maladjusted
Community Action Report

Policy Recommendations from the Theatre for Living production

If you use this report in any concrete way, please let us know at: outreach@theatreforliving.com

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maladjusted…an introduction

This report is a compilation of policy ideas generated during the performance of *maladjusted,* March 8-24, 2013 - a play created and performed by mental health patients and caregivers[1], and directed by David Diamond. *maladjusted* was born out of conversations with people struggling within the mechanization of the mental health system. Material for the play is drawn from a one-week workshop with 24 mental health patients and care-givers who shared from their real life experiences. Initially, the project's dominant note was 'patient-centered care'; this later shifted to 'human-centered care' as it became clearer that gaps in the system extended beyond patients to caregivers and family members and the need for a more holistic approach. The play brings forward real issues by people who have lived experience and who worked with the director to "create a fictional story that told the truth" Each actor developed a character inside a narrative who was not them, but who they knew very well. The play's complexity reflects the struggles people are facing with system gaps in care. The play ends with no solutions, looking to the audience (and society) for where to go next.

Policy and *theatre*?

Imagine: you, as an audience member, have just yelled "stop" and all the actors on the stage have stopped the play, mid-sentence. Moments earlier, the director, in the role of "Joker"[2] challenged you and the audience to bring your knowledge to the stage. He pointed out to you that the silence in the audience reflects the silence in society, even when something doesn't look right. We all too often wait for others to take action. You muster up your courage, and, heart pounding, take the role of an actor on the stage. Your idea comes to life as the actors respond to you and the gaps you have highlighted. Then, at the end of your 'scene', the audience is asked to give policy suggestions. Policy ideas pour in, not just in response to issues in the play itself, but in response to real life interaction with the mental health system in Canada.

Every night of *maladjusted*, 80 – 90% of the audience reported having had direct experience with issues on the stage – as patients, caregivers, family members and friends. In essence, interactive (Forum) theatre is a way to give voice to broader community, on a premise that the answers to systemic problems exist within community.

[1] The cast: Erin Arnold, Khoal Marks, Michaela Hiltergerke, Pierre Leichner, Sam Bob, Colin Ross. Martin Filby was an original creator who had to leave the cast just prior to opening for emergency health reasons.
[2] The term *Joker* comes from Augusto Boal's *Theatre of the Oppressed* to name the facilitator of the interactive theatre event. Not a court jester; think wild card in a deck of cards.

The mental health system *on stage*

The play explored many themes – three of which are broadly highlighted in this report. One theme is the misdiagnosis of people – in this case young people and the debilitating effects of heavy yet unnecessary prescriptions. Another is the concurrence of homelessness and mental illness, where lack of appropriate treatment leads to further trauma. A third theme is the breakdown of a mental health system that struggles to keep the mechanics of the system working while losing sight of human connection. At each performance, audience members brought their solutions to the stage, resulting in dynamic community sharing.

In addition to the 18 public performances, three public dialogues were held on March 18th and 19th, 2013, on the topics of: Cost of Caring: How values drive spending; What does getting better look like: The chemicalization of mental health care; and The art and mechanics of mental health care: How do caregivers function creativity within a mechanizing system? These dialogues surfaced more detailed analysis and additional policy perspectives.

Can this really be *policy*?

Over 270 policy suggestions were collected during the performances and dialogue series, representing the 2020 people from the metro Vancouver area who attended the live events. These responses were recorded at every show, then collated by theme. The policy suggestions presented in this paper include both large-scale requests and smaller scale, bit sized changes that can be easily implemented with little cost. The reason for including both is to highlight the larger issues that continue to have prominence for the communities in this region, as well as the more unique strategies percolating in the community.

The strategies presented in this paper range touch on many aspects of the mental health “system”, and are organized according to jurisdiction primarily, taking into account areas of overlap in some cases.

The voices represented in this report (shown in italics) are all from the performances and dialogues. They represent a large cross-section of values and perspectives on mental health care, and point poignantly to the experiences of all of us to in some way have interfaced with the mental health system. This paper is meant to reflect both the diversity and commonality of our perspectives.

The term “mental health patient” is used throughout the report. While “client” and “consumer” are also in current vernacular, we chose “patient” because it seems most closely aligned with the full range of mental health issues our project is addressing.

RECOMMENDATIONS

All levels of governance and policy makers

Increase public involvement in mental health policy and implementation

The energy we witnessed invested in the forum plays and dialogues attested to the need for this very public, ongoing dialogue about the mental health system in Canada. Participants who had feedback for the mental health system expressed being at a loss for ways to do this. More opportunities to decision-making processes and policy making on a large scale (not only personal) was a clear request.

Host public dialogues on mental health in British Columbia

Provide mental health patients and their families who have had direct experience with the mental health system to give feedback to the system. It would be essential for the people facilitating these public dialogues to be mandated to come into the process without preconceived outcomes and for the process itself to be truthful and respectful of the real knowledge in the community.

BC Ministry of Health: Mental Health and Addiction Services, BC Ministry of Child and Family Development, Health Authorities

1. Increase access to mental health care

Increasing access to mental health care ranges from the big picture of increasing overall number of health practitioners, to more specific kinds of care such as equitable access to psychology, on-call 24/7 prescribing doctors for high-risk situations, and after hours services for employed people.

Increase number of doctors and health workers

We heard repeatedly that the current shortage of doctors and health workers is leading to wait times, shorter visits, and burnout among employees. Recommendations to increase numbers of health practitioners include:

- Increase current number of positions for health workers, with emphasis on nurse practitioners and doctors;
- increase medical student admission levels;
- more support for immigrant doctors to upgrade and find placements.

“doctors don’t have time to adequately assess patients”

“the doctor is under pressure to solve the problem immediately”

"more medical students need to be admitted to UBC"

"less patients for each worker, more workers"

Increase access to psychology and counseling

More equitable and accessible therapy that does not default immediately to medication, including psychology and counseling. Recommendations to increase access include:

- increase funding for non-profit organizations that provide counseling on a pay scale;
- ensure counselors and psychotherapists are part of mental health teams in hospitals;
- include coverage for psychology and counseling in part of B.C.'s Medical Services Plan (MSP).

"*many [people] are getting medicated when they are feeling sad*"

"how about counseling, then medication"

"more time allotted to a therapy session before prescribing"

"30 out of 191 applications to participate in the play came from people who were wrongly prescribed medication"

Provide funding for on call, 24/7 support from a psychiatrist or doctor who can assess and prescribe medications in high-need situations

One of the major gaps identified in the project was the need for on-call 24/7 support available to treatment centers and organizations that are housing high-need mental health patients. This is to avoid the escalation of trauma and mental health breaks when a person on prescribed medication is without their medication in an unforeseen circumstance.

Increase services that are offered after regular work hours

To support patients and families maintaining jobs, offer more services after regular working hours.

"*when mental health offices are open from 11am to 8pm, then we will know that we have a more humanized system*."

2. Increase integration of mental health services

The interactive theatre events highlighted disconnects in the system and the need for more integrated, team oriented approaches, within and across services.

Increase coordination of treatment services

Expand on current systems to allow for more integrated treatment plans across multiple services and all levels of government. In addition to the online system that is in development, participants called for regular in-person internal and cross-team meetings to coordinate treatment services.

"*more direct contact between agencies with clearer communication*"

"*practitioners need a more level playing field, less hierarchical and more of a team approach*"

"*meetings where everyone in all levels, including frontline workers, can express ideas*"

"the doctor needs to be willing to be vulnerable, to not know the answer; to be transparent and recognize the concerns on the team"

Establish a mental health community of practice

Establish a community of practice across multiple domains that support mental health, such as employment, arts and music, sports, housing, counseling, and schools.

"what does getting better look like? …getting involved with community, housing, education, better work options, connections, arts, theatre…"

3. Increase span of advocacy programs

Navigating the mental health system can be challenging, particularly during times of trauma and stress on the part of the patient. The need for mental health patient advocates who support patients in accessing community support services as well as being a connecting point between caseworkers, community services and families was often repeated during the forum theatre events. This approach can also help patients advocate for themselves.

Increase funding support for advocacy programs delivered by non-profit agencies and grassroots organizations

Ensure patients have access to advocates if needed and desired.

4. Expand youth peer and educational support

A young person suffering from mental health challenges is in need of support that meets their specific needs and desires. We heard from audiences that traditional school counselors and psychiatrists might not meet their needs in a way they can

trust. Youth called for more peer support, more flexible options for completing schooling and more awareness of youth rights.

Increase peer support programs for youth

Peer support training, funding and public awareness are being called for.

"I don't need a doctor, I need a friend" (audience member in the role of Dani, 17 year old)

"teenagers need to have peer advocates in all circumstances"

Increase alternative educational support

Educational programs with more flexibility, accessibility and mental health support (i.e. counseling) for high school completion and skills training to support youth.

5. Expand support for families

A core theme of the play was the whole family context of mental health, in addition to the individual. When the whole family is cared for, there is better chance of success for the individual.

Develop family-centered residential treatment care.

Offer services that support each member of the family as well as the family system.

6. Increase support aimed at the well-being of mental health practitioners

The health of mental health practitioners was a strong theme in the forum theatre events. While the most straightforward solution is to reduce caseloads to manageable levels (as recommended at the beginning of this report), audience members also recommended services and programs directed towards the health of health workers.

Institute paid Professional Days for health care workers

Recommendation is to allow for self-care in a way that is not stigmatized the way "mental health day" has been. Similar to a Professional Day for teachers, it would allow health workers unstructured time to address case loads or for self-care.

"self-care day as a paid day; 'mental health' day has stigma"

"health workers need unstructured time in their day so they can process what has happened"

B.C. Ministry of Health: Mental Health and Addiction Services

Improve Recovery House service delivery to mental health patients

The project identified gaps in Recovery House standards and practice for those with both addiction and mental health illness. The following lists specific ways the *B.C. Standards for residential substance dependence treatment facilities* could be further updated based on community recommendations.

Adapt screening and intake processes to (non-addictive and/or physician prescribed) medication needs

During the screening / intake process, ensure there is no temporary withdrawal from medication while medications are being approved by the in-house physician. While current standards appear to support this, in practice, medication assessment is occurring at times post-intake. Suggestions from the interactive forum to enable no time gap include:

- allow for the original prescribing doctor to make a short-term prescription while medications are been assessed by the in house doctor to avoid any gaps in medication access for the patient;
- include certain mental health non-addictive medications in the *prn* list (which allows certain drugs to be dolled out as needed);
- ensure medical assessments of medication are made before or at the time of an intake.

"need relaxation of liability to be able to deal with messiness"

"need more creative thinking and flexibility"

"*people are in boxes in recovery houses*"

"In the Crest system[3], a nurse is always on duty…we need more of those"

Improve transition programs from Recovery Houses

Expand transition programs for people leaving drug treatment through connecting with community-based services, peer support; and follow up care.

"*appropriately transition people out of programs*"

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[3] CREST: Community Residential Emergency Short Stay Treatment, a program of the Fraser Health Authority

Enhance the support system for patients weaning off of medications

A gap in services available for people choosing to safely stop taking psychiatric medications for various reasons was identified. Recommendations include:

- temporary housing specifically for people weaning off of their medications to allow for a safe place during withdrawal.
- increase psychiatric support to wean off of medication;
- increase counseling support during the withdrawal process.

"*more help to come off of psychiatric meds, and encouragement to go off meds"*

B.C. Housing, Health Authorities, Non-profit organizations

Increase access to social housing

More housing for mental health patients was a policy recommendation repeated by audiences at every show. The need for flexibility in housing type, allowing for multiple and diverse needs was also emphasized.

Innovations and support for wider variety of social housing

Types of housing recommended by forum participants include:

- low barrier (pets allowed) and harm reduction housing;
- safe-houses for people who feel an illness coming on;
- housing for people once they leave a hospital (as well as care for their housing while in the hospital);
- housing for people exiting addiction recovery;
- family-oriented residential housing.

"more low barrier, harm reduction housing"

B.C. Ministry of Health, Ministry of Child and Family Development, Health authorities, non-profit community service agencies, medical training institutions, and colleges delivering professional development

Build interpersonal capacity for mental health practitioners

The relationships mental health practitioners build with patients are core to the success of the system according to forum participants. These relationships need to be hearty, withstanding the pressures and stresses that are at times heightened by a mix of issues: chronic homelessness, multiple sources of addiction, and negative, at times, traumatic experiences in care facilities (such as ER and Seclusion and Restraint). The forum theatre highlighted areas for capacity building among mental health care providers.

Conflict resolution, de-escalation and trauma reduction

Added skills to support mental health workers in supporting better outcomes without re-traumatizing patients and increasing their own burnout rate.

"find ways to not re-traumatize people in the outpatient room"

"less drastic treatments for meltdowns"

Skillful work with families

The forum identified a gap of skillful support for family members in knowing their rights, accessing support and navigating the mental health system.

"the whole family needs help"

Address unique needs of mental health patients with addiction

For frontline workers and medical professionals to build capacity in better understanding differences between addiction and mental health challenges and to better assist patients who are wishing to wean off of mental health medication that has become addictive.

"*people with concurrent diagnosis are falling through the cracks*"

"*there needs to be more understanding about the difference between addiction and mental illness by doctors and the recovery industry*"

Facilitation of mental health support groups

Effective facilitation of support groups is a skill gap identified by participants. Periodic facilitation trainings and evaluations are recommended.

Human-centered relationships with patients

For all mental health practitioners, including GPs and Psychiatrists, the forum theatre events stimulated calls for more listening, respectful and responsive dialogue with patients, using holistic diagnosis and alternative methods that include the social determinants of health of the patient, as well as leading non-drug choices. *Open Dialogue*[4] was referred to by a number of audience members as an evidence-based, dialogic treatment for mental illness.

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[4] *Open Dialogue* was developed in Finland as an alternative to the traditional mental health system. Treatments avoid medication, emphasize human relatedness and include family and social networks. There is increasing Interest in *Open Dialogue* in North America.

"listen to the reality of the clients for a more accurate diagnosis and treatment"

"doctors have taken the scientific method and applied them to people"

"include individuals in the prescribing process"

"most doctors and mental health workers treated me with disrespect"

"the 2nd psychiatrist was better – they listened, heard what I had to say, prescribed the minimum, took me off pills with bad side effects"

Health Authorities

Improve critical care and emergency response.
A mental health crisis is a traumatic event and a call was made during the events in several different ways for more humanized ways of supporting people in crisis within the hospital system.

Create teams for critical and emergency response care

To set up teams of critical care support, similar to CAR87 (nurse practitioners who travel with police officers) who are able to provide support to people who have lost their medication or are in a mental health crisis. The teams would ideally reduce police involvement and be informed of mental health medical needs. This would also take the pressure off of social workers and health workers in times of emergency.

Improve design of seclusion and restraint rooms

Develop therapeutic seclusion spaces where people are not left alone, where they have access to design elements that support mental health, such as natural light, nature, and space to move around and reflect.

Improve Emergency Room procedures

Increased flexibility in procedures that allow for alternative situations, such as giving a short supply of medication to people experiencing psychosis more easily.

"The hospital should be a place where people with mental illness could go and feel they will be treated with respect"

Non-profit and grassroots mental health organizations

“we need more flexibility for the individual in the system, it is still mechanized”

Expand on diversity of outreach to meet complex, interrelated needs.
Mental illness is rarely an isolated event, we heard from both workshop and audience participants. It often intersects with a myriad of psycho-social-systemic determinants of health. The continued integration of support across multiple domains is a challenge that the non-profit sector is well positioned to contribute to. Tangible recommendations include:

Create outreach positions for visiting people in hospitals and on the street

A desire was expressed for outreach workers who regularly visit people with mental health diagnosis living on the street and in hospitals – who are in need of support yet may have a difficult time asking for it.

Integrate bereavement counseling into youth mental health programs

Youth struggling with grief may need a combination of mental health support and bereavement counseling. Integrating bereavement counseling and peer support specifically would support youth in working through deep issues of loss.

Support mental health patients in weaning off of their medications

We heard that there is a desire to safely reduce medication use, yet a struggle to find support in doing this with a mix of housing support, counseling, and psychiatric support.

Work with schools to reduce stigma of mental health issues

Programs may be developed such as families presenting to youth about their experiences, or peers speaking about mental health issues as a way of reducing stigma.

Support families in connecting with their children

Families, we heard are in need of support being able to connect and talk with their children, as well as work with the family system in connection to the mental health of all family members.

“we need programs for helping parents talk to their kids”

Last word…on values

The intuition of the *maladjusted project* is that there is a deep valuing of human-centered care already present throughout the metro Vancouver area and beyond. It is through this lens that we examine our mental health system. While honouring the fruits of modern medicine, of efficiency and effectiveness, we see many gaps that weigh upon our collective health. For change to happen incisively and with wisdom, we may first need a conversation about values, and transparency about the values that serve as the circuitry of our system.

> "*we need to move away from the current business structure of the mental health system"*
>
> *"budget people should not drive the system"*
>
> *"there are so many unnecessary rules"*
>
> *"health care is being run like a corporation"*
>
> *"we are not prisoners of the structures we inhabit; our patterns of behaviour create the structures and, having created them, we can change them"*
> *David Diamond, Artistic Director, Theatre for Living*

One more thing…on ripening

maladjusted was born out of perceived ripeness. At many performances we heard the call for more public conversation and dialogue. If a real dialogue is a place where we can disagree…then perhaps the time is ripe to open the doors and our hearts to a human-centered dialogue, while nudging the system forward even with bite sized actions we can take today.