KEEPING CONSUMER VOICE CENTERED IN DATA SHARING AND INTEGRATION EFFORTS

Experiences from Health Care for the Homeless Network of King County

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HEALTH CARE FOR THE HOMELESS NETWORK OF KING COUNTY (HCHN)

HCHN is a Community Health Services program of Public Health – Seattle and King County, established in 1987. The HCHN Planning Council advises both Public Health and the King Co. Board of Health in their governance role.

In 2016, we delivered high-quality and low-barrier medical, dental, and behavioral health care to over 20,000 patients:

1. Directly at King County Federally Qualified Public Health Center sites
2. Through 2 mobile medical vans & our Kids Plus program
3. By 9 partners at nearly 50 sites, on the streets and encampments

2017 SUBCONTRACTED PARTNERS

Country Doctor Community Health Centers
Evergreen Treatment Services
Harborview Medical Center
HealthPoint
Neighborcare Health
Seattle Indian Health Board
University of Washington Adolescent Medicine
Valley Cities Counseling & Consultation
YWCA – Seattle/King/Snohomish
BACKGROUND AND SIGNIFICANCE

Like many parts of the country, King County recognizes that producing “better” data - data that is more precise, timely, transparent, and actionable - is a key strategy to end homelessness and eliminate related health disparities.

However, in our current state:

DATA FRAGMENTATION

Providers struggle to:
- Deliver whole person care
- Avoid care gaps and overlaps
- Alert others to significant events
- Relate full context of health

Analysts struggle to:
- Provide decision makers with actionable and timely information
- Accurately identify disparities
- Measure meaningful progress

Consumers struggle to:
- Navigate systems funded to help
- Communicate concerns
- Stay engaged & motivated in care

Agency A  Agency B

Agency C  Agency D

Impact on health & human services providers

Impact on analysts

Impact on Consumers

data systems are program specific and largely do not talk with each other
Data sharing and integration work provides critical opportunities to produce better data for better health outcomes. It also raises key questions on consumer involvement and engagement.

What are all the sectors that hold information about homeless individuals?

What is all the information homeless individuals have about these systems?

Legal, ethic and mission level responsibilities for HCH programs
1. Are we finding homeless individuals most in need of services?
2. Are we serving them well?
3. Are we using limited resources wisely and collectively?

**Data Sharing & Integration Within 2017 Needs Assessment**

- Public Health Clinics
- Behavioral Health & Recovery Division
- HIV Surveillance
- Jail Health Services
- Aging and Disability Services
- Homeless Management Info. System (HMIS)
- Medicaid Claims
- Medical Examiners Office

Listening Sessions with currently homeless individuals
Summary Themes and Discussion of Work in Progress
Q1. Who are the homeless individuals most in need of services?*

Approach to Answering: we listened for themes on differential impact and compared them to recent findings from: 1) colleague reports; 2) HCHN-funded provider feedback, and; 3) HCHN’s homeless & health dataset.

Categories that reflect differential need include individuals with:

1. Complex physical and/or behavioral health conditions, including those with chronic substance use disorders and traumatic brain injuries.
2. Histories of incarceration and/or experiences of other institutions, including foster care and in-patient psychiatric facilities.
3. Family structures and sizes that exceed system capacity or challenge funder definitions of dependent relationships.
4. Multiple identities that may be targets of systemic discrimination, including those from families with generational poverty.

‘Most in need’ is not intended to set up a hierarchy; rather aims to understand differential need for resource allocation purposes.
Family structures and sizes that exceed system capacity or challenge funder definitions of dependent relationships.

Complex physical and behavioral health conditions, including chronic substance use and brain injuries.

Histories of incarceration and/or experiences of other institutions including foster care and in-patient psychiatric facilities.

Multiple identities that may be targets of systemic discrimination, including those from families with generational poverty.

“I have seven kids…” “My child has autism.”

“I can’t stay with my chemical sensitivities.”

“I don’t remember everything. I missed too many appointments and gotta wait another three months to make another one.”

“They won’t take me because I did something stupid a few years back and have an arson charge on my record…”

“My teeth are like this cause of meth. That’s first thing people see and judge. Can’t get a job or housing with my mouth & charges.”

“My family has been in and out of the system and struggling for generations…”

“They treat me like that because I’m homeless, I’m Black, I’m young and trans.”
Q2. Are we reaching homeless individuals most in need & serving them well?

Approach to Answering: we listened for patterns of: 1) how aware individuals were of funded services; 2) positive or negative utilization experiences; and 3) frequency and impact of chronic health conditions.

Themes:

- **Pockets of Excellence**: respondents at each listening session cited helpful individual staff, volunteers, programs, and/or partnerships.

- **Pockets of Innovations**: respondents described partnerships that are using resources creatively to meet multiple needs, including co-locating services.

- **Peer to Peer Support**: multiple ways that homeless individuals reach & take care of each other, including passing on information about trusted providers.

- **Disease burden and unmet need**: level of disease burden described within listening lessons reflects documented disparities within the literature.

Overall, far too many individuals experience our health and housing systems as fragmented, confusing, and disruptive with resulting negative health outcomes.
CONCERN: BASIC HYGIENE & URGENT NEEDS

Limited access to:
- Indoor Bathrooms
- Showers
- Water
- Refrigeration
- Laundry
- Clean Clothes
- & Seasonal Footwear
- Hygiene Supplies
- Uninterrupted sleep

HEALTH IMPACTS
- Dehydration
- Urological Diseases
- Skin & Soft Tissue Infections
- Lice & Infestations
- Post-surgical concerns
- Feet Disorders
- Embarrassment & Avoidance of Others
- Anxiety & Stress

“Living in these conditions (safe parking) everyone got the flu and passed it around. You’re not able to wash your hands if the church isn’t open. There was vomit all over the parking lot. It’s hard to use a port-a-potty when you’re feeling so sick and have nowhere to go but a cold car.”

“There is something wrong with my stent (heart disease) but I’m not going back in… nowhere safe or clean to come back to. Disease and stuff spreads like wildfire here (shelter).”
CONCERN: CHRONIC PAIN MANAGEMENT AND MEDICATION ACCESS

“Uncontrolled pain from sleeping on mats, cement, & contorted in cars

• Rationing and splitting medications, adherence issues

• Limited mobility & challenges with activities of daily living, premature aging

Chronic Pain Management & Medication Access

HEALTH IMPACTS

“I never get enough sleep… woken up 6 to 7 times in a night… always dealing with issues… constant pain from sleeping all curled up.”

“I need a hotel because of the breathing machine I need for my COPD. I was told I couldn’t stay at a shelter because my machine was too loud.”

“I get tripped up at every step with my meds – getting a script, getting them filled, taking them like I’m suppose to. “I have a buddy that runs around with his in his pocket.”

“Lexapro is the medication I know works best for me & I don’t understand why they won’t give it to me.”
CONCERN: CHRONIC DISEASE MANAGEMENT

Chronic Disease Management & Supplies:
• Diabetes
• Asthma
• Hypertension
• Cardiovascular Disease

HEALTH IMPACTS

• Nutrition - limited access to what & when one eats
• Disease progression, amputations & premature death
• Chronic stress, including from limited access to supplies (inhalers, glucometers)

“We’re in stressful situations, we all have high blood pressure and are (waiting) heart attacks walking around.”

“With diabetes, you try figuring out how to test your blood sugar daily, store everything, & not be able to control when and what you can eat”…

“We’ve had someone die in our parking lot, an old woman with edema. Young people sleep on someone’s couch but you find elderly people here.”
**Dental Care:**
- Providers that accept Medicaid or free care
- Limited providers who understand homelessness
- Pain of untreated issues
- Hygiene & cosmetic appearance, breath

**CONCERN: DENTAL CARE**

**HEALTH IMPACTS**
- Disease complication (e.g. diabetes, hypertension)
- Malnourishment, limited ability to chew
- Embarrassment and shame, not smiling or showing teeth
- Depression and Anxiety

“I’ve had my dentures thrown away, my inhaler. It happens a lot in shelters and during sweeps.”

“People judge you by your smile. I never used to smile because my teeth have been so bad. I’m starting to smile now because of the people here.”

“My buddy had his eye glasses tossed.”

“There’s a lot I can’t chew so I go even more hungry a lot.”
**CONCERN: EYE CARE**

**Eye Care:**
- Providers that accept Medicaid or free care
- Limited providers who understand homelessness
- Glasses — access, having them stolen or lost

**HEALTH IMPACTS**
- Disease complication (e.g. diabetes)
- Progression of eye disease
- Impact on activities of daily living, mobility & safety

“It’s scary being out here and not being able to really see your surroundings.”

“I haven’t had a pair of glasses for 10 years. I finally got my first pair of glasses free by going to a mobile truck.”

“I have a lot of challenges of doctors not taking my particular insurance... being homeless you move around, or circumstances change and you have to get care at a new clinic that might not take your insurance... then you end up with a lapse in care.”
INSIGHTS IN DATA SHARING AND INTEGRATION

- Rich learning to be had in cross-sector work, including different methods for determining unduplicated individuals and various definitions of homelessness.
- While technical and resource barriers are significant, much of the work is about people, trust, and relationships.
- Keeping consumer voice centered in data sharing and integration efforts includes deeper exchange on privacy, communication and intended use cases.

WORK IN PROGRESS HIGHLIGHT

Proof of Concept Study: Data linkage to combine information on homeless persons receiving treatment in King County by using multiple data sources.

Partners: Public Health (Health Care for the Homeless Network & Assessment, Policy Development & Evaluation unit) and Department of Community Human Services.
THANK YOU AND DISCUSSION

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* Acknowledgment: concept design for slides 3&4 are from Eli Kern, Epidemiologist,
Public Health – Seattle & King County’s Assessment Policy Development and Evaluation (APDE) unit