

Moving towards social inclusion? Questions and reflections from a Transatlantic Mental Health Policy Symposium¹

Abstract: In September 2016 a Transatlantic Mental Health Policy Symposium was held at the Robert F. Wagner Graduate School of Public Service, New York University. As part of the EU Horizon 2020 funded ‘Citizenship, Recovery, and Inclusive Society Partnership’ (CRISP), the symposium was intended to provide a forum for discussion on social inclusion, mental health and to consider implications for policy. This paper provides a summary of key themes from the symposium, and highlights a selection of the questions generated for further enquiry².

Key themes & observations from the day

- Strength in having input from range of disciplinary perspectives
- The challenge of needing programmatic interventions to deal with immediate pressing problems while also addressing more “upstream” policy and structural changes to prevent future problems
- Tensions between mainstream and universal approaches versus exceptionalism. How do you get the balance right?
- Narratives on inclusion. Who decides who is in the room? What power and influence do those with lived experience have?
- Partnerships. How do we build alliances with other movements e.g. race, poverty? What is our common language?
- Need for stronger links between policy and research and policies to move out of silos to reflect the interconnectedness between social issues and mental health outcomes.
- Evaluation. Are we using the right outcomes and measures? Who decides what success looks like?
- Comparisons between different contexts. Do we have common definitions? How the different contexts of policy, structure and programmes impact?

¹ This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 690954.

² This paper is based on notes taken on the day of the event. This paper is intended to capture key themes. In particular some of the questions noted from the discussion have been selected; however we recognise that it has not been possible to reflect all the points made. This paper is intended to provide a starting point for discussion. We take responsibility for any significant omissions.

Background

People with lived experience of mental health problems experience significant health and social inequalities. This includes high levels of early mortality, morbidity, unemployment, poverty, and social isolation. In the period following the transition from hospital-based to community-based care, many people have faced social exclusion including discrimination, stigmatisation, poverty, homelessness, and incarceration. In response to these challenges, the 'Citizenship, Recovery, and Inclusive Society Partnership' (CRISP) is an EU funded 4 year knowledge exchange programme intended to promote learning and understanding on social inclusion and mental health. Core to this work is a focus on conceptualisations of citizenship and participation, the importance of recovery-oriented and person centred services, addressing the stigma of mental health problems and the role of public policy in shaping good mental health for society.

As part of the first year of the CRISP partnership, in September 2016 a Transatlantic Mental Health Policy Symposium was held at the Robert F. Wagner Graduate School of Public Service, New York University. Over 60 participants took part, including policy makers, people with lived experience, academics from different disciplines, and practitioners from the voluntary sector. This paper provides a summary of themes of the symposium, and highlights a selection of the questions generated for further enquiry.

Providing context: Mental Health Policy in the United States

The symposium began with a comprehensive overview of mental health policy in the U.S. and New York state provided by Commissioner Ann Sullivan, New York State Office of Mental Health. Key developments were highlighted, including the transition from institutionalised hospital care to community care; Medicaid and Medicare insurance; the Surgeon General's report "no health without mental health"; the patient rights movement, recovery movement and peer movement; and the Affordable Care Act. Positive advances included the move towards integrated health care, and improvements in employment and housing for people experiencing mental health difficulties. Nevertheless, persistent challenges include the lack of resource for mental health services, the incarceration of people with mental illness in the criminal justice system, the mortality gap for people with serious mental illness, and barriers to social integration in terms of jobs, safe housing and stigma. It was clear that whilst differences are evident in health care provision between the U.S. and Europe, many of the challenges resonate in both contexts.

Social Inclusion and mental health: Progress and paradox

Common transatlantic challenges were also clear in the presentation on social inclusion and mental health provided by Professor Sherry Glied, Dean, Robert F. Wagner Graduate School of Public Service. Professor Glied outlined a key paradox; whilst treatments and living conditions have improved, the social inclusion of people with lived experience of mental

health problems has not. Whilst more people are able to access mental health treatment, and social protection services, at the same time key trends in labour force participation and voting illustrate under-representation of people with experience of mental health difficulties. It was also highlighted that the changing nature of employment, and the skills it now demands, may have particular implications for people with mental health problems. Professor Glied advocated for continued focus on improved access to treatment, and also called for mainstream approaches to respond more sensitively to the needs of people with mental health problems if greater social inclusion is to become a reality.

Representing voices and perspectives

The importance of listening to and representing the voices and perspectives of people with lived experience of mental health problems was highlighted by Briana Gilmore, Director of Planning and Recovery Practice at Community Access. Briana outlined a framework focused on the values, structures and practices which might promote inclusion. Important questions were raised: What does an inclusive society mean? Who gets to decide? What is recovery? What does belonging look like? Who did we ask and why did we choose to ask those people? Who is already 'included', in terms of employment, nuclear families, health, economic self-sufficiency or education? What is the dominant narrative? Are persons who are isolated able to meaningfully contribute to creation of the dominant narrative? How is our approach embedded in our own personal context or privilege?

Citizenship, recovery, and stigma

Three key themes of the CRISP partnership were then considered in small breakout sessions, and key questions for public policy were generated. Some examples included:

Recovery: In this discussion, issues of conceptualisation were explored. Does recovery equate to wellness? Are people's voices being heard in policy, research and programme development? Does recovery require acknowledging diagnosis? How does recovery connect with concepts such as self-determination, self-direction and choice, and are these universal values? How to measure outcomes for recovery? How is recovery different from rehabilitation? How are outcomes for recovery measured and how do we improve them? Is work (employment) an appropriate outcome for recovery? How can systems address social determinants? What is the value of recovery and rehabilitation from society's perspective? From what norms does this derive?

Citizenship: It was highlighted that 'citizenship' is a newer idea and less familiar to some when compared to the concept of recovery. The discussion explored what is meant by citizenship including legal definitions as well as inclusion and participation in societal structures. What role do formative institutions such as school and the military have on the concept of citizenship? To what extent have policy makers considered the concept of

citizenship? Who defines what citizenship is? Who defines the norms? What is the difference between recovery and citizenship?

Stigma: In this discussion there was exploration of ways in which to challenge stigma and discrimination. Key strategies were identified including contact, education and protest. Discussion considered stigmatising practices in health services, how disclosure from staff about their own lived experience may help. The need for accommodations and structural interventions to include mental health not just physical health was highlighted. The impact of protest, and the importance of politics was also identified. Other potential solutions included improved mental health education in schools, and the need for courses on human rights, focused on fundamental principles such as fairness, respect and responsibility.

Solutions from the U.S. and Europe

As part of the first panel discussion, progress on social inclusion was discussed. The aim was to consider the following question: *“What works in improving the social inclusion of people with lived experience of mental health problems?”*. In particular the use of a human rights based approach, the role of the arts in social inclusion, and the value of the peer movement were identified as fundamental developments. The importance of ensuring people with lived experience of mental health problems “have an equal place at the table” was emphasised.

Key questions explored aspects of inclusion and the social context of health and wellness. How to address the social determinants of health without tying it to a lack of wellness? How do we find ways for jobs to accommodate for mental health problems? Is work an appropriate outcome for recovery? Do arts interventions leave communities better off? How to achieve meaningful involvement of peer workers? How to ensure peers are valued and experience parity? The need for innovation and wider understanding of the impact of ‘non-health’ sectors (e.g. housing, debt support etc.) on health was highlighted.

Social determinants of mental health

The afternoon programme explored some key social determinants of mental health. Specific topics were selected for discussion in breakout sessions, and facilitators guided discussion regarding key questions for public policy.

Race, gender and poverty: Each of these dimensions was recognised as connected with power and social structures. Race, gender and poverty impact on disparities in treatment and diagnosis and it was recognised that mental health problems don’t impact on all populations equally. The need for large scale, long-term, social movements was called for, along with policies that recognise the interconnectedness of race, gender and poverty. How to address the power imbalances within structures and leadership? How to empower individuals with lived experiences and their social workers, care givers, psychologist etc. to

be involved in social movement for change? How to build alliances that cross boundaries?
How to focus on the longer term?

Criminal justice: Key issues for public policy included those related to the criminal justice system such as: supportive re-entry, decriminalising drug use and drug reform, and reducing sentences for non-violent offences. Issues related to service provision were also identified, such as the importance of Medicaid and health care provision after release from prison, as well as access to housing and employment.

Children and Families: The importance of the family context for mental health was explored. Key issues included; the tensions and complexities of mental health diagnoses for families and how to access appropriate care. How to bring systems together to work better for families? How to develop evidence on prevention and early intervention? How to strengthen implementation research on parenting programs? How to include family/parenting issues into stigma programmes? How to encourage more cross-sector collaboration?

Integrated Health: Key issues in this area included: the early mortality of people with mental health problems, the lack of parity between mental health and physical health, and the importance of “no health without mental health”. Issues of definition regarding integrated health were highlighted; How do we treat mental health, physical health and substance use together? What does mental health mean and does it include substance misuse or not? How can the healthcare system see the value in an integrated system? How to develop communication among providers/practitioners e.g. Psychiatry, Social Work, Primary Care? How to improve systems (including electronic communication) so that the system speaks to everyone involved in treatment? How to ensure good outcomes and good quality of life? What is the role of self-management and early interventions?

What are the critical questions for public policy?

The final panel session provided an opportunity to bring together different threads of discussion from the day, and focus on public policy. The aim was to consider the following question: *“What kinds of questions do we need to ask in order to build a more socially inclusive society, with better mental health for all?”*

The need for “architecture” and a strategic (rather than a short term) vision for mental health was articulated. Key tensions included the balance between programmatic interventions versus policy or structural change, and between mainstream/universal approaches versus exceptionalism.

Issues for health care service delivery included; what are the goals of services (e.g. inclusion? recovery? citizenship? flourishing?). What are the right outcomes and measures? What kind of systems do we need to achieve these outcomes? How do we untangle the

current narrative of mental health? Does the cost/reimbursement structure fund the system we want to see? How to develop trauma-informed approaches?

Questions regarding representation and inclusion were also evident. How to include citizens in research and policy? Who makes the decisions about what 'success' looks like in research, or in policy? What level of evidence do we need and whose voices do we need? Who needs to be represented in the room where decisions happen? How do we ensure that policy perspectives from people on the ground and practitioners are captured, instead of just people doing research?

Issues of power and leadership were raised. How to best build alliances with race, and poverty movements? How to be bold and think big? How can researchers move out of their comfort zone and build partnerships? How to connect with mainstream policies and prevention including those focused on race, gender and poverty? How do we keep economic inequality and policy on the table? How much inequality are we willing to bear?

Summary

Diverse perspectives were represented from a range of stakeholders engaged in mental health and social inclusion from Europe and the U.S. This provided the opportunity to exchange perspectives from different contexts, in the U.S., Germany, Finland and the U.K, to explore common definitions and compare policies, structures and programmes. Common challenges remain, including issues of definition, differences in service delivery, and ongoing inequities in terms of prevention, practice, treatment and outcomes. At the same time there was recognition of areas of progress, passionate voices for greater equity and inclusion, and a range of questions for future enquiry. Indeed the focus of the symposium was on generating questions from a range of angles rather than providing decisive answers or recommendations. The CRISP partnership will continue to explore these questions through ongoing knowledge exchange and collaboration.

For further information on the CRISP partnership please visit: www.crisppartnership.eu

Acknowledgements

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 690954.

We would like to thank all those who participated in the Policy Symposium, and the presenters, facilitators and panellists for their contributions. Thanks also to those who took notes of the day's proceedings.