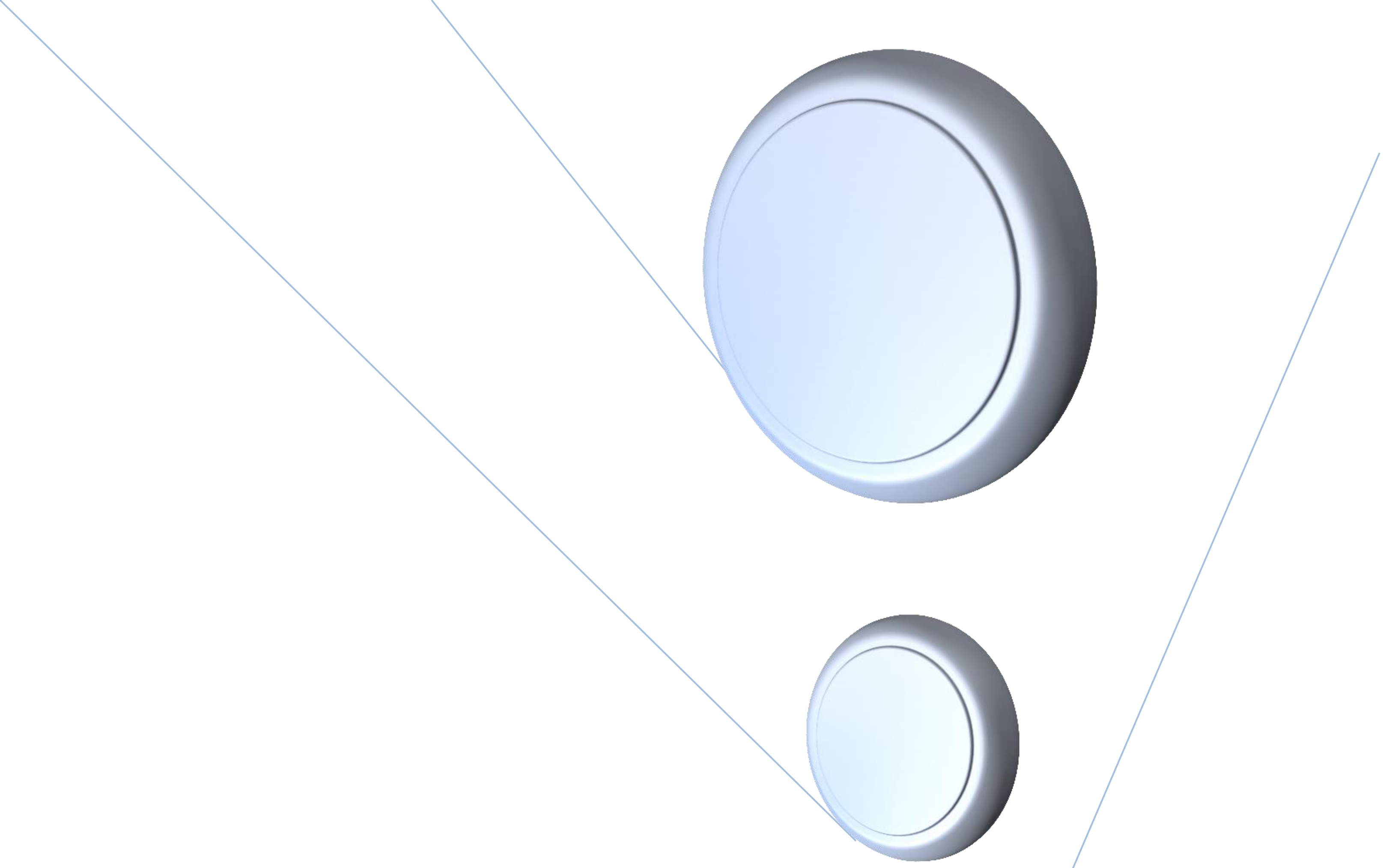

Landscape of the research

Table Discussion for Dorothy Badry

Transcription of participant notes

October 25, 2017

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Dr. Dorothy Badry
October 25, 2017

Table Discussion

What is the most pressing issue in Child Welfare in relation to FASD

- Stability of placement and assessment
    - Multi-placement trauma (avoid)
- Recommendations
    - As many resources as needed to maintain the placement or least maintain relationship connection
    - Education and training for caregivers and support staff
    - We need 'boots on the ground' hands on service
        - In the home, helping
    - Treat the service provider better/pay them well

- Acknowledge parents may also have FASD
- Diagnosis
    - They become adults without having a diagnosis = no supports as they age
- Education/training
    - Practicing with an FASD lens
    - Practice with parents, service providers
- Social workers
    - CW making assumptions that client is defiant, rude, non-compliant when they may have FASD themselves
- Recommendations
    - EDUCATE
        - Mandatory training for service providers, foster families, caregivers, families
    - Resources overview
        - If we can help service providers understand FASD behaviours they may be more tolerant, patient and not make assumptions
            - Realistic expectations
            - ↑ collaboration
    - Continue life span support, coaching
    - Recognize the grief and loss
    - Post permanency support

- Lack of education and understanding on the part of agencies and workers
- Lack of education and understanding on the part of legal systems
- Expectations may be set too high for parents
    - Whether they have children with a diagnosis or if they are parents who have an FASD diagnosis
- Recommendations
    - Having FASD training for the 2 year program, "through the lifespan'
    - Have birth parents speak to classes
        - Hear real stories

- Racial bias-systemic racism
- Multigenerational trauma
- No mandatory training in Child Welfare
- Lack f ID and diagnosis (early)
- Lack of early screening
- Lack of early intervention
- Recommendations
    - Legislation to ↑ PGO
    - More funding for case load management
        - More workers
    - When child apprehended, more services for family enhancement
    - Foster whole family instead of just child
    - More training
    - Culturally safe and significant healing supports
    - Build capacity for professionals to understand connections
        - Avoid triggers
    - Focus on brain not behaviour
    - Indigenous child advocate

- ✓ Need protocols in child welfare that do not automatically remove children because mother uses substances
    - Move focus on substance to wrapping care around the mother-child unit
- ✓ Support early attachment
    - Traditional indigenous wisdom and western science supports this
        - Why don't we do it?

- Lack of knowledge

- Not given information, info not shared
- Setting kids up for failure by not supporting caregiver with information
- No follow-up
- Supports offered insufficient
- Too much movement
    - Education does not follow the child from one caregiver to another
- Policy
    - Workers are overworked and hands are tied
    - Systems not talking to one another
    - Children’s services does not want to diagnose because they can’t support
        - Children would be harder to place

- Sharing of information with other community supports when the child becomes an adult
- Knowledge
- Recommendations
    - Being mindful of what homes you are placing children with FASD in
        - Do these families have training and knowledge of FASD
    - Before apprehension have conversation with family about process and what will happen
        - This builds distrust with families and makes them feel alienated
- Importance of diagnosis
    - Transition planning without diagnosis
    - Gaps are not identified
    - Awareness of diagnosis for the person themselves is important
- Care
    - Continuity
    - Quality
    - Education for caregivers
- Helping women to keep their children in their care
    - PCAP is overwhelmed
- Not enough money
- Not enough foster care

- Moms with FASD that have children with FASD
    - Expectations are too high
        - Mom needs to be in supported living
        - Don’t have foster homes for moms and children

  - Need coaching
  - Social workers automatically flag mother for apprehension
    - ‘you cannot parent’
      - Stigma
        - Teaching required for SW
      - Puts mom down
      - Doesn’t recognize that FASD is a spectrum
  - How do we help maintain placements? Support foster parents
  - Rural areas- lack of availability of placements
- System allowed foster home to take on too much without oversight
  - Multiple complex needs children in one home without support is problematic
    - No child with FASD is the same

- ✓ Foster parents are not trained in FASD
- ✓ Attachment disorders
- ✓ Recommendations
  - Mandatory FASD training for foster care homes with weekly support visits from caseworkers/FASD trained professional mentors etc. to provide practical tips and strategies

- Not everyone has the same level of education about FASD
- Collaboration with supports
- No respect-limited respect- for families
- Not actively seeking diagnosis
- Disconnect between medical and support workers
- Recommendations
  - Honest practical education about FASD
  - Collaboration efforts between CW, medical and support workers
  - Mandated intensive FASD training for all students in SW for every year of their degree
  - Stronger accountability for placement of children regarding life course perspective and short term

- ➢ Disclosure to foster parents
- ➢ Training for parent of FASD kids
- ➢ Family specific services
- ➢ Not all families have the same needs
- ➢ Moms need support to deal with child welfare

- Not enough supports in prevention with potential moms at risk
    - Money
- Health literacy in basic education

- Rural access to
    - Training
    - Diagnosis
    - Secure placement
        - Support to stay where they are at
    - Supporting families where they are at
    - Staff continuity
- Recommendations
    - More supports
        - Respite
        - Training
        - Ease of access
    - Drop the wording “parent driven programs’
        - Stretches caregivers
        - Must do so much research to access support
            - Don’t make easy
    - In the wheel of supports, professionals are located outside the circle

- Interdisciplinary involvement regularly to look at different areas
- How to support the whole family
- Involvement of bio family in interdisciplinary involvement
- Kinship care exploration as a first resort
- Attention to the smaller roles extended family can play even if the child has to be in care
- Enough cultural appropriately trained workers
- Family network resources
- Address legit fear of child welfare workers
- Support for family after CW is no longer involved

- Quality training for caregivers
- Mandatory training for all CS staff in all roles
- Better for aging out kids
- Permanency support for caregivers
- Better training and support for kinship
- Lifespan support for caregiver that is not child protection dependent

- Diagnostic and assessment capabilities
- Prevalence identification
- Recommendations
    - Mandatory training for all staff
    - Risk factor support intervention
    - Ongoing support for caregivers as life changes

- Basic needs- housing
- More supports for rural locations
- As a probation officer we struggle to obtain information about the client
- Delay in diagnosis is leading to less intervention and assistance from child welfare
- Stability of home placements
- Stability of CFS workers
- Recommendations
    - Recognition of diagnosis
    - Better documentation in regard to prenatal alcohol use

- Not enough families to take kids in
    - Especially in rural areas
        - But in many urban areas as well
            - Kids living in hotels
    - Continuing to find ways to support those who are fostering
    - Stigma
        - Parents won't want to say child has FASD= bad mother
    - Limited supports after diagnosis
    - Moving a lot, multiple placements, lack of secure attachment
        - And the long term consequences of this lack of attachment
- Recommendations
    - FASD supports for foster families
    - Sustainable respite

- Mothers with an FASD caring for children with an FASD
    - Acknowledge that parents have different needs
- School system overwhelming for parents and children
- Recommendations
    - Lack of education in entire system
        - Child welfare
        - School

- Caseloads too high
- One perspective
  - Training from one source
    - Dated?
    - Not ongoing
- Collaboration
  - Not always willing to defer to those with experience/knowledge of specific individual
  - Lack of inter-collaborative professional practice
  - Kids shuffled around a lot
    - No time for transition
    - No recognition of trauma of being moved around
  - ‘they are adults now’
    - Fair isn’t always equal
    - Default to law instead of acknowledging disability
- Recommendations
  - Trained in Human Rights
  - Developmental vs chronological age
  - Trauma informed practice
  - Manageable caseloads
  - Staff retention

- Recommendations
  - Thinking of the caregivers biggest complaint: a child came into their care and they don’t know their history; seeing behaviours but do not know where they come from
    - High turnover of social workers
    - Have the child’s plan with them at time of placement
    - Case conference ahead of move
      - Everyone on the team- stability vs starting over
    - Supports for child’s environment
      - Eg: lifeskills for their parents/family to create a safe environment
  - Building personal connections

- SW assumptions
- Multiple placements instead of supportive placements for children with FASD

    - Supports for foster parents
    - Ensuring foster parents are trained in FASD before placing the child

- ✓ Getting an assessment
    - Training
    - Resources
    - Professionals
- ✓ Location of where to get assessment
- ✓ Adult assessments
    - Lack of funding
    - Wait time
        - Often years, age out
    - Diagnostic criteria
        - Contact with mom to disclose
    - Sharing of information across the board with agencies
    - Lack of support once diagnosed
    - Quality of assessment, or actually getting one
    - Financing assessments
        - Time
        - Money
        - Resources
- ✓ Recommendations
    - Get more funding, resources training

- Diagnosis & assessment
    - Increase assessment in order to target interventions that are intentional and effective
- ↓focus on 'behaviour (management) ↑focus on ability and needs
- Transition
    - Coordination/collaboration with adult services
- Education for frontline staff on basic screening info
- FASD & Trauma

- ➢ Need for system to work with families who want to stay together and leverage natural supports to support success for the family
- ➢ Do not make CW decisions based on a diagnosis
- ➢ Turnover of staff in CW system difficult on families, story of individual and family is lost when worker changes
- ➢ The parents need as much help and is much a CW client as the child

- Protect the family, build family strength and function
  - Family includes child, parent, grandparent etc.

- Recommendations
  - Communicate in a positive way
    - Vs in a threatening way
  - Kinship
  - Providing more options
  - Proper tools
  - Support for the family
  - Child welfare works need more support
  - Better training
  - More compassion

- Lack of diagnosis
- Diagnostic process
- Child apprehension
  - Is simply taking kids away from an environment for a time but not fixing the actual problem
- Recommendations
  - Early intervention and education for effected children
  - Supports for pregnant mothers during their pregnancy to educate them on the dangers of substance abuse during and after pregnancy

- Immediate apprehension of infants when child suspected of FASD
  - Need more supports for birth parents, families and community
- When children are in care and have FASD, the diagnostic process is far too long
- Stigma associated with being in foster care and having FASD
- Recommendations
  - Increase support/prevention/intervention for birth families
    - Have a goal of reunification
  - Assessments at key ages for youth
    - Ie: school age, teenage years
  - Access to funding
  - Mandatory education/awareness for parents'/foster parents/caregivers/educators to help understand & end stigma of FASD

- Multiple FASD in one home
    - Support is needed 24/7
- Education and training to child welfare
- Parenting and supporting multiple adults with FASD
- Lack of foster families
- Multiple placements for a child
    - Due to lack of training
    - Burnout
    - Multiple placements in one home
- Is apprehension trauma informed?

- Because FASD does not always have physical identifiers, in a correctional setting it is difficult to identify whom may live with FASD
    - Due to privacy laws, health services does not disclose these conditions to officers, therefore, there is no modified discipline or placement for the individuals living with FASD
- I would like to see more transparency between correctional services and health services as we provide care to the individuals incarcerated as well

- Apprehension/adoption
- Lack of diagnosis
- Lack of education for guardians
- Recommendations
    - Training geared toward needs
    - Supports/ financial help from CS
    - Prevention from multiple placement
        - ↑ permanency
    - Respite that is appropriate
    - Kinship
        - Needs $

- Recognition of FASD
- Accessing diagnosis in a timely manner
- Child welfare doesn't have a practice around working with a child/family with FASD
    - Needs to work outside of its own silo
    - Work better with community partners

- Child welfare needs to be preventative, not only reactive in terms of providing family/child/school with supports
- Caregivers and children are victim of the system
- System failures
- Recommendations
  - Provide more community linked services
  - Work closer with families and foster parents
  - Re-work/re-manage child welfare systems

- Placement disruption
  - When CFS is first involved with a family they should immediately be assessing if children could be affected and then all decisions made for these kids should be coloured by these 'FASD glasses'
- Recommendations
  - Early intervention
  - Earlier diagnosis
  - Early permanency placements
    - Not 2, 3, 6 years in care
  - Education for everyone involved

- Funding
- Education to caregiver/foster parents
- Restrictions to CFS policies
- Not protection for parents
- Underpaid/low training
- Credible information vs false information
- Recommendations
  - More funding
  - More training
  - Extended supports for people with FASD after CFS involvement
  - Change in policies
  - Working with federal gov't

- ✓ Parent education
- ✓ Early intervention
- ✓ Transition from children's to adult's services
- ✓ High waitlists
- ✓ Justice supports and involvement
- ✓ Caregiver and group home education, foster parents, etc.

- How to keep child out of system
- Support birth parents
- Placement-funding foster family
    - Willing to take on a child with major disability
- Support services for FASD for families
- Stability for children
- Lawyers and judges need to be educated in FASD
- Increase funding levels for child welfare
- Adversarial approach doesn't work
- Support for adoptive parents
- Respite for birth mom and adoptive parents

- Understanding/knowledge/awareness of judges making orders
- Caregivers understanding and skills to manage
- Staff understanding and skills to manage
- Children's behaviours leading to multiple placements
- Availability of placements
    - Overloading
- Keeping everybody safe
    - Caregivers, kids with FASD, other kids in home
- Rural vs urban services
- Permanency /foster care
    - Unlimited kids in home impacts quality of care for kids and capacity of caregivers
- Conflicts in who will pay for what
- Lack of FASD informed/supported care for youth leading to involvement with criminal justice

- Training
    - How to get everyone who needs it, including caregivers
- Children's services
    - Mean, bullying
    - Fight when should be working together
    - Lack of understanding of how to help
    - Parents understand they need support but not in place
    - System challenges
        - People take baby steps (it is progress) but may be not enough so seems like a failure

- Parents had trauma and did not learn how to parent
- Difficulties in rural communities
    - Lack of resources
    - Long trips for services
    - Lack of funding
- Parents move to cities but children in rural
    - Challenge to get visits
- Systems fighting
    - Even at child birth
- System expectations and rules

- Lack of good training and understanding
- Consistency of care and proper training
- Disclosure
- Resources/supports
- Stability
- Education
- Awareness
- Assessment and diagnosis
- Funding
- Recommendations
    - Flexibility in funding/services
        - Resources into adulthood

- Child welfare workers need to consider the implications of FASD and what needs to be considered
- Lack of diagnosis resources
    - # of children that need diagnosis vs capacity/resources to do diagnosis
- Management of cases
- Recommendations
    - Comprehensive training to inform decision making due to high incidence of PAE in children being apprehended
    - Working and supporting parents of children with FASD before apprehension
    - Training to inform practice
    - Creating system that keep video [perhaps should read family?] intact

- Social workers not recognizing generations of FASD
- Can't vs won't care
- Trauma informed practice intergeneration trauma
- No supports
- No follow through
- No in home support
- Transition when aged out
- Training for staff
- In AB, not a brain injury if ↑IQ
- Employment assistance

- Keeping moms and kids together
- Having high expectations on children in care
    - Setting them up for failure
- Stigma and not enough training for caregivers on how to live with someone with FASD
- Lack of supports for caregivers
    - Instead of supporting them, you remove them to another place without providing continued care
- No PDD support up north from adolescence to adulthood
- Recommendations
    - Age out supports
    - More support to transition
    - Group homes that don't age out
    - Housing with supports

- Workers more educated about FASD
    - All disciplines
    - Put into post-secondary curriculum
    - Mandated
- Diagnosis and assessment
    - 2-3 waiting list
    - Try to build supports in the period during wait time is a challenge
- Community capacity
- Education

- FASD is a diagnosis for both mom and baby
- Assessment for FASD has to be completed it maternal alcohol use has been suspected or known

Fetal Alcohol Spectrum Disorder: Landscape of the research

Dr. Dorothy Badry

October 25, 2017

- Be mindful of labeling people without evidence
- Judging mothers and apprehending children based on mother's diagnosis

- Services ending at 18
- Transition to adulthood leads to adverse outcomes including homelessness
- Over-rep of indigenous children
  - 90% in some provinces
- 'just good enough' parenting to support bio parents and families
- Need to support and expand customary adoption and care
  - Includes subsid…[unable to decipher rest of word]
- Use block funding vs per diems to support child care
  - This allows agencies to do preventative work
- Need to delink CFS extension with staying in school
  - May have already attained school success and if they are required to stay they won't
- Training piece for foster parents can mean child is not safe- inconsistent
  - Without training kids keep moving between housing placements
    - Results in trauma
- Need FASD informed training and practice

- ✓ Most pressing issue- positive
  - Now not hiding drug and alcohol use rather than hiding so people will adopt
  - Now asking more questions, have training on having difficult conversations
- ✓ Most pressing issue- negative
  - Support is all child focused and reactive vs family focused and proactive
    - Especially when parents were in care themselves
  - Foster care providers very minimal
    - Stigma
    - Burnout
    - Over extended
- ✓ Recommendations
  - Not continuing to be one of the systems that creates a hige divide in life course child →adult

- Education Re: FASD for support workers, families
- No financial stability in families/caregivers
- Lack of understanding of healthy brain development
- Trauma and lack of trust with child services in first nation communities
    - Need to open up the conversation and remove stigma
- Addressing historical trauma in parents of children with FASD
    - Offer education
    - Psychoeducation
- Lack of indigenous healing

- Lack of knowledge among social workers of FASD
    - *'I know she has FASD, but she doesn't follow through'*
    - Writing moms off if they have FASD
    - Why can't we have mom and child in care together
- Long term relationships aren't there
- CFS not educating clients on the process of CFS
    - *If I get a call from CFS, are my kids going to be taken away?*
- Social workers need FASD specialists to support them in meetings and debriefs when working with clients with FASD
    - So moms with FASD need support workers when involved with CFS but/and social workers need supports to understand FASD more than just FASD training once a year

- Diagnosis, children/youth, caregivers
- System wide response
- Women are scared to call police when they are abused
    - if they call, the police come a few days down the road
    - family services steps in, thinking they have the right to apprehend the children which is so wrong to me
- if they go into foster care we don't know how they are treated
- If the understanding was there, the support would fall into place
- Not enough time→6 weeks of training, for example, for foster parent and then you are done
- A diagnosis with understanding is necessary
- Individuals who are hard to work with→disruptive to family, ineligible to go to respite care
- Each time a person is 'placed' some of the work gets undone
- Having built-in respite care would be awesome

- What about having a team of families caring for a child instead of just one family?

- Lack of understanding of FASD in social workers, bio parents, caregivers and this leads to:
  - Lack of support in meeting needs in ways of
    - Prevention of FASD
    - Intervention for FASD
    - Parenting support
    - Respite needs
    - Appropriate expectations for individuals and care givers
    - Kinship care
- Funnel funds into appropriate channels like education, lifeskills training for youth, respite for caregivers, lifelong housing supports (group homes for adults with FASD) as a transition

- ✓ Placements- lack of training of caregivers
- ✓ Lack of knowledge of social workers needs for training
  - FASD specific & youth specific
- ✓ Transitioning out of care
  - Shouldn't be 18
  - Extensions of care usually means switching placements
  - To get extension you need to meet certain requirements
    - May be unattainable for our youth
- ✓ Recommendations
  - Youth specific training
  - Care should end later (maybe 21) with option of extension of care

- FASD informed workers and all staff
- Transitioning into adulthood
  - 0 service/support after 18
  - 0 natural supports in older youth (unpaid)
- Support for foster, adoptive and birth families in FASD best practices

- ➢ Getting them assessed
- ➢ Getting confirmation that mom did drink
- ➢ Communication everywhere in AB between offices
  - Birth moms know where to hide
- ➢ At risk diagnosis is ridiculous

  - Can’t get services with that diagnosis

- Overworked welfare staff
- Too much paperwork
  - Don’t have time for human aspect

- Mandatory FASD training for CFS Staff
  - Extensive and up to date
- All children should be screen for a range neuro-behavioural issues
- CFS should be more holistic approach
- Work more collaboratively with other agencies
- Understanding of multi-generational FASD and better supports for those caregivers

- Child welfare workers need to understand, acknowledge and reframe their relations with indigenous communities and families
  - This misunderstanding can affect lifespan [can’t decipher]
    - Identity/well being
- Training with FASD is important but then that looks at/works with indigenous communities is a priority [not sure if deciphered correctly]
- Much damage has been done
- Much partnership could take place