAE
Pre-Diagnosis
 Early Screening
 Function-Based
 Interventions

South
Prevent -Reduce
Secondary Conditions
 Early Diagnosis
 Support Youth+ Family

Direction-Below
 Connction Earth

Good Sleep connected
 To Each of the 7 Directions