



Landscape of the research

Table Discussion for Simon Laplante

Transcription of participant notes

October 25, 2017

Table Discussion

As a researcher, what is your greatest challenge when it comes to understanding caregiver needs?

- Lack of respite care for caregivers. Families (extended) lack of understanding alienates the caregivers and youth from 'normal' interactions and assistance
 - Social services need to disclose the possibility of FASD in order for the caregiver to start out with the right support and interventions
 - Social services, AISH, PDD, etc. can put money into appropriate supports (housing, cleaning house, house skills) in order for the youth, young adults so be successful without this responsibility falling on the caregiver continuously this causing burnout
 - Appropriate transition supports in place for youth and their families so kids don't fall through the cracks. Caregivers can't let go to no one. No one seems to be there to help out upon adulthood
 - PREVENTION!!!
- Continued support. Seemed to be doing it all
 - Identifying FASD
 - Privacy concerns not known
 - In the context of being in institution
 - Other shareholders in criminal justice system taking genuine consideration to FASD issues
 - ??? [can't decipher]
- Decimals, % ages, fractions
 - Aging & Transitions
 - As a parent as I age
 - Whole body disorder- FASD
 - Strategies & support
 - Advocating for support
 - 4 caregivers- 9 table members
- ✓ Aging & Transitions & Strategies & Supports
 - ✓ How suspected FASD clients are effected by transition from child to adult
 - ✓ Safety implications
 - ✓ Possibly with guardianship not having ownership of choices
 - ✓ Inability to have unsupported transition

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- ✓ How to address crisis in transition plan
- ✓ How to address caregivers aging out
- ✓ Need community based strategies plus supports to allow at home supports to be effective when clients are having challenges at school, justice, housing, medical

- ✚ Advocacy for supports
- ✚ Because we are their external brain
- ✚ Build capacity on person at a time by being their voice
- ✚ Communication- we speak for them
- ✚ Build trusting relationships
- ✚ Advocate for clients through holistic medical needs

❖ Son-

- supportive housing (safe)
- Job
- School
- Early intervention & support
- Early diagnosis (Sask)
- Reason:
 - @ birth extremely pre-mature , cerebral palsy diagnosis
 - Physio
 - O/T
 - therapeutic preschool @ 4mos old
- supports across the lifespan
- light of the prairies- not for profit
- each pay \$740/month
- working pay
- other two- social assistance
- ministry of social services- staffing
- work-ed program
 - still has job 16-17yrs
- group living –supportive living- 24hr care most days
- (4) reasonably independent
 - Chores, cleaning, cooking/laundry
- Meds under lock and key
- A typical group home is not going to work
 - Can come and go as they want
 - Friends over
 - Expected to have a cell phone

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Safety measures
 - Diagnosed w/ FASD @ 8yrs old
 - Followed by Child Development Program
 - Daughter diagnosed
 - No idea where daughter is
 - Early intervention
 - Educational supports- crucial
 - Get in trouble →self esteem ↓
 - Last one:
 - Researchers need to hear from caregivers
 - Day to day functioning with examples
 - Caregiver view priorities that are relevant
 - NOT ENOUGH TIME!
 - Caregiver burnout- issue
 - Researching long term prevention burnout
 - FSCD Respite care
 - Advocates
 - Not everyone diagnosed will qualify for PDD issue
 - Information not being shared in Calgary (youth to adult)
 - Funding for training, learning, keeping up with what FASD is
 - Transitions in adulthood
 - Milestones
 - What does FASD look like in seniors, aging populations
 - How is parenting different for parents with FASD
 - How do we best support people with FASD in parenting
 - Gaps in service based on IQ
 - Those who have FASD, but have an IQ above 70 so they don't qualify for PDD funding
 - Funding in general when it comes to services
 - What supports are there for caregivers who are aging or retiring
 - Where the housing supports and funding...permanent and lifelong
- ✓ Respite- meanings, functions, mechanisms of success, funding issues, respite snacks- Anita Gibbs
 - ✓ Siblings, neurological, impact on their lives, other kids, etc.

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- ✚ Planning prior to diagnosis, without diagnosis we can get help/understanding for our children
- ✚ Educational supports for our children
 - Our children have specific needs and schools have difficulty understanding our kids needs
 - There is no programming for kids with FASD
- ✚ Supports before crisis
- ✚ Day to day functioning- start with meltdowns, energy required
- ✚ More training for caregivers subsidized
- ✚ Supports for ages 6-18
- ✚ Good early intervention but nothing after that

- ❖ Make FASD awareness and education mandatory to doctors and psychiatrists to better diagnose and give support
- ❖ Need for financial supports
 - More trustee and financial supports for FASD housing
 - Example: speaker had to ARND- proof a house
 - More money for education for schools and support to actually manage/support with FASD
- ❖ More research needed for assessments to actually determine where a person is at functionally as IQ does not useful for FASD to get supports and funding
- ❖ School systems and teachers need to not only be informed and educated but they need to modify learning environments and lessons to meet children's needs

- Caregiver feedback
 - Raising second generation of children
 - Housing- losing housing & supported housing not with caregivers
 - No support with “unsubstantiated FASD”
- Frontline worker
 - There are 24hr housing agency
 - Not necessarily works for folks with FASD
 - Need blend of harm reduction and therapeutic
- Caregivers
 - Kids are living abject poverty
 - They are resilient & creative but there are huge financial issues/challenges
 - Strategies when not diagnosed with FASD
 - Static encephalopathy

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Medical knowledge
 - Drs don't treat kids well
- The disconnect within the medical profession with the whole body disability
 - Drs don't get it
- The invisible disability
 - Education from the top down
 - Some teachers have the education but Principals don't
 - Kids suspended on the word of Principal
- Each school has to be told the story
- Not just an IEP- life plan- use SOAR plan
 - **S**tructure the environment
 - **O**ptimize the strengths
 - **A**dvocate for what is needed
 - **R**espect autonomy
- Trying to empathize with caregivers but not having lived the experience
- Not being able to provide 'more' to caregivers due to scope/limitations of the research
- Easier to access families already getting supports, how to you access those not in touch with the system?
- Some researchers don't interact directly with caregivers
- Diversity of needs
 - Do we tap into a truly representative sample/
- Practicality of getting the results back to the families
- We work with very vulnerable population, historically we may [have] caused damage even if we were well-intentioned
 - Balancing scientific rigor with patient perspective
 - Need for grants can shift how we frame things
- ✓ Probation officers
 - How to interpret the Dx assessment
 - Training judges/prosecutors
 - Evidence based
- ✓ Who is supporting the ind. With FASD?
 - Building relationships
 - Knowledge for P.O.
- ✓ How to get the information form the birth mother around alcohol

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- ✚ Children with comorbid mental health disorders
- ✚ Lack of understanding
- ✚ Help caregivers understand the trajectory of FASD
 - moving past 'healthy babies'
- ✚ realistic expectations for children with FASD
- ✚ being involved with very complex systems
 - hard to understand the systems and advocate for kids within the system
- ✚ lack of understanding & education of other professionals involved

- ❖ How to transition from Y to A
- ❖ Affordable and faster diagnosis
- ❖ Collaboration with other services
 - Education
 - Break down barriers
- ❖ Services dedicated specifically to FASD
 - Housing
- ❖ More support services for the rural community
 - Only women's shelter
- ❖ How to find and maintain successful consistent respite services/supports
- ❖ Address gaps re: PDD and IQ

- It takes too much time for caregivers to educate every doctor, teacher, new support worker
- Caregivers who do all this individual educating have big worries:
 - What if the family moves
 - What about transition to high school
 - At the start of each school it's 'here we go again'
- It would be good to, upon receiving a diagnosis, get a central go to person- someone who is not necessarily involved all the time
- Establishing a community collaborative network of navigators

- Finding appropriate FASD resources
- Dogma
 - People have higher expectations for people with FASD
- Outside supports
 - Caregivers have too many jobs/roles
 - 'we just want to be their parents'
 - 'I am her manager but also work full time'
- Finding adult services

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- FASD is a disqualifying condition within AHS mental health
 - Relationships
 - Was loneliness that got him back in jail
 - Need for natural relationships
 - Relationships that prevent recidivism
 - Minimum sentences
 - Need something different that supports the need of the individual
 - Expectations the person can meet
 - Services that are preventative and not crisis based
 - Having counselling and supports that are available
- ✓ People in community don't understand
 - Give direction without order
 - Lack of understanding and education
- ✓ Many diagnosed with FASD present really well at first
- ✓ Example:
 - Have no eviction clause
 - Some people don't understand why can't you evict if they are violent
 - It is important to have front line workers who know how to de-escalate
- ✓ It would be helpful for researchers to go more in depth with practical ideas/hands on strategies
- ✓ Also would be more helpful to have concrete research on alcohol consumption and pregnancy.
 - No alcohol is still the best option but it would be helpful to know specifics
- ✚ Rural- accessing anything
- ✚ Schools
- ✚ MH
- ✚ Criminal Justice
- ✚ No supports
- ✚ CFS
- ✚ Researcher focus
- ✚ Development models
- ✚ Nutrition research
 - Can it help functioning
- ✚ In learning together documents

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- ✚ Aging & transitions
- ✚ So many fall through the cracks and some end up on the street
- ✚ Also this would include aging of the caregivers

- ❖ In the learning together document the following priorities were identified
 - FASD as a whole body disorder
 - Aging & transition
 - Strategies & supports
 - Advocating for support
- ❖ As all of our clients have different needs, we did not think it was right to choose 1
- ❖ The clients we serve rotate through all these priorities sometimes in a couple week span. Currently our table has clients:
 - Going through court
 - Transitioning or attempting to transition to stable safe housing
 - Advocating to school about children with FASD
 - The advocating goes hand in hand with helping the teachers and school come up with strategies for the children that will work
- Marijuana for calming
 - Use of drops
- Return people to homes better than institutionalization
- Jobs
 - Employees take advantage
 - Over work, under pay

- Northland schools
 - Teachers need to learn how to teach and handle children with FASD
 - They always say it is a budget issue
 - Also with HDAD
- I'm thinking about the future...how am I gonna handle my grandson in the future

- Caregivers:
 - Not enough resources, need to get creative
 - More support, more resources
 - Lots of gaps (knowledge)
 - Training best practices
 - Understanding and implementing
 - More training

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Training to educators/crown
- Learn harm reduction techniques
- Utilize support teams
- Have reasonable goals/expectations
- Parent/grandparent education/training
- Best practices in collaboration
 - No one has appropriate resources to do it on their own
- ✓ Justice
 - Jail/court system
 - Not enough support within the system
 - No FASD friendly programming
- ✓ Health
 - Awareness
 - Not treated well
 - No support
 - Negative
- ✓ Education
 - FASD not in program
 - Misdiagnosis
 - ADD/ADHD/ODD
 - Misinformation
- ✚ More education for supports of these individuals
 - Specifically on how diagnosis affects behaviour
 - Not linking it to the disability
- ✚ Concerns about what's going to happen to these kids when they get older
 - *'what's going to happen to them when I'm not around'*
- ❖ Learning together document
 - all of them are important it is difficult to pull them apart
- ❖ In developing a strategy we are looking at all of these
- ❖ For families to chase resources it must be exhausting
- ❖ Aging is very important
 - as FASD persons age their caregivers are faced with challenges
- ❖ Transition points in a lifespan can be very challenging and accessing the right supports
- Professionals not being educated

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- FASD supports not there
- Culturally sensitive
- Caregiver- need more education

- Researcher
 - Gaining access to caregivers and those who work with them to hear their stories
- Caregivers
 - Struggle with respite, how to connect, where to go, funding, etc.
 - Research specific to groups
 - Facilitation, dynamics
 - Lots of research 1:1 mentorship but not a lot in groups
 - Lifespan- lots on kids, more on older
 - Housing- biggest difficulty

- Challenges
 - Access to supports
 - Advocacy for children with FASD
 - Always have to advocate on step higher
 - Teacher → Principal → Superintendent
 - Educating others around us
 - Policies are inadequate
 - Invisible disability
 - Single parenting is especially difficult
 - Government & institutional systems do not work together
 - Banks, social services, schools
 - Housing is always in jeopardy
 - Evictions etc.

- ✓ Finding a caregiver to provide for the persons affected by FASD when caregiver is aged and no longer able to care for them
 - Supportive living homes to provide them their own space
 - 24hr supervision
 - Support for caregiver
 - Family support as a whole

- 🚦 FASD as a whole body disorder
- 🚦 As support workers we need real tools regarding this to help individuals understand what is happening to them physically
- 🚦 More teaching and availability for holistic medicine

- ❖ Residential Addiction Treatment for Women
 - Hardest thing in my job is to get them to my office
 - When I get them to my office they don't see how their behaviour affects other people
 - In residential, try and implement supports but in group living other clients see 'special treatment'
 - Once they're out of treatment, I see some, they don't want to connect once they are done treatment or they have a 'failure' and come back to see me
 - Helping clients be prepared
 - Overwhelming to manage all the documents they need when they don't have supports in the community
- Aging out of service without diagnosis or service plan
 - Cohort of children with good services vs cohort without → outcomes
- Quick and simple information (tangible and plausible) to provide caregivers
 - Caregivers include agency staffers
- Acknowledge Dr. Badry's Caregivers FASD on CanFASD
- Best practices evidenced based that will work, standardized
- Advocating for Support
 - 0 strong network
 - Struggles with addictions
 - Destroyed relationships
- Caregiver
 - Lose custody of their children...cannot work through the system end up...
 - Connecting with funding those who don't qualify for PDD
- FASD
 - We are just starting to figure
 - No one in their court
- Disability unable to engage consistently but the system supports are too rigid therefore not accessible
- Outcome based programs
- Steps to get support is not achievable to that support
- Priority
 - Strategies and supports

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Caregiver needs are unique
 - Cannot generalize strategies and supports for all caregivers
 - Trial and error
 - Need to determine what strategies will work
- Advocating for support, especially in the education system

- ✓ Education/educators understanding that consequences don't work
- ✓ Medical/psychologist/psych nurses understanding behaviours and how FASD impacts brain function
- ✓ Require constant support to be successful
 - Ie: as an adult to learn to complete daily living skills
 - Ie: cook and eat healthy
- ✓ Whole body disorder impacts all parts of real life and daily living
- ✓ Patterns of presentations of FASD and help systems understand
- ✓ Housing which meets needs and supports deficits in ability to complete daily living skills

- ✚ Effects on the whole family
- ✚ Communication barriers
- ✚ Persons with FASD cannot communicate their problems
- ✚ Uneducated people do not understand the complex issues involved with FASD
- ✚ Understanding how they function

- ❖ As caregivers in the legal system (probation) we struggle with the balance of being a supportive person in the individual's life while following through on our role as a supervisor responsible for legal obligation
- ❖ As other we also struggle with getting individuals the proper help they need, whether than be treatment, counseling or more one on one care
- ❖ Getting the other key players to understand the struggles the person faces
 - Ie: lawyers, court systems

- Unaware of what an education plan looks like with our two children who are suspected of FASD
- Lack of understanding of what FASD is and how to best support those who have FASD (teachers/educators)
- Understanding how FASD affects the aging brain (school age, teen years)
 - Ie: are they only assessed once?
- Researcher focus
 - Best practices to promote growth in the classroom

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- School- lack of educational support
- Caregivers burnt out
 - Lack of support and aging care givers
 - Lack of understanding and knowledge for specific clientele
 - Lack of resources
 - Caregivers have to miss work
 - Violence with FASD and managing emotions
 - Getting people medicene is challenging
 - No rides, assessments are expensive
- ✓ Earlier diagnosis
 - Younger –earlier diagnosis
- ✓ Child welfare system
 - Placement stability is Key!
 - FASD should be the first consideration when we look a permanency, regardless of race, as a soon as CFS is involved
 - Risk of FASD should be assessed and every decision going forward should be coloured by those 'FASD glasses'
- ✚ Adult services for adults who have a hard time recognizing they need support
- ✚ What social/program supports can help an adult that falls between service cracks
- ✚ What are the best practices around helping transition to adulthood
- ❖ School biggest struggle
 - Need supports
 - Social
 - Academic
 - Very isolated
- ❖ Health issues
 - Needs diagnosis, treatment, support to get to appointments, appropriate professionals
- ❖ Strategies and supports
 - Huge area
 - Need supports for all diagnosis and range of issues/concerns
 - Difficulties in adolescence

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Aging and transition large concern for caregivers
- Children attached to CFS if at 24 supports aren't in place they tend to fall through the cracks
- Whole body disorder
 - Physical issue affecting whole body
 - Aches and pains increasing
 - Females complaining of reproductive issues
 - Cysts, irregular periods, hysterectomies in their 20's
- The opportunity to address upstream issues
- Schools
 - Lack of resources in the education system
 - Lack of understanding the complexities of FASD
 - Lack of training and resources for teachers
 - Barriers such as Dx needed for EA support
 - School support staff may not have the support/network to support families
 - Curriculum changes
 - Geographical barriers
- Lack of diagnosis and how to get one in a rural community
- Lack of knowledge of FASD as a caregiver/teacher/social worker
- Strategies and supports is a priority for a single mom of a 20 yr old not yet diagnosed that is facing incarceration
- ✓ As a caregiver foster parent support is aimed at westernized practices not on bio families affected by disorder in first nation families
 - Access to training from the indigenous perspective
- ✓ If people want to get access to supports they have to sign agreements, first nations get categorized (?)
- ✓ Not always culturally sensitive
- ✓ Too high expectations/occupational balance
- ✓ What does retirement look like for caregivers
- ✓ What does retirement look like for seniors
- ✓ Employ-abilities for those impacted
- ✓ Need to revamp employment policies in consideration for people with FASD
- ✚ The amount of resources and supports
- ✚ Collaboration needs to improve between agencies

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- ✚ Finding the supports in the individual's community
- ✚ Building relationships for transitioning from school-aged to adulthood
- ✚ Individuals need guidance/purpose
 - Be able to work with income support to help with these purposes
- ✚ More adult supports

- ❖ Judges & Justices/Policy makers
 - What is understanding level and what do they need to know to move this forward
- ❖ Education system
 - How are out kids identified/supported?
 - What if they are not diagnosed
 - Problem of working with obvious behaviour
 - Kids and others fall through
- ❖ Deferred diagnosis
 - Lack access to supports during these times
- ❖ Policing @ community level
 - Understanding
 - How do we act/react in the moment that makes things better or worse
- ❖ Caregiver burnout

- Aging caregivers
 - No one else can look after them
- More support for aging caregivers
- More housing
- Educate girls when young about pregnancy and drinking
- Extend respite instead of putting them in residential facility

- FASD as whole body disorder
- Aging and transition
 - Lack if AISH, PDD
 - Aging caregivers → what happens when caregivers aren't there
 - No financial means
 - Lack of support after 18
 - Caregiver burnout → no respite care b/c no one trained
 - Moves placement to placement
 - Hard for person to accept help

Fetal Alcohol Spectrum Disorder:
Landscape of the research
Simon Laplante
October 25, 2017

- Universal benefits aren't enough to keep person out of poverty
 - May be difficult to access