



## Landscape of the research

Table Discussion for Jocelyn Cook

Transcription of participant notes

**October 25, 2017**

*Table Discussion*

**Using Data to Improve Outcomes**

*Why care about data? Who cares about data? How can/should data be used?*

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- Tailored to the audience you are presenting to
- Taking the research to a broader audience
  - I.e.: not just presenting at an FASD conference
- Delivering data back to the patients, caregivers etc. in a way that is more understandable than a scientific journal
- Local, provincial, national
  - Comparing similarities and difference between different clinics and regions
- Transitioning towards policy
- Trying to connect with the general public in layman terminology
  - News, media etc.
  - Images, infographics
  
- Money for services
- Inform policy so we can think outside the box
  - Gov't people don't care unless its written and 'legitimate'
- How is data disseminated? Does it change our daily practice?
  - I read an interesting journal article but is it meaningful for my practice?
  
- ❖ Helps people have concrete understanding
  - Data puts you in the care and the stories drive the car- anonymous
- ❖ Data gets funding
- ❖ Data gets attention, gets people on board, gives credibility
- ❖ Who cares about data?
  - Managers, funders
- ❖ Data gives direction and information
  
- ✚ Why care about data?
  - Data can provide direction
    - Baseline
    - Funding
- ✚ If we have data we can share compare contrast
- ✚ Who cares about data anyway?
  - Decision makers
  - Funders (justification)
- ✚ How can/should data be used?

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- It should be used to designate appropriate funding and resources to the various providers
  - Statistical purposes- measurement
  - Know what areas to focus on
  - Ethically-unbiased- without tunnel vision
  
- ✓ Money follows evidence
- ✓ Data important for support
- ✓ Reflections of society
- ✓ Better understanding
- ✓ Preventative side
- ✓ Second opinion
- ✓ Better understanding of stigma
  
- Data used for impact, leverage funding
- Direct policy
- Data needs to be in a format that makes sense to the audience
- Wide person approach vs single system
- Data support by a human story
- Need to commit resources to ensure data is collected and analysed and used effectively
  
- Why care about data?
  - Advocating for gov't services
    - They already use data for funding decisions
  - Data drives service provision
- Who cares about data?
  - Funders
  - Politicians
  - Managers
  - Everyone should care so we can all utilize the data, research etc.
- How can/should this data be used?
  - Funding
  - Resources
- Why care about data?
  - Funding
  - Best practice
  - Explanation for why we work the way we do
  - Commonalities/trends
  - Validation
    - Why things we do work or opposite why doesn't it work

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- Magnitude of the issue
- Easier to streamline approaches
- Raises awareness/knowledge
- Who cares?
  - Funders
  - Researchers/statisticians
  - Gov't/policy makers
  - Parents/caregivers
  - Doctors/diagnostics
  - Program developers
  - Public likes #'s
    - Easier to understand
- How should data be used?
  - Inform policies/practices
  - To educate
- ❖ Why care?
  - Provision of services
  - Identify trends
  - Knowledge is power
- ❖ Who?
  - All
- ❖ How to use it/how to make it meaningful
  - Informed practice
  - Consistent messaging
  - ↑ funding for more staff
  - Create services that are tailored
  - Education & training opportunities
  - Fosters better understanding for all involved
  - Fills the gaps
- ✚ Intention of data needs to be shared
  - Purpose
- ✚ Data that confirms the cost of not making FASD a priority to use to advocate for improved programs and services
- ✚ Data should be informing policy and money distribution
- ✓ Data leads to funding
- ✓ Data back to our stories
- ✓ Clients and family voices are stronger than frontline workers when approaching the gov't

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- ✓ Waiting for the time when data catches up with what we know
- ✓ Clinical data vs caregivers & service providers
  - What we think they are vs what do we know
- ✓ Data to advocate
  - Who cares?
    - Everyone should
    - Decision makers
  - How do we use data?
    - Helps define needed programs/ fund allocations
    - Used for education
    - Help define proactive programs
    - Used to show effect of program
    - Used for all types of business decisions
    - Justify expenditures
- Why care about data?
  - Drives response & services
  - Creates buy-in from service providers, schools
  - Informs- policy, service delivery
- Who cares about data anyway?
  - People who it effects
- How can/should
  - Be used respectfully with client
    - Eg: birth families
  - Create awareness in larger community
  - Shift in what data
    - Recognition of prevalence but now what
- Data important to influence policy
- Maintain successful policy → can support why things are going well
- Supports access to funding
- Drives training, education
- Needed for decision making
- Need quality questions to get good meaningful data
- Shows people why something is important
- Shows population trends
- ❖ Why care about data?
  - Data gets funding
  - Safety

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- Evidence based
- Informs practice and can adjust practice
- Involving caregivers
  - Difference theory vs practice
  
- ✚ Data can guide practice
- ✚ Needed to validate ongoing work and to fund it
- ✚ Can be used to develop strategies and practices
- ✚ Can be used to identify gaps in service and support
- ✚ Can be used in the future to fill gaps
- ✚ Can be used to develop guidelines and practices for diagnosis
  
- ✓ Why care about data?
  - Provides reassurance to clinicians about best strategies
  - May secure funding
  - Guides programming/making decisions
- ✓ Who?
  - People/agencies wanting to promote/continue services
  - Funders
  - Doctors
- ✓ How to use?
  - To inform our practices
  - Inform programs
  - Provide teachable moment for clients
- Why?
  - It's a way to get the information interpreted/documentated for all parties to see
  - To understand the behaviours
- Who?
  - Data helps other service providers understand behaviours
  - More info can help
- How to use?
  - Education/training
  - Basing off policies/practices
  
- Why?
  - Tells you what works
  - Gaps in services
  - Where to put funding
- How to use?
  - Outcome based to each agency used

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- *Data is sexy* ♥ Jackie
- Helps inform practice
- Professionals are looking for data
- Research attached to funding
- Gives us the tools/characteristics
  - Describe what going on with assessments
- Progress
  - ❖ Why?
    - The future
      - Growth
      - More awareness
    - Factual bottom line
      - What you are working with
        - Knowing and dissecting
  - ❖ Who?
    - Professionals
    - Politicians
    - Financial sources
  - ❖ How to use?
    - For the increase of awareness and knowledge
    - Better support for individuals who are impacted
    - Families
    - To improve and develop services, training and support
    - Inter-agencies
- ✚ If we don't have data don't have information then can't understand
- ✚ Data and services in today's society [can't decipher] validity
- ✚ When data leads to action and helps people
- ✚ Evaluate success
  - Lead to interventions and practice
- ✚ Use data to increase funding by numbers
- ✚ Data can drive policy
- ✚ Data [can't decipher] justice system
- ✚ Worldwide numbers are similar
- ✚ We all care
- ✓ Why?
  - To learn best practices and develop
- ✓ Who?

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- Everyone- for different reasons
- ✓ Jobs are based on, without data we wouldn't know if we are on the right track
- ✓ Jobs and roles continue to change and adapt as the data shows best practices
- In education data helps with how we provide for children and young adults to make them successful in the school system
- The schools should be able to have that data available to proceed to help these children
- Why do we care?
  - It tells us where and what the need is
  - It is factual
  - It tells us what is working and what's not
  - It gets ride of preconceived ideas around what the real issues are
  - Not sure if the solicitor general is collecting data on FASD
- Need more input from caregivers so that research can be more applicable to frontline work implications
- Important to understand both the kids to design intervention and support
  - # domains affected etc.
- Important to understand IQ does not define the disability
  - For disability funding
- Important to understand the women for effective interventions with them
- ❖ Why do we care about data?
  - The answers are in the data
  - Advocates
  - Other people's opinion
  - Data helps us celebrate best practice
  - Researchers
  - We all care about data
  - Many different ways to share it
- ✚ Why should we care about data?
  - Gets money
  - Evidence based
  - Training purposes
- ✚ How can we use it?
  - Program, supports, navigation



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- Planning
- Collaboration
- ✚ Who cares?
  - The data shows who needs to care
  - Policy makers
  - Government
- ✓ Why care about data?
  - Best practice
  - History
  - Starting point
  - Evidence based practice
    - What does the data say about best practice and strategy?
- ✓ Who cares about data anyway?
  - Funding
  - Housing first
  - Education agency
  - Best practice of care/funding
- Why care about data?
  - Helps get resources
    - Stories draw decision makers in
    - Data convinces them to sign the cheque
- What kind of data do agencies need to help them with funding?
- Who cares about data?
  - Policy makers
  - Senior managers
  - Accountants
- Why care about data?
  - b/c informs policy and practice
  - gives insight into what's happening so that can be used for
    - funding
    - advocacy
    - research
    - policy
    - interventions
    - support
    - prevention
- Everyone should care about data

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- the kind of date or 'how much' or to 'what degree' varies a lot, I think
- How to use data?
  - In ways that:
    - Support
    - Trigger change
    - Impact funding
    - Impact health, education etc.
- Who cares about data?
  - Funders
  - Caregivers
  - Educators
  - Families
  - Doctors/medical professionals
  - Police
- Needs to be appropriate to the group you are giving the information to
- Needs to be a correlation of multiple shareholders in the FASD field
- ❖ Informs best practices, creates awareness of actual prevalence, translates to policy and service provision
- ❖ Who cares?
  - Policy
  - All systems
  - Families/caregivers
- ❖ Data should and can be used to
  - actually mobilize
  - knowledge dissemination
  - funding
  - best practices
  - prioritizing FASD and looking at FASD as a gestalt-whole picture
    - PAE bigger than anyone knows/talks about
- ❖ Data can help inform messaging and prevention but also ensure families [can't decipher] have access to appropriate, culturally safe and responsive interventions b/c parenting FASD is hard, esp when you are the only FASD informed person in your child's life
- ❖ DATA=TRUTH
  - Push to medical community to insist upon FASD and trauma informed training
  - ↑ in true diagnosis of FASD if more systems and physicians are FASD competent

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- ✚ Why care?
  - No data/no funding
- ✚ Who cares?
  - We should all care about data
- ✚ How to use?
  - In every way possible
  - Provides validity for non-users
  
- ✓ Why care about data?
  - Data is important for change
  - Data is a driving force
  - Medications and side effects
  - Data helps to inform [can't decipher] are best practices
- ✓ Who care about data anyway?
  - Everyone including client
  - Program development
  - Health system
  - Education
  - Systems change
- ✓ How can/should this data be used?
  - Inform
  - Educate
  
- Data informs gov't on policy/procedures
  - Data should be used in practice but we need people who understand the data and will be able to 'splice-n-dice' appropriately
- Data can also help us understand the nature of comorbidity
  - FASD/ADHD
- Data should be used to provide information to be providing information about best practice
- Data will also show what strengths/limitations the individual with FASD has, to further the supports provided
  
- Why care about data?
  - Data proves the need for services
  - More data more funding
  - So we can make informed decisions about our practices
  - See what else is going on in the world
- Who cares about data anyway?

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- Government policy makers
- Taxpayers want to know
- How can/should this data be used
  - To secure funding
  - To collaborate gov't bodies with other agencies
  - To inform
- Indigenous population
  - TRC
  - Take data from the people
  - Researchers have not contacted the indigenous people
- Have people dealt with trauma?
- Data and money
  - Data proves we need money
  - Data proves we need research
- We need more workers
  - Data can prove what frontline workers are saying
    - Dollars cut for transportation
    - Waitlist...ie. Diagnosis
- Challenges for prioritization
  - Everyone different so how prioritize who gets what service
- Data helps rural communities access resources
  - Waitlists
  - Cost for diagnosis
- ❖ Why care about data?
  - Progress
  - How to track positive and negative outcomes
  - Funding
- ❖ Who cares about data?
  - Everyone
  - Important information about FASD is great
    - We need a better way to present the data so that it's universally understood
    - Keep is simple
- ❖ How can we make data useful?
  - Make data easier to understand for people with an FASD and caregivers
  - More simple stat posters that are aimed at everyone
  - Education in schools to students about different mental health and FASD

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- ✚ Why care about data?
  - Data drives funding, policies
- ✚ Who cares about data?
  - Parents and caregivers care about data so that this information can be passed onto social workers, program supports
- ✚ How can this data be used?
  - Provide standardized guidelines for medicating people with FASD
  - Data provides basis for policy change such justice, law enforcement, courts and the way they deal with FASD clients
  - To prove to funders that there is a need for increased in \$ for program providers that offer supports to families and people affected with FASD
- ✓ How can/should the data be used?
  - Help other professional recognize FASD, leads to diagnosis and hopefully supports
  - Help identifying why affect regulation exists in the rates it does
    - Are there things that can be done to prevent this from presenting?
  - Can really help to determine what best practices for supports should be
  - Policy makers need to see the data and if is need to be incorporated into systems
- Have qualified people interpret the data to get meaningful results
- Why care about data?
  - No data → no resources/support/gov't assistance
- Who cares?
  - Gov't
  - Funders
- How can data be used?
  - Make it meaningful
  - Best support the most appropriate programs
  - ↑ resources
  - To educate and reform
- We want to know the data as caregivers
- ❖ Data is what gets us funding
- ❖ Don't want to see people- want to see numbers

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- ❖ Policy makers
  - ❖ Data give us a place to start discussion
  - ❖ Caregivers/workers looking for answers
  - ❖ Worry about what data is legit
  - ❖ Scientists
- 
- ✚ Data is used to identify presenting issues, determine trends, find the gaps
  - ✚ 'how should the data be collected' seems to more relevant question
  - ✚ What about programs outside of the networks?
    - How do we get that data?
    - Everyone should contribute to, report to the same database
  - ✚ Psychologists don't get funded to fill in the 28 page data collection form so many don't contribute
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- ✓ Good to know what trends are so more prepared when working with individuals
  - ✓ Good to share results with everyone involved in individual's life
  - ✓ To help normalize the trends
  - ✓ Drives policies
  - ✓ Provides info to develop best practice in the field
- 
- Why care about data?
    - Funding
    - Informed decisions with data
    - Standards of practice
    - Shows where and when services are needed
    - Need to know where we are and where we are going
    - Ensure medical fields get what they need
  - Who cares about data?
    - Each field for their own individual purposes
    - Families and caregivers
  - How can/should data be used?
    - To effect positive and necessary change
    - To spread awareness and need
      - Education
    - Data should be easily accessible to everyone