

DATA GOVERNANCE STORIES

WINTER/SPRING 2016



First Nations Health Authority
Health through wellness

Gwen Phillips, Director, Governance Transition, Ktunaxa Nation
BC First Nations Data Governance Initiative Provincial Champion

Appreciative Inquiry and Population Health

Community Development Nation Rebuilding

✓ People

✓ Land

✓ Traditional Knowledge and Language

✓ Economy



First Nations Research: Answering our own Questions

- When I was doing some work with a First Nation Community near Hamilton Ontario, a Council member shared a story with me that about how the ladies in the community were sitting around one day, chatting and they agreed that it seemed to be a long time since a baby boy was born in any of their families...
- They decided to actually look into it and the health team did a bit of research to look at the number of male and female babies born in the community, going back as far as they could with the Canada Prenatal Program data and analyzing other community data (baptisms) that they had access to, as well as conducting a community survey, and they did in fact conclude that over the course of 40 or so years there was a steady decline in the male to female birth rate ratio; in the early years, things seemed to even out over a 3 or 4 year period – boys to girls, but in more recent times, things changed and it looked as if when the study concluded over a decade ago, for every 6 girls born, there was one boy born and this was the case consistently for quite some time.
- Eventually, a National study was carried out and this birth trend was correlated to the increase in petro-chemical activity in the region that increased on an equally alarming curve; a documentary called 'the disappearing male' featured these findings.

Community Healing & Intervention

(Program - Process) – CHIP – The Awakening

- When negotiating Local Education Agreements (1989), we asked ourselves why our children weren't successful learning and functioning in the provincial school systems
- Learned about FAS (ARBD) and related it to our historical *circumstances* (poverty, residential schools, 40 years of alcoholism within the community, similar birth defects and learning difficulties???)
- Began to really focus on the root causes of our communities issues rather than just the manifestations – the *behaviour*
- Started to move away from program delivery and focus on Individual and Family Wellness - Individual Training Plans, Family Growth Plans, Education *Environment* Plans...
- Determine our own destiny, our *Vision*, and build our own economy based on our Ktunaxa values and cultural strengths – the *ultimate social, cultural, physical and economic environments*
- **ENGAGE** Community (government, citizens, resources) in becoming life-long growth and support network – self-sufficiency
- **COMMUNITY**: internal and external relationships - Identify and enlist a team of advocates- social support network
- Devise and implement **HEALING** Strategy
- Assess needs and opportunities and develop **INTERVENTION** Strategy

First Nations Research Ethics and Data Ownership

- In the early 1990s the Ktunaxa Nation was in the early stages of developing their Independent School System and negotiating Local Education Agreements with the public schools serving their communities when they entered into a Research project with Researchers from the University of British Columbia.
- At that time, there were very little guidelines for conducting Indigenous research and the Researchers claimed ownership of the data produced from the full psych-educational assessments and medical examinations that were conducted on over one hundred participants who were children, in addition to data generated through personal interviews with parents and caregivers.
- Some of the participating parents might have also have been ‘classified’ as FAE...
- This data was governed by the existing mainstream regulations that were in place at the time, and the data was destroyed as per the institution's data retention policy; we trusted them as the ‘experts’.
- Many of the research participants that were children at the time, are individuals that were concluded to have been affected by fetal alcohol exposure and they are adults now, wanting access to this data but it has been destroyed!
- To the Ktunaxa, this is unethical!

Understanding Community



Understanding Ourselves

- Each one of us is unique, with a set of gifts and challenges that impact our lives daily.
- Each one of us has grown and lives within a different **environment**.
- Our personal traits and **characteristics**, our choices and experiences (**behaviour**) and our current environments influence our life's outcomes.
- People with FASD require on-going nurturing and support; chronological age and developmental age may differ greatly – may never “grow up” and may always be the ‘community’s children’.
- We can manipulate the environment and create opportunity for people to experience success and participate meaningfully in community.

We all want the same things...

- People want to be happy and healthy.
- People want to belong; to be culturally active.
- People want a healthy environment in which to live.
- People want to contribute; to be productive and valued.
- People want to be self-sufficient; to have jobs that they enjoy doing and that provide enough income to meet their needs.
- People want to feel safe and secure.
- BC First Nations Leaders want the same thing:

Healthy, vibrant, self-determining BC First Nations children, families and communities!

Strategic Planning and Nation Rebuilding: Learning from the past, planning for the future...

Starting **W**ith **O**ur **T**ruth

(absence of negatives or presence of positives)

Celebrating who we are and our history in our ancestral homelands...

- Can't fix it if you won't admit is broken
- **Blame, shame and guilt is no foundation for our Nation**
- Individual expressions of collective impacts; collective healing to support individual injury
- Knowing, understanding and accepting our personal and collective history and its impact on our lives
- Youth and single parents chronically disengaged
- Everyone needs to be honoured in their journey and ***Appreciative Inquiry*** and ***Population Health approaches to Community Development***— building on inherent strengths and reducing barriers

Determinants Of Wellbeing

1. Culture

2. Biology and Genetic Endowment
3. Healthy Child Development
4. Physical Environments
5. Social Environments
6. Gender
7. Social Support Networks
8. Education
9. Personal Health Practices and Coping Skills
10. Health Services
11. Employment/Working Conditions
12. Income and Social Status

Wellness Indicators: Looking beyond the numbers

- Research enables First Nations to ask and answer our own questions – to tell our own stories, in our own words
- Individual Indicators, when linked together and aligned with Outcomes, create complete picture of wellbeing
- Common Outcomes enable global reporting of our progress towards achieving common Vision
- Sometimes we learn things we didn't know were related...



Strong, healthy citizens and communities, speaking our languages and celebrating who we are and our history in our ancestral homelands, working together, managing our lands and resources as a self-sufficient, self-governing Nation.

Various levels of Indicators

National

The purpose of this Act is to govern the collection, use and disclosure of personal information by organizations in a manner that recognizes both the right of individuals to protect their personal information and the need of organizations to collect, use or disclose personal information for purposes that a reasonable person would consider appropriate in the circumstances.

Provincial

Regional

Indigenous Nation

Community

Family

Individual

Determinant: Culture

Outcome: Connected to Cultural Heritage



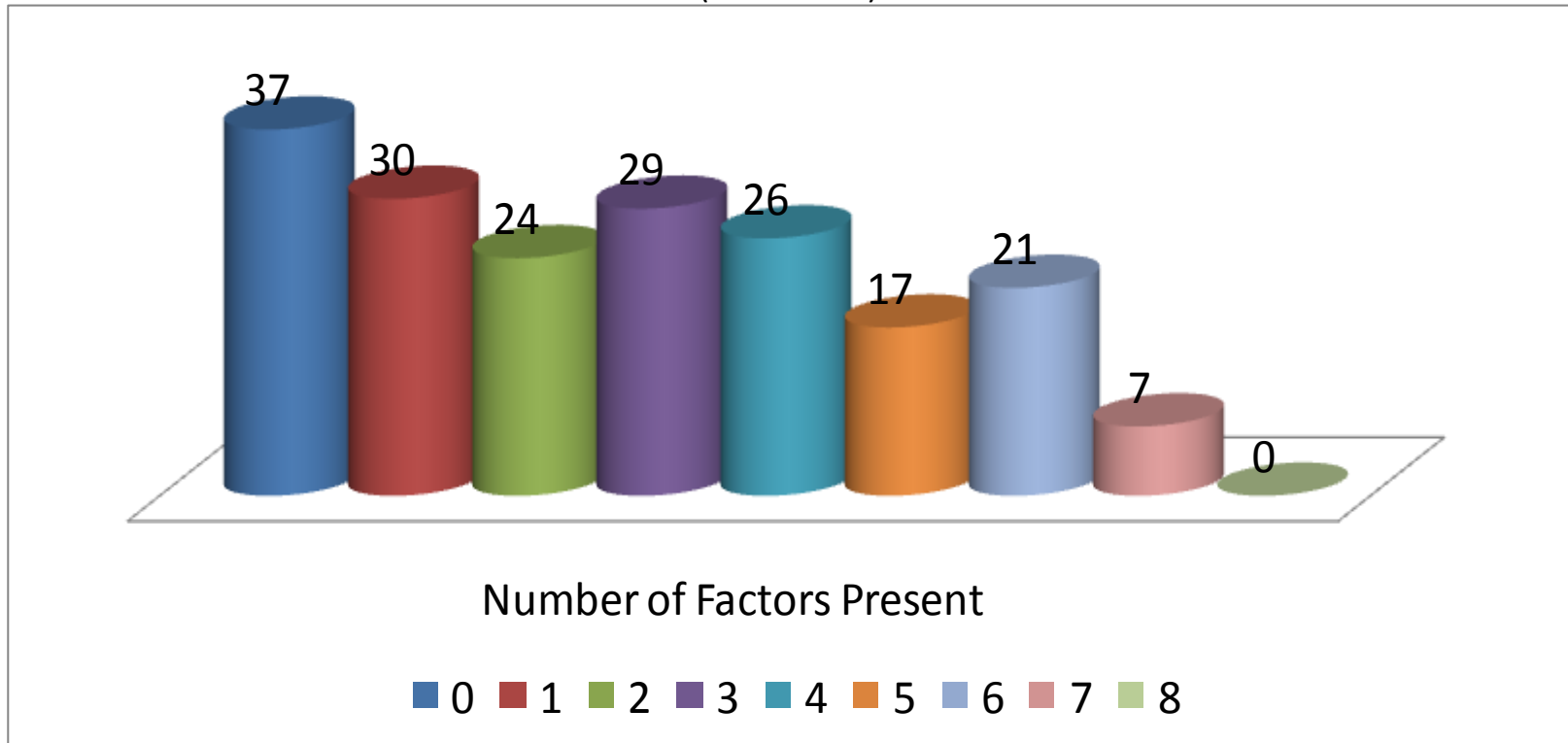
Current Provincial level Indicators

- Life expectancy
- Mortality rates (deaths due to all causes)
- Status Indian youth suicide rates
- Infant mortality rates
- Diabetes rates
- Childhood obesity
- Practicing, certified First Nations health care professionals

What trend do you see?

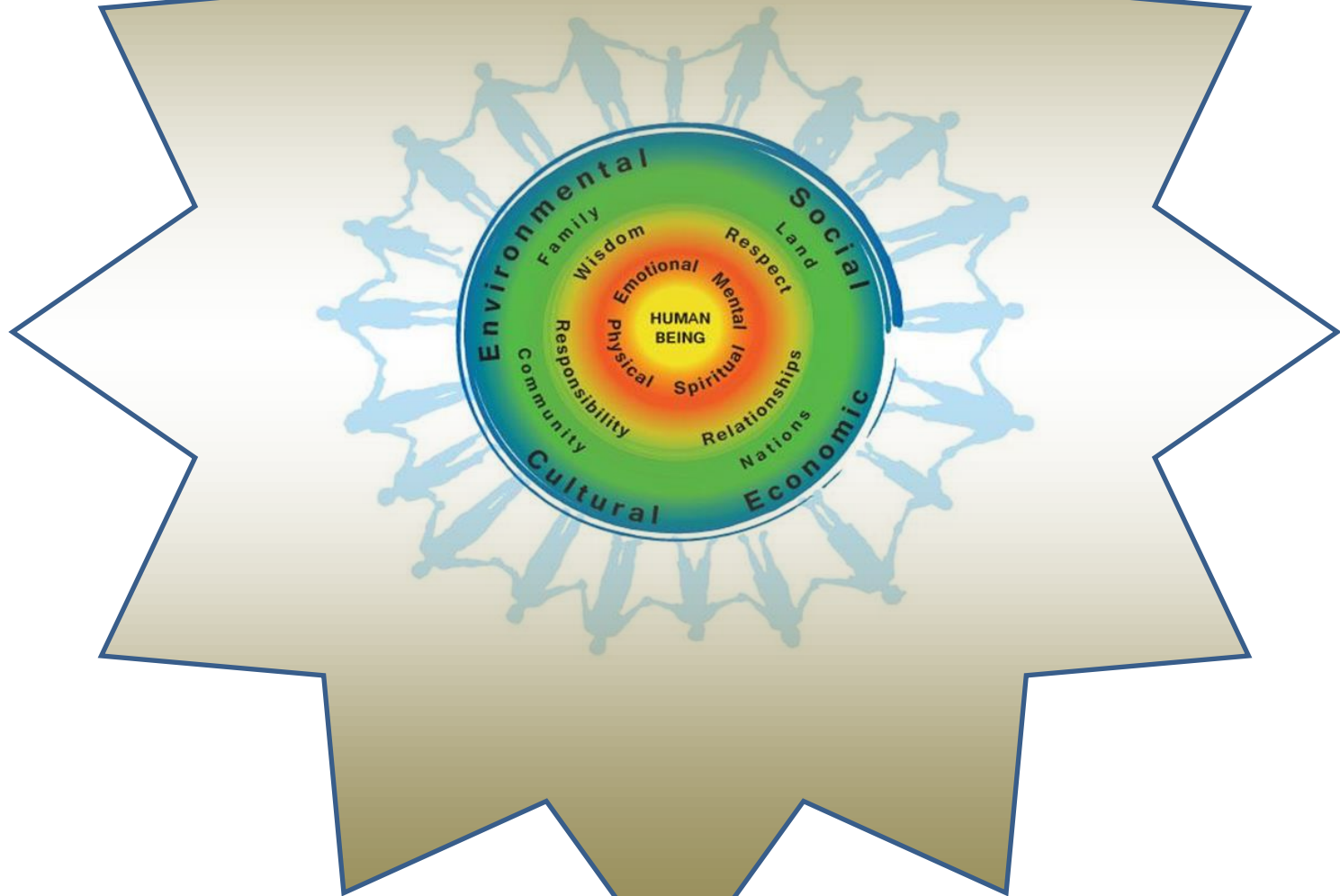
Total Suicide Rate per 100,000 by Number of Factors Present

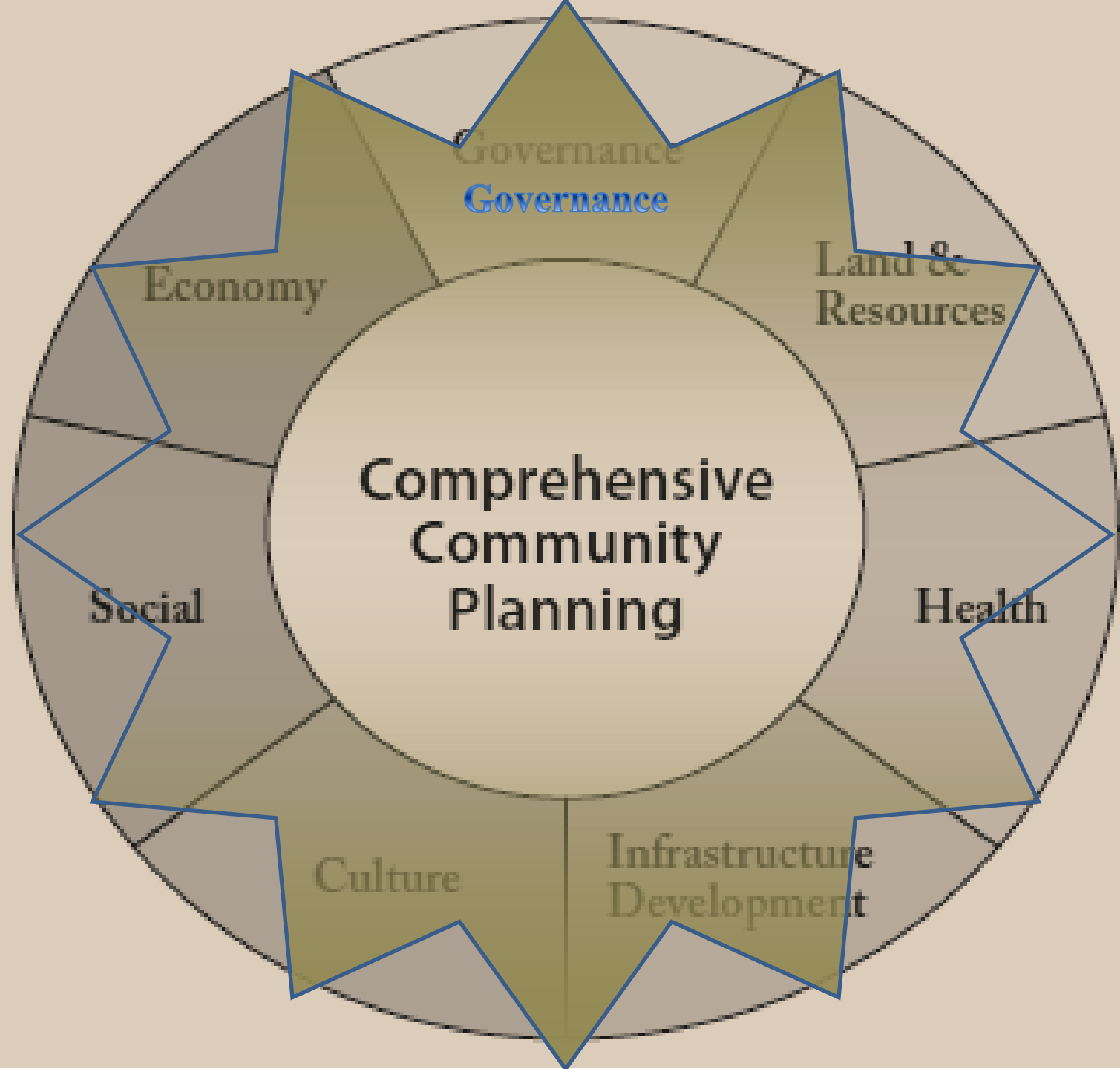
(1993-2000)

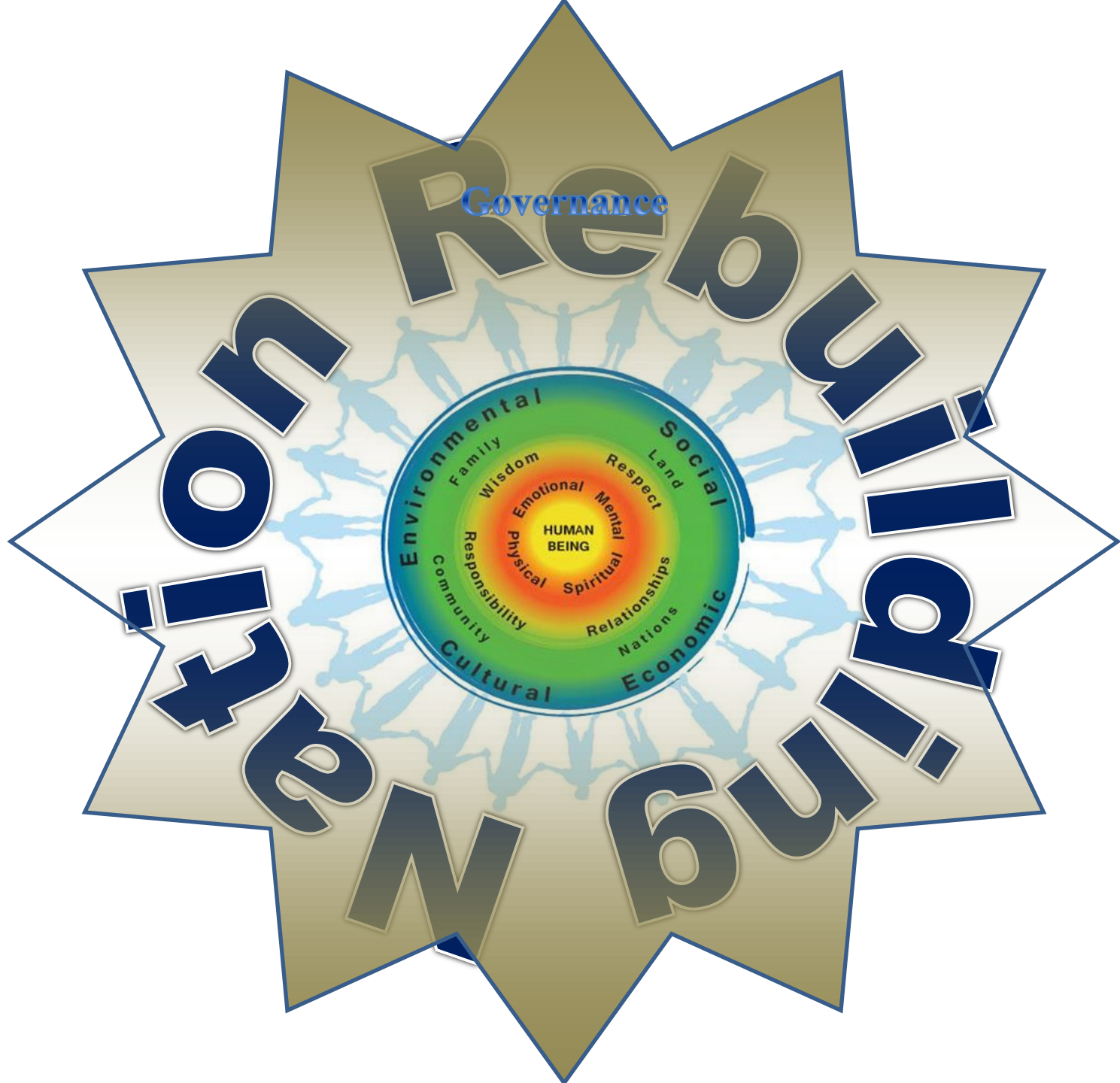


Factors: Health Services Education Services Local Policing
Cultural Facilities Child Welfare Control Land Claims
Women in Government Self-Government

Governance



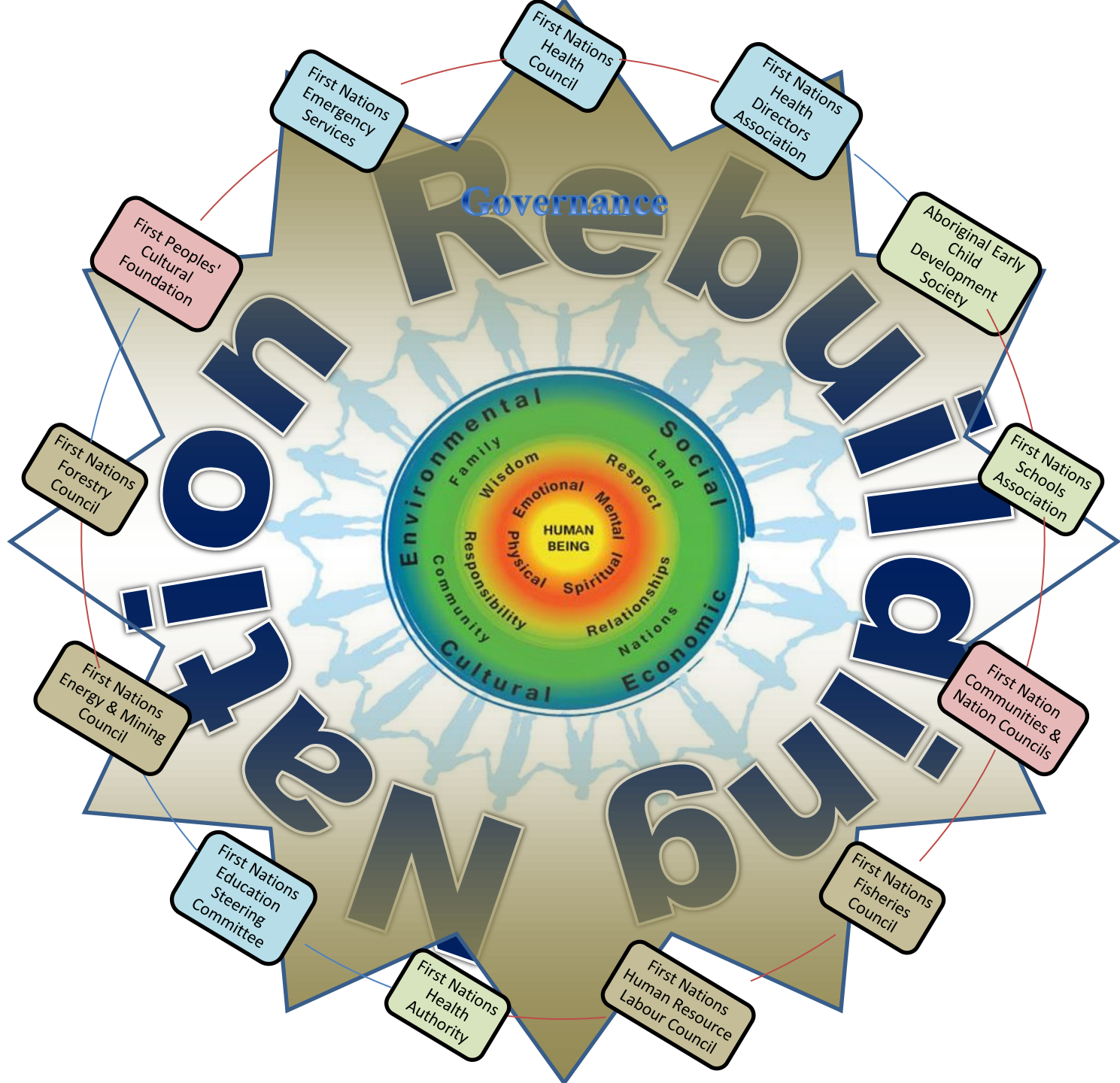




Governance

Nation Rebuild
Membina





Strategic Approach

- Building strong, healthy families – not just getting rid of problems...
- Implementing values-based governance – not just adopting status quo...
- Balancing interests across the Sectors – not competing with each other...
- Having ecosystem based land use planning – not just resource development...
- Managing an Economy – not just managing economic development...
- Clarifying the relationship of people to the land; possession, occupancy and use (tenure) – not just developing the land...



Strategic Approach

- Building strong, healthy families – not just getting rid of problems...
- Implementing values-based governance – not just adopting status quo...
- Balancing interests across the Sectors – not competing with each other...
- Having ecosystem based land use planning – not just resource development...
- Managing an Economy – not just managing economic development...
- Clarifying the relationship of people to the land; possession, occupancy and use (tenure) – not just developing the land...

ABSENCE OF NEGATIVES

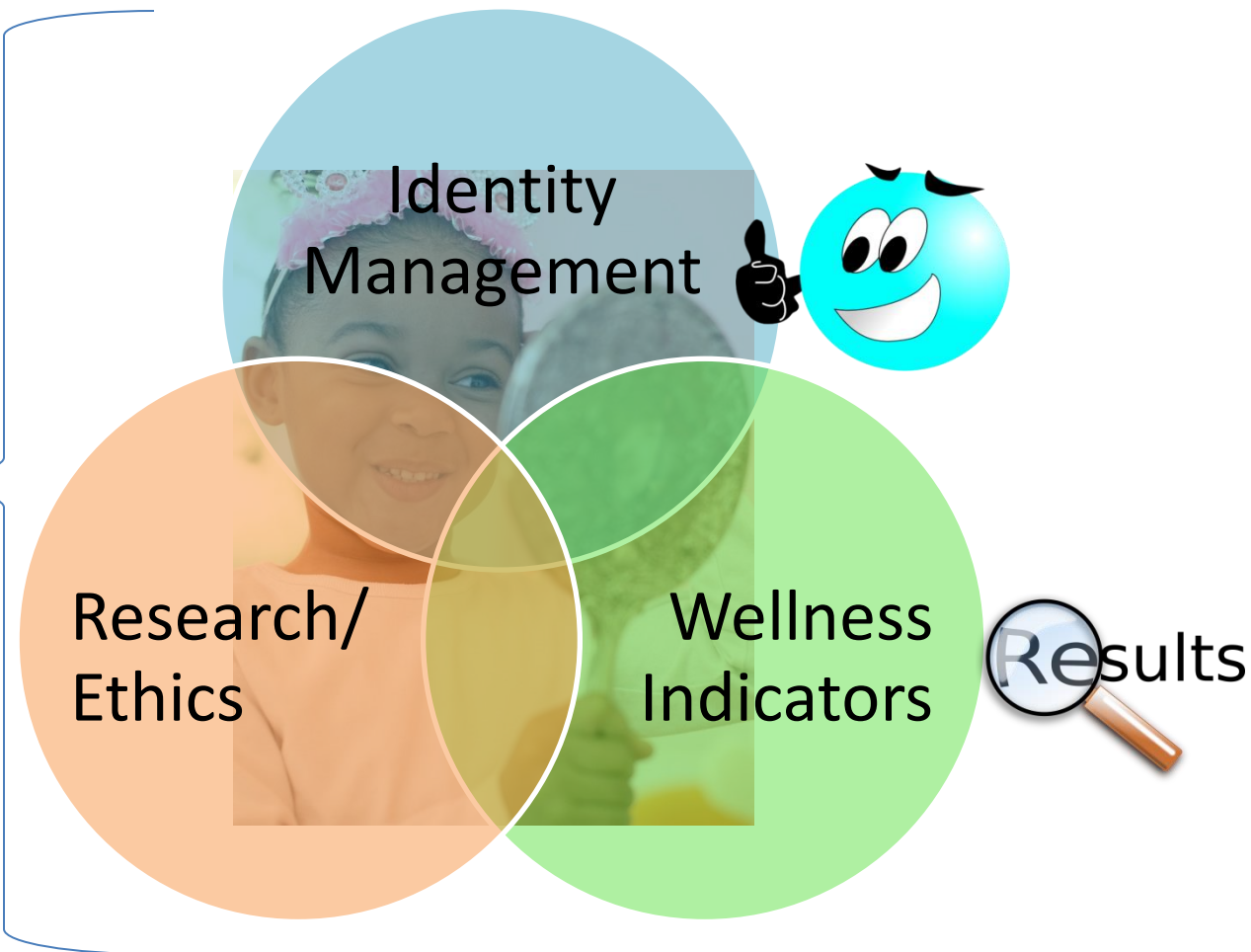
OR

PRESENCE OF POSITIVES



Putting all the Data Governance pieces together

**Data
Governance**



Attitudes and Options

Watch your thoughts,
thoughts become words...

Watch your words,
words become actions...

Watch your actions,
actions become habits...

Watch your habits,
habits become character...

Watch your character,
character becomes destiny...

Attitudes and Options

Watch your thoughts,
thoughts become words...

Watch your words,
words become actions...

Watch your actions,
actions become habits...

Watch your habits,
habits become character...

Watch your character,
character becomes destiny...

unknown



Vision