

From Rhetoric to Action: Justice, Equity, Diversity, and Inclusion in Coordinated Specialty Care for Early Psychosis

Shannon Pagdon, B.A., Sarah S. Shahriar, B.S., Samuel Murphy, M.S.W., Christina Bomnae Babusci, M.S.S., Ana T. Flores, M.S.W., Ariana J. Rivens, M.A., Arielle Ered, Ph.D., William R. Smith, M.D., Ph.D., Nev Jones, Ph.D., Peter L. Phalen, Psy.D., Monica E. Calkins, Ph.D., Melanie E. Bennett, Ph.D.

Attention to inclusivity and equity in health research and clinical practice has grown in recent years; however, coordinated specialty care (CSC) for early psychosis lags in efforts to improve equity despite evidence of ongoing disparities and inequities in CSC care. This Open Forum argues that marginalization and disparities in early psychosis research and clinical care are interrelated, and the authors

provide suggestions for paths forward. Commitment to equity and justice demands recentering the perspectives of those most affected by early psychosis services and investing in the integration of historically excluded perspectives across all aspects of practice, policy, and research.

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Since the Recovery After Initial Schizophrenia Episode (RAISE) initiative in 2008, investments in coordinated specialty care (CSC) for early psychosis in the United States have made substantial contributions to improving access, quality, and outcomes of CSC services. The federal government investment in CSC through the Community Mental Health Services Block Grant led to hundreds of new CSC programs. NIMH's Early Psychosis Intervention Network (EPINET) has accelerated CSC research through its EPINET National Data Coordinating Center (ENDCC), eight learning health care hubs, and >100 CSC programs across 17 U.S. states.

Although the benefits of CSC have been established, rural, socioeconomic, and ethnoracial disparities in access to, engagement in, and outcomes of CSC remain. Simultaneously, involvement and coleadership of individuals with experience of psychosis remains underdeveloped and undersupported. In keeping with calls in the United States for investment in justice, equity, diversity, and inclusion, including in the NIH-funded workforce, we highlight challenges to equity in service user access, engagement, and outcomes; family member access and engagement; CSC team diversity and inclusion; and prioritization and decision making among researchers, centers, and funded initiatives. Justice, equity, diversity, and inclusion initiatives demand dismantling structural barriers and inequities (e.g., racism, classism, and ableism), equitable distribution of resources, and meaningful integration, representation, and leadership of diverse voices—particularly of those most affected by

discrimination and exclusion. We conclude with recommendations, examples, and steps forward.

CHALLENGES TO EQUITABLE CSC SERVICES

Access and Engagement Among Service Users

CSC access and engagement are inadequate: national EPINET data show that 24% of service users terminate services before discharge, with 15% being lost to follow-up (1). Inequities exist within these rates. Rural populations are disadvantaged because CSC programs cluster in urban and suburban locations. Underrepresented minority service users experience a longer gap between symptom onset and first contact with mental health services compared with their White peers (2). Black service users are approximately three times (95% CI=1.2–5.2) more likely to be lost to follow-up than are White users (1). Common access and engagement barriers for ethnoracially and culturally diverse service users include cultural and religious discordance, stigma, mistrust, and limited familial involvement (3). As the qualitative literature reminds us, aspirations of providing person-centered, recovery-oriented care do not always match service users' perceptions (1, 4–6).

Access, Engagement, and Cultural Sensitivity for Family Members

Family psychoeducation and support are core CSC components. Although family involvement improves service

user engagement, family participation fluctuates and decreases over time (7). Structural factors (such as program hours, child care needs, and distance) and CSC teams' lack of cultural and linguistic competency pose barriers to family engagement. Black and Latinx families are less likely to participate than are White families (7), and Black family members report discrimination when navigating services (8).

Diversity and Inclusion Among Clinical Staff

There is widespread concern about the lack of socio-structural, ethnoracial, and linguistic diversity among early psychosis clinicians (9). Black, Latinx, Native American, and Asian clinicians are minimally represented on CSC teams, even in geographical areas where the general population has a greater share of underrepresented minority groups. Lived experience of psychosis is insufficiently represented. Team members with lived experience generally work as peer specialists—often the lowest compensated team members. These positions commonly offer part-time hours, limited benefits, and poor career mobility.

PRIORITIZATION AND DECISION MAKING IN NIMH EARLY PSYCHOSIS INITIATIVES

CSC outcomes remain inadequate and inequitable. Secondary analyses of RAISE data have revealed that all primary benefits of specialized services, compared with treatment as usual, accrued mainly for individuals in the top socioeconomic status quartile (10). Worldwide data indicate that CSC benefits erode in the years after discharge (11). Recovery rates have remained essentially unchanged for decades across high-income countries (12). Alongside endorsement of involuntary intervention, the stigmatizing belief that individuals with schizophrenia are dangerous has grown in the United States since the 1990s (13). Even though people with lived experience and their families hold critical insights to address these challenges, they remain markedly underrepresented in CSC research. Underrepresentation is even more stark for individuals with lived experience and intersecting minoritized backgrounds (14).

As the chief CSC research structure, EPINET provides a clear illustration. In the first round of EPINET funding, hub leaders, the ENDCC, and the EPINET Steering Committee made decisions about policy and data collection without prominent inclusion of ethnoracial minority leadership or integration of lived experience into research. No formal mechanism for (or requirement of) service user participation was announced. The new call for EPINET funding recommends that applications “promot[e] effective communication and collaboration among service users, clinicians, program administrators, and scientists to boost participation in co-designed practice research”; service user input is “strongly suggest[ed]” (<https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-24-105.html>). Such statements represent progress, yet precise guidance is needed for investigators in

research planning and execution and for reviewers and program officers in proposal review and oversight.

Recommendations without concrete expectations and mechanisms to ensure accountability are unlikely to alter practice. Lack of diversity among national CSC leaders and investigators shapes the services that are prioritized and the questions that are pursued. For example, the literature on adherence to antipsychotic medications in early psychosis far surpasses that on peer support and service user experience of coercion or discrimination.

SOLUTIONS AND PATHS FORWARD

Policy makers, programs, clinicians, funders, and researchers must prioritize integrating people with lived experience and those from underrepresented ethnoracial and socioeconomic minoritized groups as consultants, trainees, coresearchers, and primary investigators. Individuals with intersectional marginalized experiences are uniquely positioned to contribute to solutions to the interaction between inequities and CSC access, engagement, and outcomes. The research interests of groups historically excluded from research should be nurtured at all levels.

Policy makers, programs, and clinicians can take several immediate steps. In practice, avenues for change include investment in trainees from underrepresented groups, including those with lived experience, across the education-to-practice pipeline. For roles that require formal training (e.g., social worker, counselor, psychologist, nurse, or psychiatrist), schools should foster interest in early psychosis research among students from underrepresented backgrounds and with lived experience. For roles that do not require formal education (e.g., vocational support or peer specialist), fellowships (e.g., the Health Resources and Services Administration's Behavioral Health Workforce Education and Training program for paraprofessionals) should be leveraged to recruit trainees from underrepresented backgrounds and those with lived experience. Family members from marginalized backgrounds or with lived experience can be recruited as family peer support specialists and offer a distinctive perspective. Because disadvantaged individuals face barriers to many formal training programs, academic-community partnerships, such as those in EPINET, should be leveraged to support providers' socioeconomic mobility, for example, in transitioning from lower-wage roles to higher education programs in mental health fields. Programs such as the Peers to Higher Education initiative of the Wayne State University School of Social Work provide a blueprint (<https://socialwork.wayne.edu/peers>). Culturally informed, recovery-oriented training should be provided to all team members, regardless of their background.

Investment in a diverse education and career development pipeline also is essential in research. Dedicated funding for trainees from underrepresented backgrounds and with lived experience will create opportunities for career development. Research staff positions could be used as

targeted opportunities to train individuals personally affected by or underrepresented in the research workforce, and special funding could be created to enhance diversity among psychosis research leaders. Within our Connection Learning Healthcare System (CLHS) EPINET hub, we integrate students and researchers with lived experience in leadership roles, employ them as research staff, and provide opportunities to lead CLHS-linked projects. For example, a researcher who worked as a CSC peer specialist now leads research on peer support implementation across CLHS. Service users' insights into unexplored research topics must be sought after completing CSC. For example, the service user-led Psychosis Outside the Box project (<https://rethinkpsychosis.weebly.com>) has called attention to aspects of the psychosis experience, including subjective impacts of language and labeling, that have been neglected in research and practice (15). NIMH and NIMH-appointed reviewers should value (and reward) investment in justice, equity, diversity, and inclusion through recognition, funding, and structure of research.

Research institutions must ensure that contributions of underrepresented minority individuals and those with lived experience are valued, not tokenized. Drawing on international work on the impact of participatory research methods (16), funding agencies should provide guidance on these methods and train reviewers to scrutinize participatory plans and reward meaningful involvement and penalize nominal inclusion. For example, advisory boards that offer service users and families no meaningful participation in project development or decision making should be recognized as suboptimal "minimal" inclusion. The U.K. National Institute for Health and Care Research's guidance on co-producing a research project could serve as a model.

Identity alone is not a substitute for sustained critical thought and investment in collective processes of critical consciousness (or *conscientization*, i.e., the development of a collective awareness and understanding of underlying mechanisms and effects of power, privilege, and oppression). Underrepresented minority individuals, especially those in early career stages, face great pressure to conform, as do lower-status providers in practice settings. Justice, equity, diversity, and inclusion is not simply about "bringing people to the table" but transforming the table through deep engagement with diverse perspectives and a willingness to change the status quo and cede one's own power and control.

POSITIONALITY STATEMENT

This Open Forum includes three coauthors with personal experience of intervention for early psychosis, four from ethnoracial minority groups, and several with other disabilities or family experiences of serious mental illness, including experiences of disability-related homelessness, poverty, and public sector social welfare services. Service experiences represented within this group include voluntary and

involuntary hospitalizations, long-term use of antipsychotic medications, partial hospitalization, and disengagement from mental health services. More than half of the coauthors fall under demographic categories recognized as underrepresented in the NIH workforce. We also acknowledge that we are not diverse enough. We must transform services and policies so that leadership reflects those affected by psychosis.

CONCLUSIONS

The new round of EPINET funding represents an opportunity to move from rhetoric to action for justice, equity, diversity, and inclusion in CSC research and practice. Whenever entrenched inequality is at play, courage is required to own what has happened in the past and invest in change that is real, material, and grounded in the present with eyes to the future.

AUTHOR AND ARTICLE INFORMATION

School of Social Work, University of Pittsburgh, Pittsburgh (Pagdon, Babusci, Flores, Jones); Department of Psychiatry, Perelman School of Medicine, University of Pennsylvania, Philadelphia (Shahriar, Rivens, Ered, Smith, Calkins); Department of Psychiatry, University of Pittsburgh, Pittsburgh (Murphy); Department of Psychology, University of Virginia, Charlottesville (Rivens); Department of Psychiatry, University of Maryland School of Medicine, Baltimore (Phalen, Bennett). Send correspondence to Dr. Bennett (mbennett@som.umaryland.edu).

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This Open Forum reflects a collective group writing process and calls into question the traditional hierarchy of authorship. The authorship order of this Open Forum positions those who are most junior (and precarious) first, ending with those who are most senior.

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