

~~Future Directions for Coordinated Specialty Care~~ Embracing Transformative Change

Nev Jones PhD

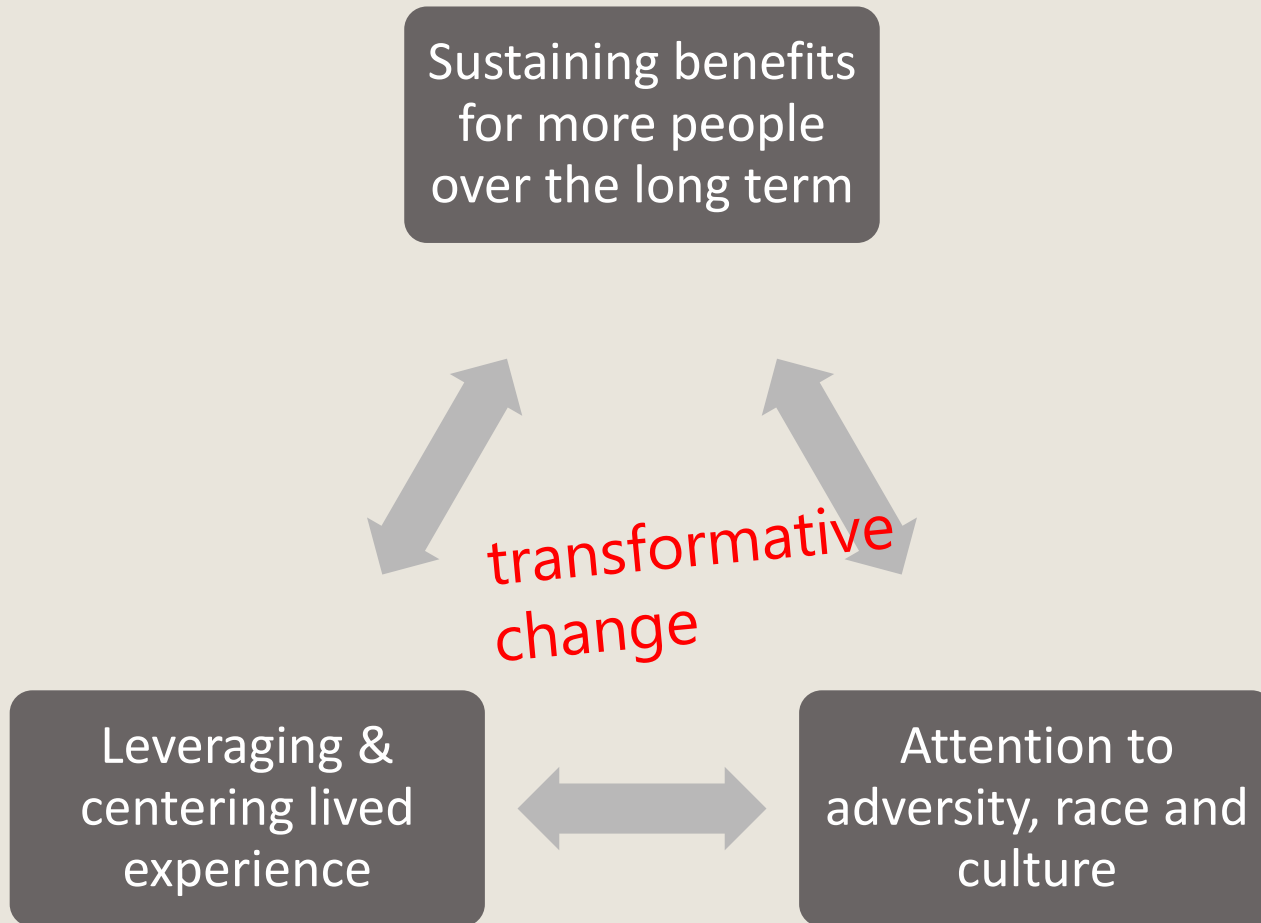
Department of Psychiatry & Behavioral Neurosciences

Morsani College of Medicine

University of South Florida



Future Directions



Empirical motivation

- Most the benefits of early intervention programs are lost by 3 - 5 years post-follow up (Nordentoft)
- Outcomes & engagement with services are profoundly shaped by class, race and social disadvantage
 - An estimated 60-80% of those with schizophrenia diagnoses will be unemployed or under-employed 10-14 years following an initial episode (Morgan, Stralin)
- In models including social & structural disadvantage, level of symptoms had only a tiny impact on engagement & outcomes (Jones et al 2019)
- Persistent disparities/inequalities affecting African-American clients & families (Jones et al 2020a,b; Oluwoye et al, 2020)
- Lack of career mobility, career options, low wages within the peer workforce (Jones et al 2019, 2020)
- Approximately 40-50% of CSC clients disengage or are discharged within the first year of treatment (Mascayano et al 2020)
 - Early discharge predicts poor outcomes

TRANSFORMATIONAL TIMES ASK FOR TRANSFORMATIONAL CHANGE



The hard questions

- How can we adequately attend to the intersections of race, poverty, welfare benefits, arrest/incarceration, disability and recovery?
- How can we give young people what they want and need in a way that brings about *sustained* change?
 - During CSC *and* after
- What would our systems, programs and policies look like if truly co-produced & co-led by those who experience psychosis and their families?

Asking these questions at both the micro *and macro* level

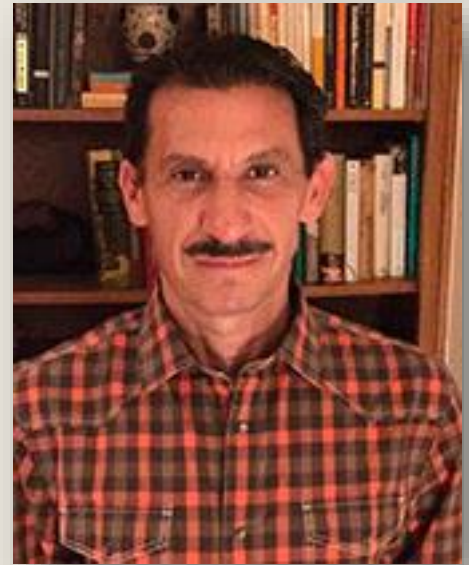


"...we as a nation must undergo a radical revolution of values. We must rapidly begin the shift from a "thing-oriented" society to a "person-oriented" society. When machines and computers, profit motives and property rights are considered more important than people, the giant triplets of racism, materialism, and militarism are incapable of being conquered...True compassion is more than flinging a coin to a beggar; it is not haphazard and superficial. It comes to see that an edifice which produces beggars needs restructuring. A true revolution of values will soon look uneasily on the glaring contrast of poverty and wealth...A nation that continues year after year to spend more money on military defense than on programs of social uplift is approaching spiritual death."

—Martin Luther King Jr. (April 1967)

Asking questions in ways that address epistemic justice

- Service users/patients & families, including those from diverse racial/ethnic communities, as sources of input & information
 - vs individuals with the power to directly shape services & provide cross-cutting expertise



"...people's participation...is allowed, and their contributions are in fact used for knowledge production and knowledge-transmission purposes; but nonetheless, they are not treated as subjects of knowledge or "epistemic agents"—but only as sources of information—that is, as objects"

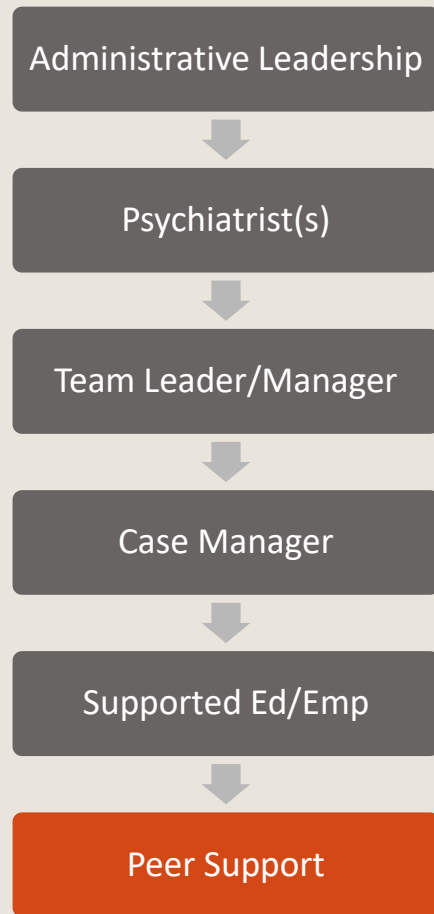
- Jose Medina

1. lived experience

- If we want to engage young people
- If we want to improve services
- If we want to improve outcomes
 - It all begins with a deep understanding of service users' experiences, priorities & needs
 - > sustained engagement with these experiences
 - > and the integration of staff/leaders with lived experience

Which does not mean

Status & Compensation



or

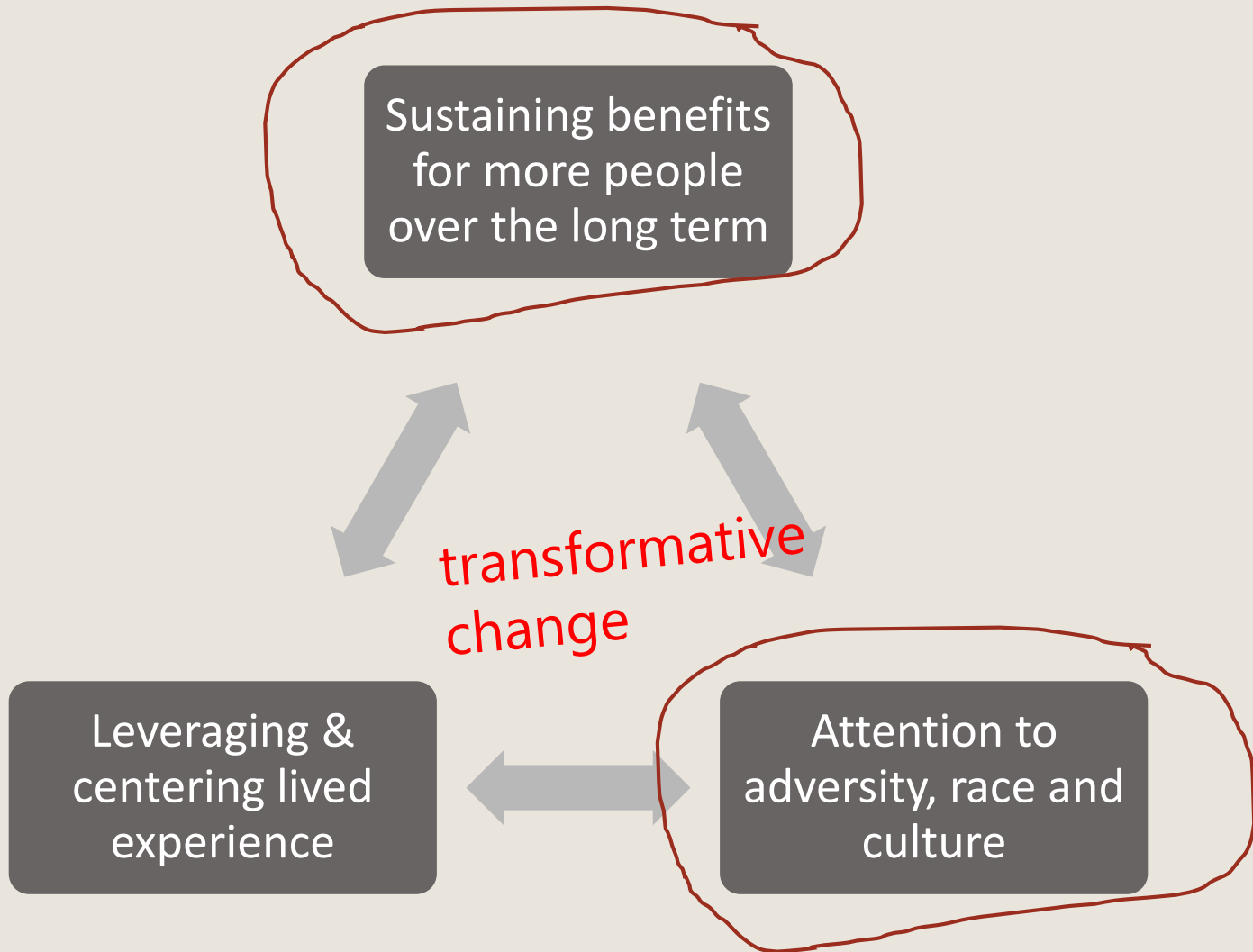
Decision Making Authority



instead



Future Directions



Sustaining benefits/change



Autonomy

Actions/behaviors
are self-aligned

Doing X because I
want to

Competence

Belief in one's
abilities

I can do X

Relatedness

Belief that one
belongs & is
included; positive
social identity

Doing X has social
meaning/value

psychosis?

autonomy, autonomy support & the example of medications

"I really liked my psychiatrist and therapist, so I took meds while I was in the program, but yeah, I was waiting until I left so I could go off them"

"it was really never on the table to discontinue and so I did so as soon as I left"



competence, work

parent: "the [CSC] program was amazing...they did sort of try to help with a job but honestly we see no way...he's just not capable of working"

Former client: "I'm not really sure about myself anymore... I was working a part-time job when I left, but then I lost it after I ended up back in the hospital"

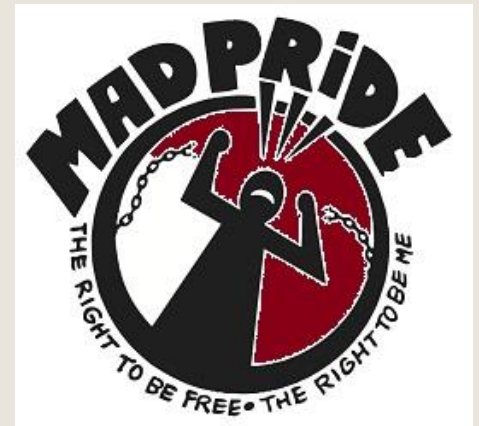


relatedness, belonging

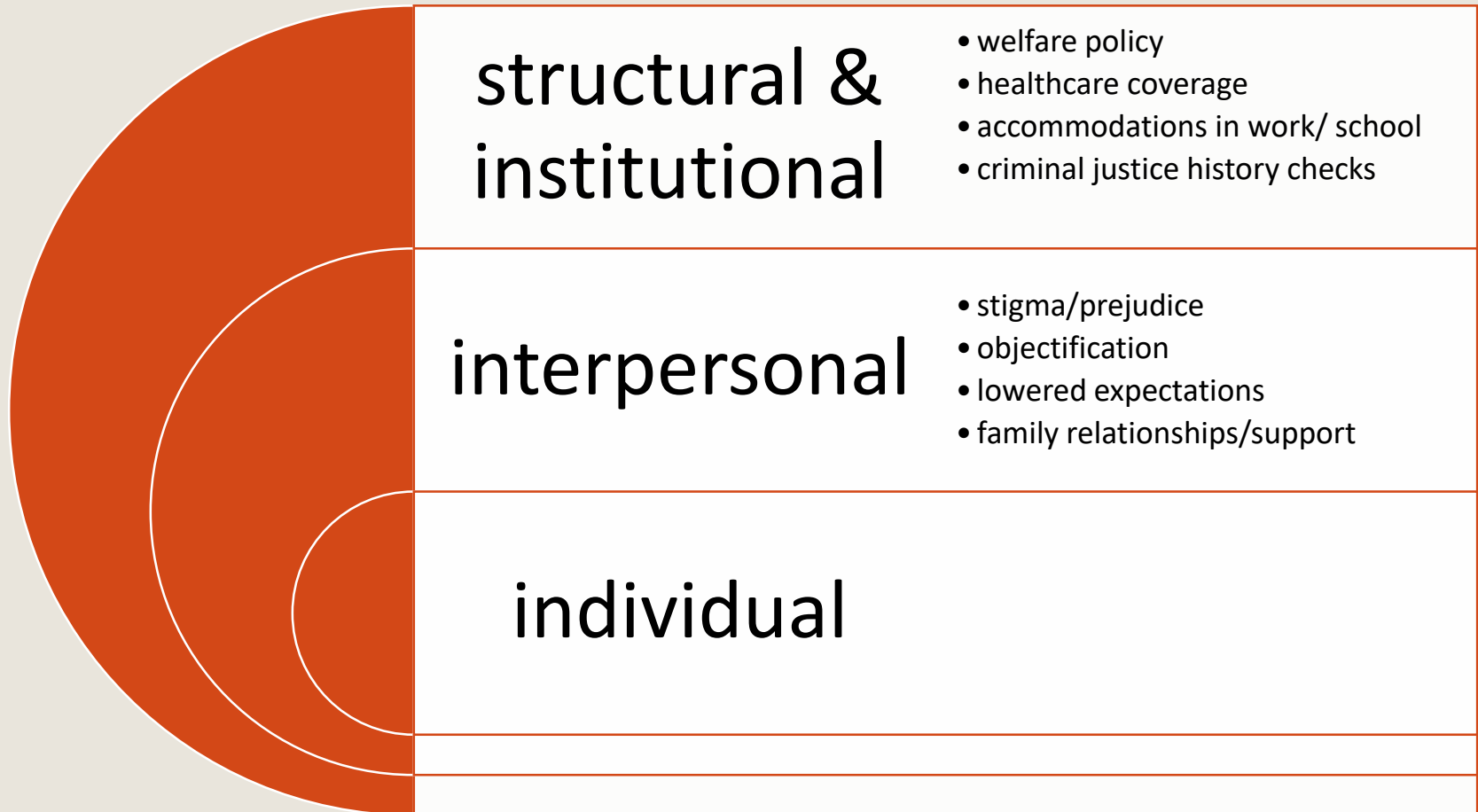
former client: "you know, the stigma, I don't think anyone wants to be known as someone with schizophrenia"

former client: "f**k that sh**: psychiatry is the genocide of black people; I don't belong there"

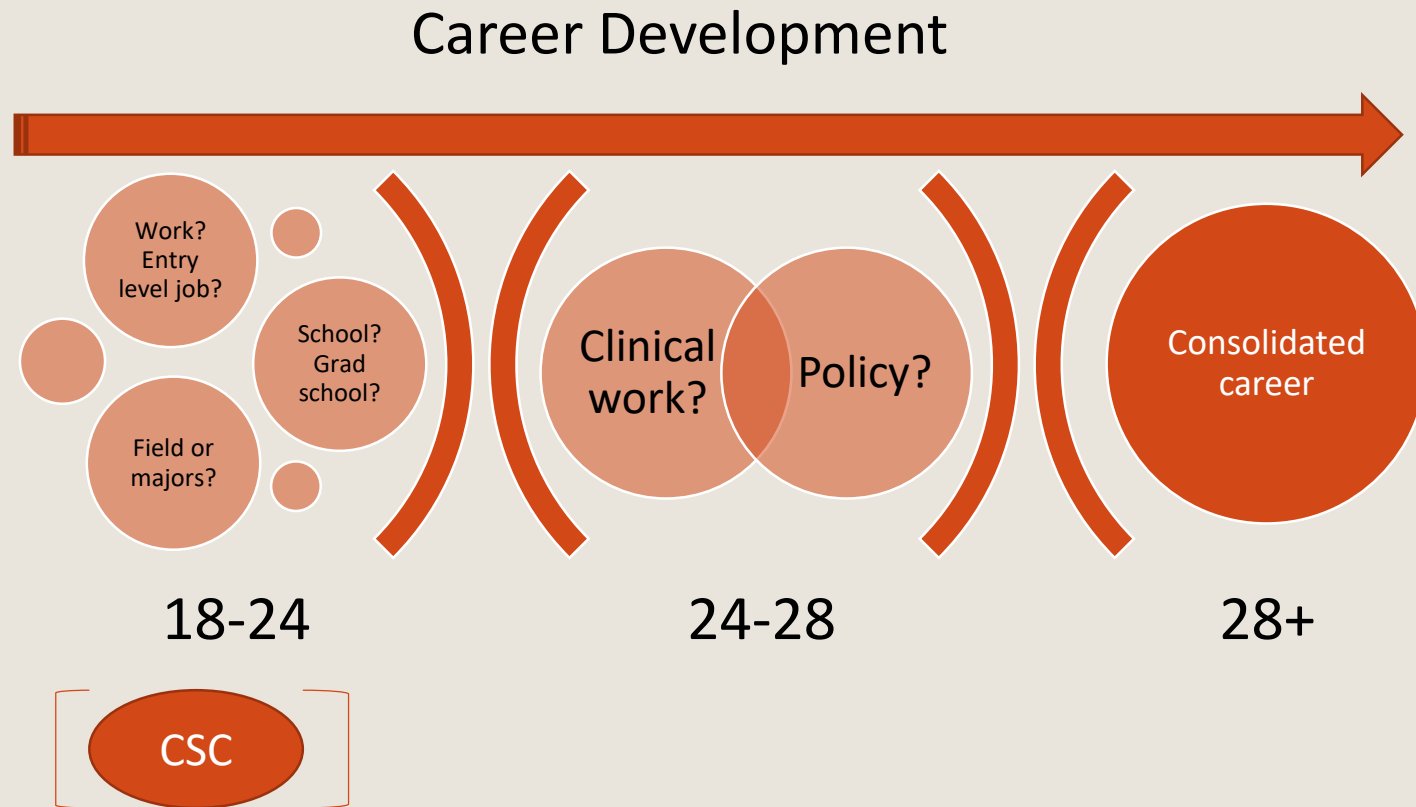
former client: "I don't actually have psychosis, that was a mistake"



structural barriers to autonomy, competence, belonging



timescales



TRANSFORMATIONAL TIMES ASK FOR TRANSFORMATIONAL CHANGE



References & grounding research

- Chang, W. C., Chan, S. K. W., Lee, E. H. M., Hui, C. L. M., & Chen, E. Y. H. (2019). Extended early intervention versus standard psychiatric care for adults with first-episode psychosis. *Hong Kong Med J*, 25(1 Supplement 3).
- Jones, N., Basaraba, C., Piscitelli, S., Jewell, T., Nossel, I., Bello, I., Mascayano, F., Marino, L., Wall, M. & Dixon, L. (in press). Clients' preferences for family involvement and subsequent family contact patterns in Coordinated Specialty Care for early psychosis in New York State. *Psychiatric Services*.
- Daley, T., Jones, N., George, P., & Rosenblatt, A. (2020; in press). First person accounts of change among young adults with a first episode of psychosis. *Psychiatric Services*.
- Jones, N. Perry, C., Olowuye, D., Mascayano, F. Kamens, S., Manseau, M. & Compton, M. (2020; in press). Structural disadvantage and culture, race & ethnicity in early intervention in psychosis services: International landscape and provider views. *Psychiatric Services*.
- Jones, N. Gius, B., Daley, T., George, P., Rosenblatt, A. & Shern, D. (in press; 2020). Coordinated Specialty Care discharge, transition and step-down policies, practices and concerns: Staff and client perspectives. *Psychiatric Services*.
- Jones, N. Teague, G., Wolf, J. & Rosen, C. (in press; 2019). Perceived organizational climate and support among peer specialists working in peer-run, hybrid and conventional mental health settings. *Administration and Policy in Mental Health and Mental Health Services Research*.
- Jones, N. Kosyluk, K., Wolf, J. & Rosen, C. (in press; 2019). Perceived barriers to the mobility and advancement of the peer specialist workforce in the United States: Mixed methods findings from a national survey. *Psychiatric Rehabilitation Journal*.
- Jones, N., Niu, G. Thomas, M. Riana, N., Hinshaw, S. & Mangurian, C. (in press, 2019). Peer specialists in community mental health: Ongoing challenges of real-world inclusion. *Psychiatric Services*.
- Jones, N., Godzikovskaya, J., Zhao, Z., Vasquez, A., Gilbert, A. & Davidson, L. (2019). Intersecting disadvantage: Unpacking sub-optimal outcomes within early intervention in psychosis services. *Early Intervention in Psychiatry*.
- Jones, N. Rosen, C., Helm, S., O'Neill, S., Davidson, L & Shattell, M. (2018). Psychosis in public mental health: Provider perspectives on clinical relationships and barriers to the improvement of services. *American Journal of Orthopsychiatry*.
- Jones, N., Rosen, C., Kamens, S. & Shattell, M. (2018). "It was definitely a sexual kind of sensation": Sex, sexual identity and gender in the phenomenology of psychosis. *Psychosis*.
- Jones, N. Kelly, T., Luhrmann, T. & Shattell, M. (2016). "Did I push myself over the edge?": Complications of agency in psychosis onset and development. *Psychosis*, 8(4), 324-335.
- Jones, N., Kelly, T. & Shattell, M. (2016). God in the brain: Experiencing psychosis in the post-secular United States. *Transcultural Psychiatry*, 53(4), 488-505.
- Maraj, A., Veru, F., Morrison, L., Joobar, R., Malla, A., Iyer, S., & Shah, J. (2018). Disengagement in immigrant groups receiving services for a first episode of psychosis. *Schizophrenia Research*, 193, 399-405.
- Morgan, C., Lappin, J., Heslin, M., Donoghue, K., Lomas, B., Reininghaus, U., ... & Fearon, P. (2014). Reappraising the long-term course and outcome of psychotic disorders: the AESOP-10 study. *Psychological medicine*, 44(13), 2713.
- Moreno, C., Wykes, T., Galderisi, S., Nordentoft, M., Crossley, N., Jones, N., Cannon, M., Correll, C., Byrne, L., Carr, S., Cheng, E., Gorwood, P., Johnson, S., Kärkkäinen, K., Krystal, J., Lee, J., Lieberman, J., López-Jaramillo, L., Männikkö, M., Phillips, M., Uchida, H., Vieta, E., Vita, L. & Arango, C. (in press). How mental healthcare should change as a result of the COVID-19 pandemic. *Lancet Psychiatry*.
- Nordentoft, M., Rasmussen, J. Ø., Melau, M., Hjorthøj, C. R., & Thorup, A. A. (2014). How successful are first episode programs? A review of the evidence for specialized assertive early intervention. *Current opinion in psychiatry*, 27(3), 167-172.
- Strålin, P., Skott, M., & Cullberg, J. (2019). Early recovery and employment outcome 13 years after first episode psychosis. *Psychiatry Research*, 271, 374-380.