Behavioral Health Integration Project
San Luis Obispo County

Consumer & Patient Focus Groups
January 2015

Compiled Responses & Summary Report

Prepared by:
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Summary Report

The Behavioral Health Integration Project (B-HIP) invited patients from Community Health Centers (CHC) and consumers from Transitions-Mental Health Association (TMHA) to participate in a series of focus groups to discuss primary and behavioral health care in San Luis Obispo County. Eight focus groups were conducted January 13-16, 2015 throughout the county. A total of 75 people participated. A consultant familiar with the local mental health system of care facilitated the sessions, and most sessions were observed by a B-HIP representative.

The participants self-identified as having a mental illness or mental health difficulties. Their conditions, and the impact on their lives, range from mild to serious. In general, CHC patients reported mild to moderate conditions; TMHA consumers reported more moderate to serious conditions.

Most CHC patients receive both primary and behavioral health care from CHC, while most TMHA consumers get their primary care from CHC or private providers, and behavioral health care from County Behavioral Health Services and TMHA. A few participants have private insurance and do not see providers at CHC or the County, but do attend T-MHA programs.

Focus group statistics include:

DATE	AFFINITY / LOCATION	# OF PARTICIPANTS
January 13, 2015	CHC patients San Luis Obispo clinic	4
January 13, 2015	TMHA Peer Assistance and Advocacy Team San Luis Obispo meeting	20
January 14, 2015	CHC patients Nipomo clinic	8
January 15, 215	TMHA Consumers Arroyo Grande Wellness Center	11
January 15, 2015	CHC patients Grover Beach clinic	7
January 15, 2015	TMHA Consumers San Luis Obispo Wellness Center	12
January 16, 2015	TMHA Consumers Atascadero Wellness Center	10
January 16, 2015	CHC Patients Paso Robles clinic	3
	TOTAL PARTICIPANTS	**75**
Facilitator: Dale Magee, Catalyst Consulting Observers from B-HIP: Joel Diringer, Adria Arko		

Participant demographics include:

	N = 68	
Person with mental illness or mental health challenges	100%	
Family member of person with mental illness	26%	
Age	18-24	3%
	25-34	12%
	35-44	4%
	45-54	35%
	55-64	37%
	Over 64	9%
Gender (some did not answer this)	Female	60%
	Male	37%
Race / Ethnicity (could select more than one)	African American	1%
	American Indian	4%
	Asian/Pacific Islander	4%
	Hispanic/Latino/Chicano	18%
	White, non-Hispanic	69%
	Other	3%

THE QUESTIONS

Participants were asked six open-ended questions focused on their experiences accessing primary and mental health care, the quality of service delivery, and their opinions about the "integrated, whole person" care concept and suggestions as planning for an improved system moves forward.

The set questions were:

1) Are you getting "whole person" health care? Why / Why not? What's working? What isn't working?
2) Do you have any trouble getting your health care (mental or physical) now? (i.e. transportation, distance, childcare, available practitioners, long waits, etc.). If so, what are they?
3) Some concerns with a "whole person" integrated system are: sharing information between people (loss of privacy); primary physician will know psychiatric problems; information breaches, etc. Do those concern you? Any other concerns/problems you could see popping up if providers merge or coordinate more?
4) How would you make the system better? Particularly around physical health and mental health care working better together? (Su*ch as: one system, one building, shared records, shared info, doctors working together, team approach, combined treatment plans, child care, rides, etc.)*
5) What about meds? (Access, cost, anything.)
6) Given all that you've experienced, know about, has been mentioned today…What is the one thing you would change to get better "whole person" care? What is most important to make the system better for "whole person" care?

FINDINGS AND IMPRESSIONS

The concept and potential of better system-level integration were well-received and of interest to the participants; however, this was not their "burning issue" or greatest priority. The majority of their comments reflect a more basic-needs orientation: the desire to just get to see a provider (consistently); be treated in a respectful manner; and access care in a way that is not cumbersome.

Many of the participants' daily lives (especially those in the TMHA groups) revolve around treating and managing their physical and mental health conditions. Therefore, accessing simple, basic care is most pressing and on their minds. Participants welcomed the idea of system changes, and acknowledged that the "root cause" of problems they have could be addressed; but that high-level, future-focused view and planning does not seem on the forefront of their minds. Rather, their daily, immediate experiences and needs dominated the focus group conversations. However, those comments do lend great benefit to system planning efforts.

Major findings regarding system-level integration are noted following the overall most common themes from the groups.

The compilation of all responses are at the end of this report.

Overall most-repeated, common themes among all the groups

An overall feeling of having to fight, push, or work for care was reported. Participants have the impression that the system is not there to serve them. Rather, it is there if one can get to it, and get through it. Participants frequently commented that they do not feel a sense of, “They are here for me." "They care for me.” or "They are committed to me."

The following major themes emerged from all eight focus groups:

- Physician consistency
  - Keep their doctor/psychiatrist consistent. Do not change them.
  - Too much turnover. Have to start over frequently; disruptive to care.
  - “Doctor does not know me.”
- See psychiatrist more frequently
  - Appointments are too short; and too long between appointments
  - More psychiatrists needed
- More time with primary care doctors
  - Appointments are too short; and too long between appointments
- Respectful treatment
  - Listen to patient; ask patient questions
  - Be courteous
  - “Believe us!”
- Improve customer service
  - Provider and ancillary staff’s attitudes
  - Timeliness and follow through
  - Accuracy
  - Assistance in getting care and knowing options

- Providers change frequently - PCP, Psychiatrists, NPs, Social Workers
- Advocates ("System Navigators") are highly desired
    - Direct, very involved "hold my hand / get me to the care I need" assistance is wanted
    - Want assistance in knowing what is even available and then accessing it
    - Want someone to attend appointments with them to advocate and "not be intimidated" by the doctor
    - Opinion is that a provider "believes and listens" to an advocate more than the patient
- Getting care is cumbersome
    - "Hassles, hoops." Inconvenient processes often mentioned.
    - "Lots of steps" and "Lots of going back and forth."
    - Providers are spread out. "Back and forth." "Have to go all over the place."
    - Appointments are not scheduled for the same day
    - Patients/consumers not aware of all that is available
- Allow more than one doctor appointment/day
- Medication
    - Doctors not asking what they take
    - Doctors do not know them, do not know side effects or interactions
    - Often end up without medication, or gaps

Most common themes <u>from CHC patients</u>

- Change in doctors is a very big deal. High impact.
    - Doctors change - they don't like it and don't know about it
- Long waits for appointments
- Not enough time with doctors in the appointment
- Overall shortage of staff - primary care, ancillary care and support staff
- Customer service
    - Comments about rude, slow, brusque, judgmental, irritated, inpatient staff
    - Follow through and accuracy are lacking
- Phone system / call center
    - Unhappy with wait times and quality of service
- Test results are frequently not available. Care/treatment is then delayed.
- Medications not covered by CenCal are frequently prescribed
    - Patient cannot afford them
    - Patient chooses to not take them; self-manages their medications

Most common themes <u>from TMHA consumers</u>

- Psychiatric care concerns
    - Not enough psychiatrists; very long wait to see one
    - Change too often
    - Do not see them enough; do not see them for long enough
- Interaction with provider
    - Not listened to, not talked with
    - Condescending, not respected
- Advocates / System Navigators
    - Highly desired
    - Assist in securing care, and will speak up for person
- System is difficult
    - Belief that person has to work the system, have to fight for care
    - System is not assisting
- Simple, basic care is desired
    - They have low expectations, do not seem to be asking for much
    - Just want to see psychiatrist, get the correct mediations, and be treated kindly
    - Managing their illness/obtaining care is their "job" - it is a major effort and focus and requires a great deal of their time and resources

Selected verbatim comments:

- "Don't make us be sick before you will help us!"
- "We go through psychiatrists 'like crazy!'"
- "CHC's automated system is awful, can't get live person…ironic, the recording says, 'We listen.'"
- "It's great that I am taking and getting what I need because the doctors have listened to me!"
- "Let me talk!"
- "The moment they start paying attention to me just doesn't come."
- "It is not Doctor/Patient; it is Doctor/Computer"
- "My FSP advocate is more important than my psychiatrist."

Findings and impressions specifically regarding system-level integration

The idea of integration is well-received, even though it was not specifically noted as a priority. Obtaining immediate, basic care - such as just getting to see their primary care physician or psychiatrist - is a challenge for many of the participants, so system-level improvements may seem beyond their influence, unrealistic or too far-future. In no way should this deter the B-HIP partners from pursuing integration.

CHC patients, in general, were able to offer more system-focused comments and suggestions than TMHA consumers. (All participants could offer specific improvements, and some are connected to integration.) This may be due to lower-level mental health involvement or that CHC itself has some "one stop shops" and other tangible demonstrations of integration.

TMHA consumers were more familiar with community resources than CHC patients. For instance, most CHC patients did not know what TMHA is or what it provides. Seemingly, better integration would lead to increased awareness and maximization of all providers and resources.

Of note is that the highly-desired System Navigators/Advocates/Resource Specialists are the de facto integrated system. These providers ease access across systems and facilitate "whole person" care.

When asked about benefits, possibilities, or drawbacks of a system more focused on "whole person" health care, the following emerged as the most positive aspects and desires of an integrated system:

- Want to see more than one provider in a day. Want to be able to "clump" appointments with primary care physician and psychiatrist.
- Overall, E-records are seen as a great benefit and help in getting more complete care.
- Co-location was preferred by most participants.
- Medications may be managed better. It would be easier for all caregivers to know what medications were being used, increase awareness of side effects (that may be misinterpreted or attributed to something else), and prevent negative drug interactions.

The concerns most often expressed in all of the focus groups were:

- Primary care physicians may treat patients differently/poorly if the PCP knows they have a mental illness. Many participants stated they have been stigmatized or doubted by PCPs or their doctor questions their credibility and competency. Participants would like mental illness awareness and sensitivity training to be provided and required.
- Concerns over the confidentiality of medical records was frequently mentioned. Participants believe that sharing records has great benefits, but are worried that some PCPs will treat them differently (as noted above) and that non-medical staff would see their mental health records and not keep that confidential. CHC patients expressed most concern about staff telling others (outside of the medical community) about their mental illness.
- Loss of privacy by being seen at a co-located facility was not of concern to most.

CONCLUSIONS

The focus group participants shared their opinions and experiences willingly and candidly. They were also appreciative of being asked to comment, and for the opportunity to influence positive changes.

Of most importance to the participants are keeping their physicians consistent, spending more time with their doctor at each appointment, seeing their psychiatrists more frequently, improving customer service, accessing care more conveniently/less cumbersome, allowing more than one physician appointment per day, providing "system navigators," and treating patients with respect and kindness.

While system-level integration did not emerge as a primary theme or a priority concern, the benefits of collaborative planning and action among primary care and behavioral health providers would positively impact some of these major, most common themes.