Tanya Shute & Laura Hall FOR OPDI “Peer Support: Honouring the Past, Treasuring the Present, Shaping the Future” Conference October 7, 2019

RE-BUILDING “THE EVIDENCE” FOR CONSUMER/SURVIVOR INITIATIVES

Draft For Laura

- “Indian” asylums for “Mad Indians”
- Mad Studies/Antipsychiatry & Settler thinking
- Savage/Civil paradigms
- What does it mean/how is the movement implicated in settler colonial CS movements (…organizations, services etc.)
- Crazy = loss of tribal connection/tribal destruction
- Culture-based services versus Indigenized organizations

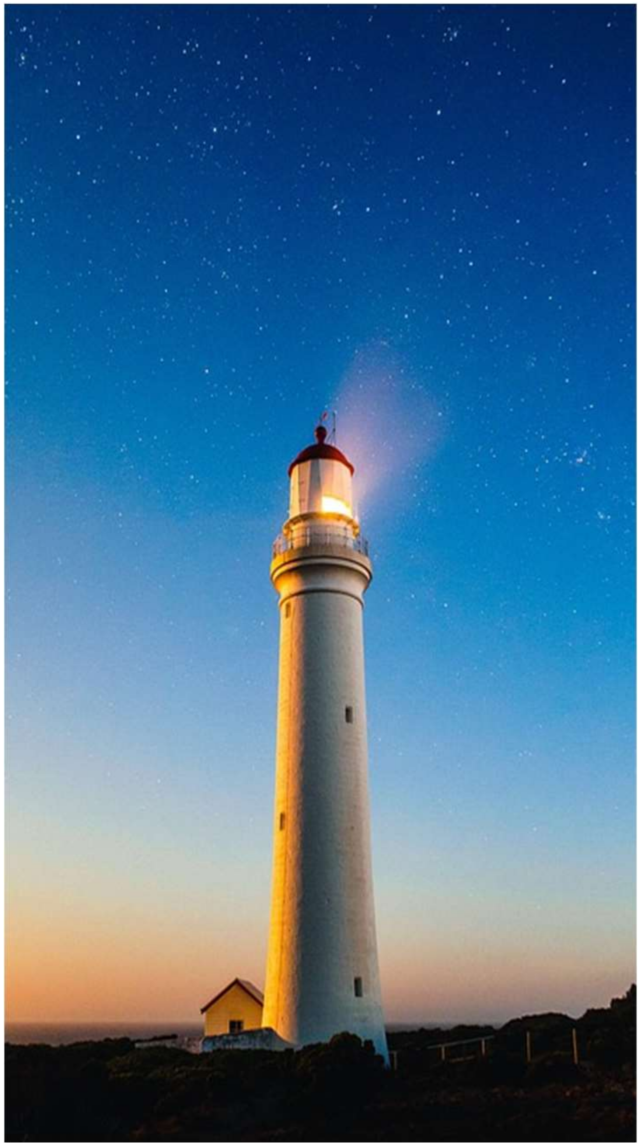
CSI Research context

- CSIs emerging from user/ex-patient movement therefore accountable to more profound principles than organizational performance and funders
- Participatory but not always led/autonomous
- Ontario research dropped off after 2010
- Current landscape

Current landscape influencing need for empirical research

- Ford (enough said)
- CSIs– who are, who aren't, the $ is blurry, even to CSIs
- Centralization: e.g. centres of excellence etc.
- Accreditation pressures
- Professionalization pressures
- Independence/trustee relationships with mainstream instead of with one another
- "niche" services or memberships
- Reorganizing LHIN structures & de-funding public health
- Empirical limitations of existing research, and lack of current data

Lack of transparency (their agenda) or documentation (our oversight)



- 1991 CSDI = 3.1 M
- 36 CSI projects funded in 1991-92
- 1996 change in legislation to allow for non-c/s control
  - As of 2008, over 1/3 were controlled by mainstream orgs./partnerships (Nelson et al., 2008)
  - 36 partnerships, 13 independent?
- No current data
  - Need to map our organizational history
  - Need to map our funding trajectory as an important part of the C/S movement story
  - Current data reporting under functional centres obscures CSIs, instead reporting/showing us functional centres

Peer Support & “Evidence”

- Whose evidence?
- The empirical official studies are mixed
  - i.e. Furh et al. (2014) meta-analysis versus Lloyd-Evans et al. (2014)
- But the system has bought in (*) and when it does, what happens”
  - Lose locus of autonomy
  - Professionalization (strengths & limitations)
  - Appropriation, assimilation & losing its connection to the consumer/survivor/user movement

Indeed, we have made significant gains. We have moved from “feasible” (Simpson & House, 2002) or (“Users can be involved as employees, trainers, or researchers without detrimental effect”(Simpson & House, 2002) to a place at the table after having demonstrated effectiveness. Where to from here?

- How does the data CSIs have to collect and report serve us? If it doesn’t, let’s change it.
- Where do we see where we want to see CSIs in the long-term? What do we need to get there?
- How can we establish our own requirements of what constitutes “evidence”?

For example, we are “best practice” employers

- Look at what CSIs and their leaders do!
- Hire and meaningfully employ people most MHO would disregard or only view as service users
- Governance exemplars
- Doing every thing with nothing
- Innovations (e.g. warm lines)
- All while accountable to a social movement – no deviation from values and principles

CSOs/CSIs Outcomes-Effectiveness Studies

- Overall impact on system-outcome indicators such as reduced hospitalization days/crisis services days, better transitions from hospital to home, etc.
- Improved quality of life outcomes: improved “social functioning”, decreased isolation, impacts on self-esteem, impacts on internalized stigma, increased community integration/contact/activism
- Negative cases: “ghettoization”, less general community activity, contact with peers replaces the general “other”
- Limitations: hard to adhere to positivist “evidence” benchmarks (e.g. non-experimental, small sample sizes)
- Distinction rarely made about the degree of autonomy over services provided by the CSOs studied* (personal empowerment & organizational empowerment positively related (Segal & Silverman, 2002; Segal, Silverman, & Temkin, 2010)
- What would c/s want studied as indicators of effectiveness? (e.g. recovery-oriented outcomes, activism etc.)

Social Change/Systems Influence Studies

- Impact on service level planning and coordination to improve services for c/s
- Decreases in stigma due to public education efforts
- Increasing the volume and credibility of c/s voices

- Literature notes impact may be limited by less-than genuine participation/collaboration/tokenism
- Organizational independence is a variable

- Organizational empowerment and user empowerment may be connected

- Concern that under funding cuts and pressures, organizations prioritize individual service delivery over systems level work and advocacy/activism

In 1996, legislation regarding the mandated autonomy of CSIs was changed to allow for non-consumer control of these organizations out of government concern for several organizations who had begun to have administrative/management challenges.

* No provincial government (in collaboration…) reports since 2009 Builder Report

Bringing Survivor-Research principles to CSI “evidence”

- Decolonizing peer support and consumer/survivor organizations
- Utilizing survivor research principles/grounded in the movement that created CSOs
- Participatory, yes, but how about led & sanctioned?
- Action-oriented instead of meeting the “need for evidence”
- Stop participating in data collection that could jeopardize
- Control our own data
- What else?

We propose…

- Better understanding of why there is a lack of Indigenous-led/Indigenous-centric culture-based CSIs
- Begin to address the settlers-only perspective on CSI practice
- An environmental scan of independent and managed (to any degree) CSRO that receives funding as a CSRO (not the peer support or family functional centres)
- Auditing who the MOHLTC sees as a CSI versus who we recognize
- Forensic timeline of CSI budgets (FIPA)
- Determining how we can use the data we produce for the LHINs ourselves and how we can correct for statistical faults in how we report stats now
- Work toward creating a participatory CSI research agenda for future research and to invite researchers
- There are studies that demonstrate who uses these services, but need to document the highly skilled workers and leaders as part of our "evidence base"
- how we increase our capacity for research by us, for us: A participatory research agenda to guide future research, focusing future studies on what we need and want, and according to principles that honour the movement.
- What else?