

APPENDIX 01:

ASH Brain Health System Redesign

Qualitative Field Work
and Stakeholder Findings

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Summary

This appendix provides supplemental information from the Design Institute for Health’s qualitative field work and information gathering study in support of recommendations made by Dell Medical School in this report to the Texas Health and Human Services Commission (HHSC) for the redesign of the Austin State Hospital. The qualitative study that informs this overview was gathered from as many primary sources as possible within the constraints of both time and budget to complete this project. Primary sources included patients, providers, caregivers and family members, sheriffs, judges, peers, and mental health service administrators within the Austin State Hospital (ASH) service area. Currently, the ASH service area is made up of 38 counties for adults (18 years old and above), 57 counties for adolescents (12-17 years old), and 75 counties for children (4-11 years old).

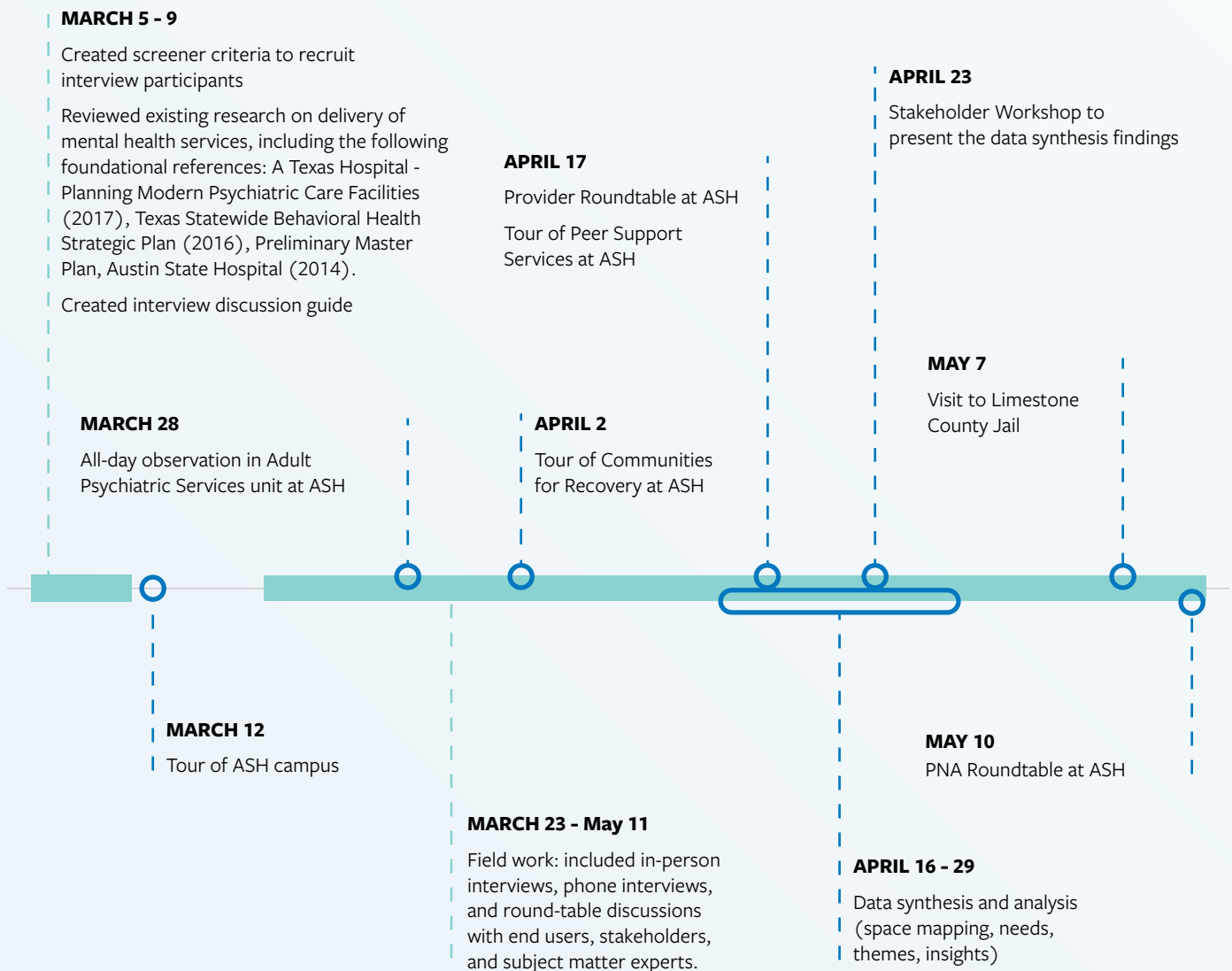
We designed our approach to capture a wide array of how mental health care within the ASH service area is perceived. In our information gathering, we encouraged people to share personal stories of their experiences with mental illness and the delivery of mental health care. We were equally curious about the experiences of people who had been directly served by ASH and those who sought help and services from other organizations. Our information gathering relied heavily on qualitative data collected from in-person interviews (typically in homes), phone calls, round-table discussions, and on-site observations.

Our qualitative findings reinforce the prescient opportunity, first identified by the Texas Statewide Behavioral Health Strategic Plan (2016, HHSC), to reorganize current mental health services around a continuum of mental health care. Specifically, the qualitative findings point to the need for the development of a shared interface between patient and provider across the continuum of care that empowers the person around their continuum of care and drives greater connectivity, coordination, and alignment among the delivery of services. Furthermore, our qualitative findings indicate a need for more effective integration and access to both upstream and downstream mental health services and resources that occur before and after a mental health crisis. Our field work manifests a perception of the service array and system that may be at odds with what the system actually delivers. That gap suggests that one intervention is to address the barriers preventing better use of the existing system in concert with new innovations and offerings. These opportunity areas identified will help build a continuum of care that better meets the needs of people today and reduces the overall cost of caring for people with mental illness in the future as Texas’ population grows.

Qualitative Findings Timeline

Our generative information gathering work took place between February 26 and May 11, 2018. During this phase, we identified a number of stakeholders and end users to interview and observe. We cast a wide net in order to both gather as representative a sample as possible from the population in the ASH service area and to seek out extreme lived experiences with ASH and across the mental health ecosystem.

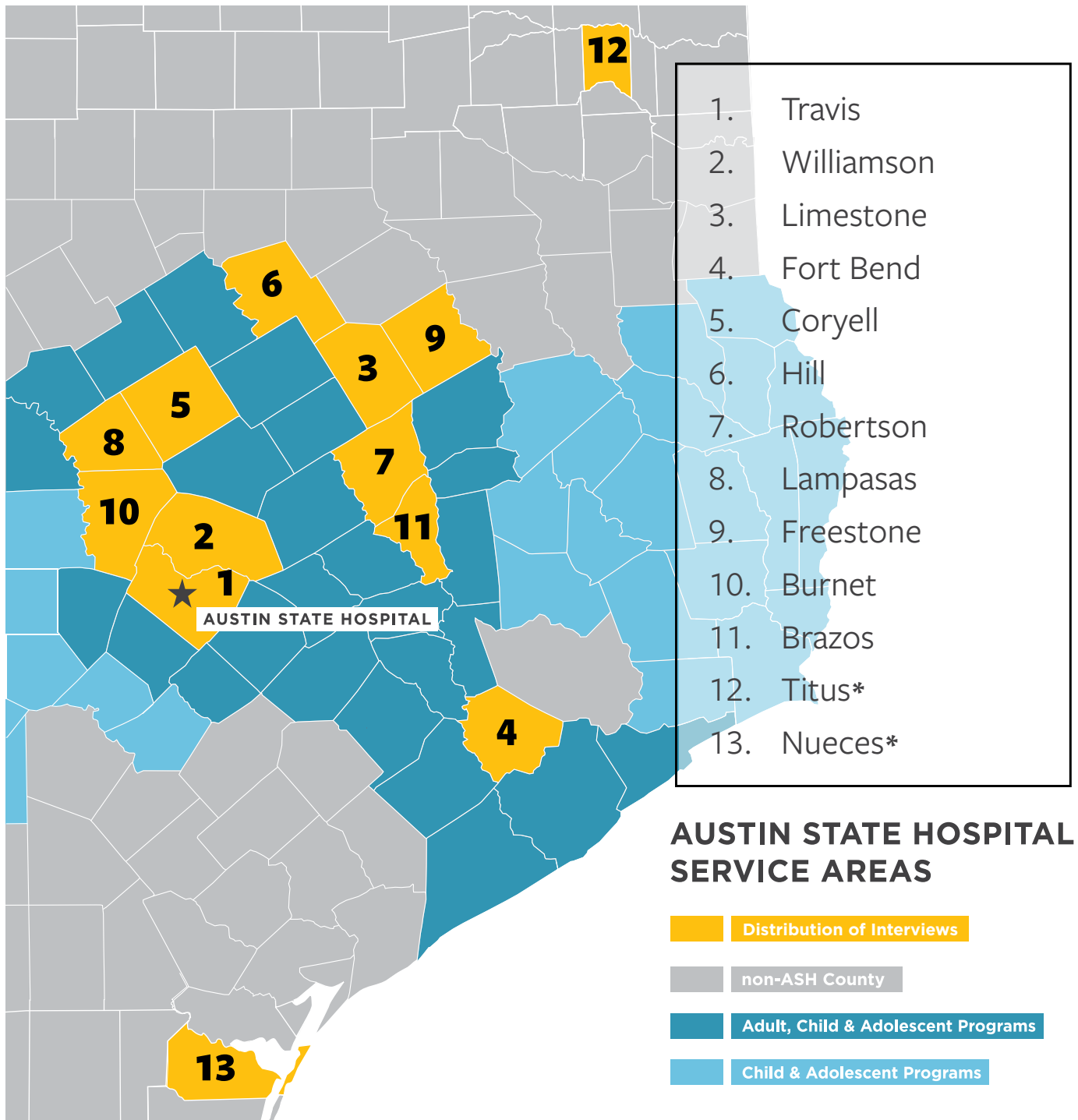
QUALITATIVE FINDINGS TIMELINE





Who We Learned From

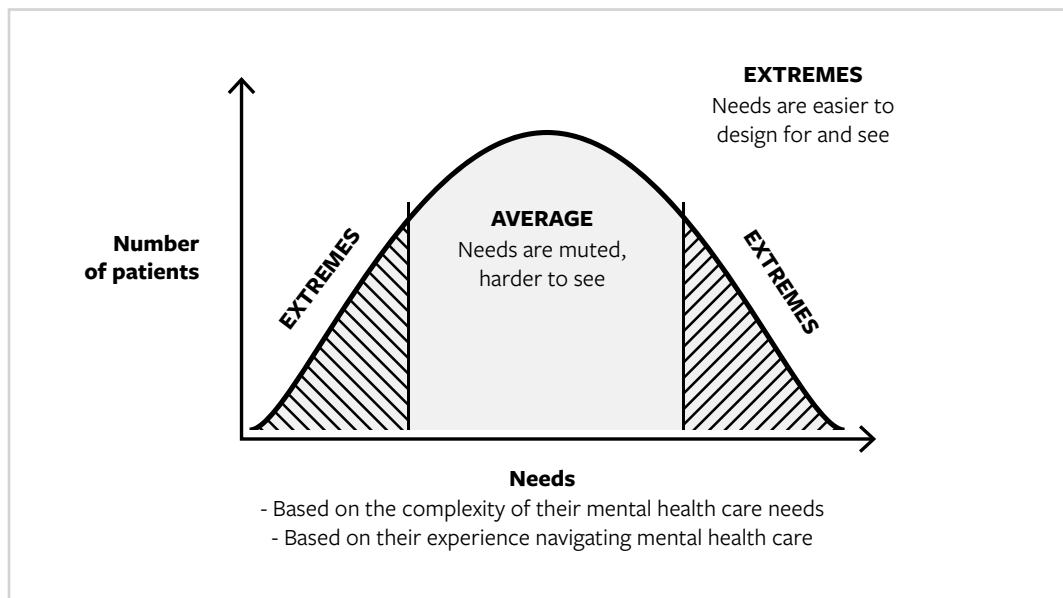
13 Counties



* Interviews outside the ASH service area included relevant stakeholder types identified by steering committee (e.g. CEO of a rural hospital) who happened to be in other counties.

Who We Learned From

In order to efficiently recruit participants from the ASH service area who would contribute the most valuable perspectives, we attempted to identify voices that exemplified the “extremes” – people whose situations were not typical and thus had experiences with the system that exposed major stress points or novel workarounds and solutions to their needs.

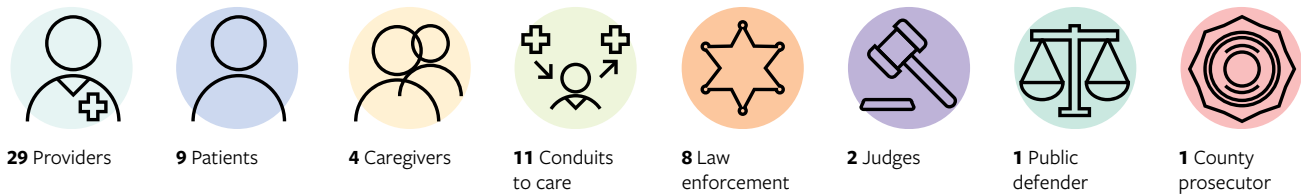


We developed screener criteria that would help us gather a variety of voices, perspectives, and experiences. In our recruiting, we sought a diversity of locale (rural vs. urban), ability to pay (privately insured vs. payment assistance), age, ethnicity, and gender. We also developed a set of exploratory archetypes that we layered onto our recruiting criteria to ensure we reached people across a range of situations and roles across the continuum of care. Additionally, we focused on mental health conditions rather than Intellectual Developmental Disabilities or Substance Use Disorders. As is the case with qualitative work, there are always more people to speak with and more questions to ask than there is time and budget to address. With that in mind, we made note of open questions we think are worth pursuing at a later date as well as a short list of other people we may call upon to help us understand further what mental health experiences are like. For example, while mental health services for children and adolescents are within the scope of this project, we were not able to directly interview this group during this phase. Instead we spoke to parents or caregivers (largely at their request) of children who had experienced mental health services at ASH and across the larger service area. The lists of potential contacts for future interviews are available upon request.

We believe in person-centered care and empowering language. We prefer to use the terms “person” and “people”, but in order to clarify roles throughout the report, we will use the terms patients, providers, caregivers, etc. for clarity.

Distribution of Interviews

We were able to collect rich stories from 65 people who represent a wide variety of experiences from 13 counties including: Travis, Williamson, Limestone, Fort Bend, Coryell, Hill, Robertson, Lampasas, Nueces, Freestone, Burnet, Brazos, and Titus counties.



Consent and Interview Format

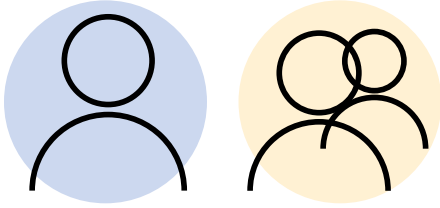
As part of our interview ethic, we asked for each participant's consent to be interviewed ahead of time. In an effort to help protect their privacy, we invited each participant to sign a consent form that determined how they wanted the information they would share with us to be used in this project and in the future as part of the ASH Brain Health System. Their options included audio, video, or still photography recordings. To recognize the value of their time and expertise, we compensated patient and caregiver participants with \$150 incentive (note: Sheriffs, judges, and other elected and government officials were not offered incentives). The incentives were either presented in cash or mailed (for phone interviews). All participant consent forms and receipts are available upon request.

We conducted several observations on-site at locations that represented aspects of the existing mental health care system. The goal of an observation is to gather a working knowledge of roles, interactions, and interventions in the context of a specific environment. Several members of our team conducted these observations over multiple hours in a single day. During the course of an observation, we encountered a number of people as they were engaged in tasks in real-time. As a result, we only had the opportunity to have short conversations and did not go into in-depth interviews. Thus, we did not require the consent forms during the observations.

Of note, every person we interviewed signed the full use consent, and often expressed to us that they wanted their story to be offered openly in order to do the most good to improve mental health care for others.

We developed an interview guide for all the patient and caregiver interviews to foster an open-ended discussion of their experiences with mental health services at ASH and across the ASH service area. Interviews ranged from 60-90 minutes for providers, law enforcement, judicial, and conduits to care. Patient and caregiver interviews were 90 minutes long.

Most interviews were in-person, although we conducted a few by phone.



Patients + Caregivers

We engaged patients and family members who could articulate a variety of experiences with mental illness and the mental health care system. Participants could offer perspectives on access and availability to services in different environments (rural vs. urban), venues (ASH vs. other state hospitals vs. private facilities), payment models (no insurance or Social Security Income vs. Indigent Care Programs by county vs. private insurance), and treatments (medication vs. talk therapy). We were also interested in the individual approach that participants took to managing their mental health and illness, including the different techniques or workarounds each employed to coordinate their care and communicate with their providers and support network.

Base recruitment criteria:

The following criteria were used as a base framework to begin to identify patients and/or caregivers across the ASH service area to recruit for the project.

Age

Extremes: 18-24, 60+

Mainstream: 25-45

Severity

Extremes: Serious Mental Illness (SMI)

Mainstream: Other Conditions

Condition / Events

Extremes: Schizophrenia, Attempted Suicide, Major Depression and Anxiety, Schizoaffective Disorder

Mainstream: Depression and Anxiety, Bipolar Disorder, Mania, PTSD

Time in Care

Extremes: Less than 2 days, more than 6 months

Mainstream: 2 weeks in care

Gender

Select slightly more women than men (60/40 split)

Distance to Care

Select slightly more people living in rural environments (or with heavy burden to travel to site) versus people in urban areas (with relatively no trouble reaching site) - 60/40 split

Eligibility

Primarily select people covered by the ASH service area and if possible look for one or two who seek mental health services outside ASH system of care

Ethnicity

Extremes: Asian American, Native American

Mainstream: Caucasian, African American, Hispanic

Exploratory Archetypes for Patients + Caregivers

In addition to the base recruitment criteria noted above, we also developed exploratory archetypes that we layered onto our recruiting criteria to ensure we reached people across a range of situations and roles across the continuum of care we wanted to hear about. The exploratory archetypes were created based on initial observations and aim to capture situational descriptions of people experiencing the system from different vantage points based on role, mindset, and understanding. The exploratory archetypes are listed below and noted in the recruitment in final participants.

Determined Caregiver

This individual is an informal caregiver who does not take no for an answer and is pushing the system for answers on behalf of their family member or friend.

DIY Healer

This person is creating their own workarounds to his or her mental health care and has made it a personal mission to figure out a path to recovery that work for them. This person may do this out of necessity because they do not have access to traditional care pathways.

Engaged Seeker

This person acknowledges that they have mental health issues and wants to be an active part of his or her care planning. They want to be integrated into the discussion of their condition and treatment options so they can have a say in the direction of their care.

Experienced Companion

This informal caregiver has a wealth of experience with mental health conditions and has knowledge of how the system works. This person is committed to navigating the condition alongside the patient.

Frustrated Advocate

This person has a lot of knowledge of and experience with the mental health care system and has a desire to smooth the path for others. However, he or she consistently faces barriers and struggles to get those with the ability to make change to listen.

Obstructed Caregiver

This informal caregiver is trying his or her best to get appropriate care on behalf of a family member or friend but faces significant obstacles and challenges that include misinformation, geography, policy, access to payment assistance, and lack of transparency.

Persistent Seeker

This person acknowledges that they have mental health issues and is actively seeking help. He or she doesn't take no for an answer and pursues treatment and resources even if that care is hard to find or access. Does not typically create his or her own solutions and seeks established resources.

Reluctant Seeker

This person acknowledges that they have a mental health issue, but are/were reluctant to seek help for any number of reasons, including not wanting to burden someone else, access issues, perceived severity issues, cost barriers, distance issues, etc.

Shamed Avider

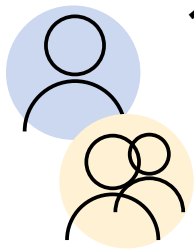
This person acknowledges that they have a mental health issue, but are/were reluctant to seek help because of the perceived stigma, including, but not limited to, cultural acceptance, work sensitivity, social circle acceptance, etc.

Wait-Lister

This person has reached out for help, but for whatever reason has been thwarted by the demand of that service and is now waiting to get help.

Final Participants

Final participants were chosen based on meeting the base recruiting criteria and representing a predetermined attitudinal archetype that would help us ensure we sought out people at the “extremes” of mental health interactions and experiences. These archetypes, described previously, combined with an open-ended interview format, allowed us to learn what matters to people, in their own words, across a diverse set of experiences and backgrounds.



1. Female, 46 – Travis County PATIENT (AND FAMILY CAREGIVER)

CONDITIONS/EVENTS: Mild depression, PTSD

Persistent Seeker: Crisis led to a suicide attempt that triggered inpatient treatment at ASH. Medications are only part of her recovery – she actively seeks relational therapy and believes that breaking the silence about mental illness can lead to better treatment and recovery.



2. Female, 46 – Travis County PATIENT (AND FAMILY CAREGIVER)

CONDITIONS/EVENTS: Severe anxiety, PTSD, bipolar disorder, depression

Frustrated Advocate: Crises led to suicide attempts that triggered multiple inpatient treatment at ASH. She struggles to get people to believe that her side effects are a result of her medications. She is proactive and involved in her, and her family's, mental health care.



3. Female, 20 – Travis County PATIENT

CONDITIONS/EVENTS: Mild anxiety, depression, substance use

Engaged Seeker: Crisis led her to get recommendations for a different therapist. Since she is on her parent's insurance she has been able to be selective about her providers. She has chosen to pursue only psychotherapy based treatment. She is involved in her care and, rather than using prescriptions, she relies on her support network, resilience, knowledge, experience from others, and self-awareness to move towards recovery.



4. Female, 45 – Travis County
CHILD CAREGIVER

SON'S CONDITIONS/EVENTS: Autism, ADHD, bipolar disorder, PTSD, depression

Determined Caregiver: She is her son's biggest cheerleader and advocate. She is also well-connected within the mental health and autism communities, highly educated about early childhood development, and knowledgeable about how to navigate the health care system.



5. Female, 34 – Williamson County
PATIENT

CONDITIONS/EVENTS: Mild anxiety, depression, substance use
Shamed Avoider: She acknowledges that she has mental health issues but she's reluctant to seek help because she's been thwarted in the past. She has attended group therapy at ASH*. She doesn't trust the system and feels that the breakdowns have contributed to her trauma. She would like help that is intentional and individualized, not just the bare minimum based on her limited resources.



6. Female, 34 - Travis County
PATIENT

****CONDITIONS/EVENTS:** Severe anxiety, depression, bipolar disorder, mania, schizoaffective disorder, schizophrenia, substance use

Reluctant Seeker: She has received inpatient treatment at ASH and acknowledges that she has serious mental health issues but she's reluctant to seek out more help than the bare minimum (medication) because she believes that she can't afford it. She feels that medication alone can bring her to an adequate level of recovery.

** Self-reported care history is unedited - noting this is not a service of ASH.*

*** Self-reported diagnoses are unedited - noting that a person can't have bipolar disorder and schizophrenia, but understand lots of misdiagnoses and misunderstandings exist.*



7. Female, 26 - Coryell County
PATIENT

CONDITIONS/EVENTS: Major depression, anxiety, suicidal ideation

Wait-Lister: She is proactive about her care and knows the signs that indicate that she should get help. She has reached out for help but has been impeded by the lack of services. Since she lives in a rural county, mental health resources are scarce and it has taken a long time for her to find care and receive services.



8. Female, 57 - Fort Bend County
ADULT CAREGIVER

SON'S CONDITIONS/EVENTS: Severe schizoaffective disorder

Obstructed Caregiver: She diligently tried to care for her son whose care has included multiple inpatient stays at ASH. She feels she's prevented from learning valuable information because she no longer has legal guardianship of her son. She has a lot of guilt and regret and is in the dark about the true cause and nature of his condition. She doesn't feel in control of the situation or how best to take care of her son.



9. Female, 66 - Fort Bend County
ADULT CAREGIVER

SON'S CONDITIONS/EVENTS: Severe paranoid schizophrenia, substance use, dissociative identity disorder

Determined Caregiver: She organizes care for her adult son who has received inpatient care at ASH twice and has also been to other state hospitals in Texas. Even though she doesn't feel she has all the information she needs, she is actively trying to find solutions. She does not take no for an answer and always has documents and records – proof – at the ready. She wants to hold the system accountable to make sure her son is justly treated.



10. Male, 65 – Williamson County
PEER

CONDITIONS/EVENTS: Bipolar disorder, substance use, anxiety, multiple suicide attempts

Experienced Companion: He uses past experiences, which include inpatient care at ASH, to connect with other people who are struggling with their conditions and help them navigate mental illness and the mental health care system. He is passionate about his work as a peer and feels that it has saved his life.



11. Male, 27 – Travis County
PATIENT

CONDITIONS/EVENTS: Mild schizophrenia, major depression and anxiety

DIY Healer: He is living on limited resources so he has become creative at piecing together his own care plan and strategies for recovery. While he has been in crises that have triggered inpatient care at three different psychiatric hospitals (never been able to get a bed at ASH), he has taken on the responsibility to bridge those short-term solutions to his daily life.



12. Female, 62 – Travis County
ADULT CAREGIVER

SON'S CONDITIONS/EVENTS: Severe schizophrenia

Determined Caregiver: Even though she doesn't feel she has all the information she needs, she is actively trying to find solutions for her son who is currently in inpatient care at ASH. She does not take no for an answer and is ready to train others how to be more effective when treating people like her son. She wants to hold the system accountable to make sure her son is justly treated. She believes that education and open communication can begin to dismantle the stigma that prevents people with mental illness from getting equitable treatment.



13. Male, 40 – Travis County
PATIENT (currently at ASH)

CONDITIONS: Severe schizophrenia

Reluctant Seeker: He just wants to get better, but he feels like the deck is stacked against him. He has been in the system so long and has found that there are many barriers and not enough connective services to help him begin to heal in a meaningful way. Currently, he is a forensic patient at ASH and his definition of being restored (to health) differs vastly from the system's definition (to legal competency). In many ways, he is stuck.



Providers

We sought a wide variety of providers who encounter people with mental health conditions and their families as they traverse the mental health system. To get a broader perspective of the range of care offered in different venues, we interviewed and observed providers at ASH, Local Mental Health Authorities (LMHAs), a medical center, peer support, and private practice.

Base recruitment criteria:

The following criteria were used to being to identify providers across ASH and the ASH service area to recruit for the project.

Role

Include the following: Nurse, Social Worker, Psychologist, Psychiatrist, Licensed Counselor, Nurse Psychotherapist, General Therapist, Peer Specialist, Case Worker, Care Director/Admin

Gender

Select women and men equally

Ethnicity

Select historically underrepresented groups (e.g. African American, Asian American, Hispanic, etc.)

Facility

Extremes: Facilities outside of ASH main campus

Mainstream: ASH main campus

Time in System

Extremes: Less than 6 months, More than 7 years

Mainstream: 2-3 years of service in ASH

Authority

Extremes: non-MD / non-licensed professionals who help care for patients

Mainstream: MDs and licensed professionals

PROVIDER ROLES

Below we provide descriptions of the many different types of providers and provider roles we interviewed and observed.

APS (Adult Psychiatric Services)

The inpatient facility for adults at Austin State Hospital. APS units are distinct by location on campus and are labeled with a number and two letters (e.g. APS 4 West E).

CAPS (Child and Adolescent Psychiatric Services)

The inpatient facility for youth (ages 4 to 17) at Austin State Hospital. It provides acute care mental health services, therapeutic programs, and on-site school.

Charge Nurse

A registered nurse (RN) who is responsible for the operation of the nursing unit for specific periods of time (e.g. a shift).

Educator

A person who facilitates and provides instruction to patients and family members.

LMHA (Local Mental Health Authority)

Community mental health centers that provide services to a specific geographic area of the state (local service area). Each authority plans, develops policy, coordinates, allocates, and develops resources for mental health services in the local service area.

LVN (Licensed Vocational Nurse)

A nurse who provides basic medical care to patients under the supervision of doctors and/or registered nurses (RNs).

Peer Counselor Advocate

A certified individual who is supervised as they provide peer support services based on clinical need as identified in a patient's treatment or recovery plan. A peer counselor advocate utilizes their recovery expertise and experience in their work with patients.

Peer Support Director

A person who develops the peer support services programs, designing them to meet the needs of patients who have psychiatric and substance use disorder diagnoses. The director oversees peer support specialists and ensures that the programs promote and support a recovery and resiliency model of rehabilitation. This includes services and opportunities that promote continuity of care, community integration, and an environment of trust and healing.

Peer Support Specialist

This person has significant life-altering experiences and has been certified to support other individuals who struggle similarly with mental health, psychological trauma, or substance use. They assist their peers in clearly stating their goals for recovery, learning and practicing new skills, monitoring their progress, supporting them in their treatment, modeling effective coping techniques and self-help strategies, and supporting them in advocating for themselves to facilitate recovery.

Psychiatrist (MD)

A physician who specializes in psychiatry and evaluates patients to determine whether their symptoms are the result of physical illness, a combination of physical and mental ailments, or strictly psychiatric. Psychiatrists can prescribe medication.

PNA (Psychiatric Nursing Assistant)

A person who works under the direction of nursing and medical staff to assist patients in a mental health facility with daily living, educational, and recreational activities. A PNA may also restrain aggressive patients and help with de-escalating tense situations.

Provider Roles cont.

Psychologist (PsyD)

A person licensed to evaluate, diagnose, treat, and study mental processes. Psychologists are experts at psychotherapy and are trained in a number of methods such as behavioral therapy and systemic approaches. Psychologists generally do not prescribe medication.

Recreational Therapist

Therapist who employs games, sports, crafts, and other leisure activities to help patients maintain their physical and emotional well-being. In doing this, they also help patients integrate into their community through group activities.

RN (Registered Nurse)

A nurse who is licensed to provide treatment to patients suffering from various medical conditions. They assist physicians in providing care to patients and may administer medication, monitor patient recovery and progress, and educate patients and their families on disease prevention and follow-up treatment.

Rehabilitative Case Manager

A person trained to help put together the services needed for a recovery plan, which may include helping to plan, organize, coordinate, monitor, and evaluate services and resources for a person in care. A case manager doesn't usually provide direct patient care.

Rehabilitation Educator

A person who implements programs to educate staff on clinical practice, documentation, regulatory compliance, and program development for rehabilitation.

Social Worker

A person who is licensed to work directly with individuals and families to help them cope with mental illness and other associated issues (such as poverty, abuse, trauma, and unemployment). Many are State licensed to provide counseling and connect individuals to resources and service providers that can empower people to meet their own needs.

Specialty Services

The inpatient facility at Austin State Hospital that provides psychiatric inpatient services to adults over the age of 60, adults 18-60 who require longer-term treatment, people who are dually diagnosed with mental illness and intellectual developmental disability, and people who are deaf and have mental illness.

Treatment Coordinator

A person on the patient's care team who is the patient's primary contact and who helps protect the patient's interests by working closely with other health care professionals to ensure the best resources are being used to aid the patient in recovery.

Providers Interviewed and Observed



14. “Dr. J” – Dr. Juguilon, MD
Psychiatrist, ASH
Travis County



15. Dr. Keeley Crowfoot, PsyD
Psychologist, ASH
Travis County



16. Richard Webb, RN
APS 4 W F, ASH
Travis County



17. Sarah Collins, RN
APS 4 W F, ASH
Travis County



18. Alex Lopez, RN
Charge nurse, APS 4 W F, ASH
Travis County



19. Claudette Rhea, RN
Charge nurse, APS 4 W F, ASH
Travis County



20. Justina Duru, LVN
APS 4 W F, ASH
Travis County



21. Stephanie W.
Social worker, APS 4 W F, ASH
Travis County



22. Valerie
Social worker, APS 4 W F, ASH
Travis County



23. Ann L.
Treatment coordinator, APS 4 W F, ASH
Travis County



24. Karen Sams
Dir. Education and Rehab, ASH
Travis County



25. Yvonne
Educator, APS 4 W F, ASH
Travis County



26. Yessena Rojas
Recreational therapist, ASH
Travis County



27. Marilyn W.
Supervisor Education & Rehab, ASH
Travis County



28. Shatisha, PNA
CAPS, ASH
Travis County



29. Sarah, PNA
Specialty Services, ASH
Travis County



30. Kenneth, PNA
APS 6 W E, ASH
Travis County



31. Charles, PNA
APS 4 W F, ASH
Travis County



32. Victor, PNA
APS 4 W F, ASH
Travis County



33. Allen Schlinke, RN
Asst. Dir. of Nursing, ASH
Travis County



34. Tracy Abzug
Social worker, Integral Care LMHA
Travis County



35. Dawn Webb, RN
RN Supervisor, Integral Care LMHA
Travis County



36. Dr. John Nguyen, MD
Assoc. Medical Director Crisis, Residential, and Substance Use Services, Integral Care LMHA
Travis County



37. Amanda Groller
Disaster Response Team Program Manager, Gulf Coast Center LMHA
Galveston and Brazoria Counties



38. Ariell Gills
Rehabilitative Case Manager, Gulf Coast Center LMHA
Galveston and Brazoria Counties



39. Valerie Millburn
Peer Counselor Advocate
Travis County



40. Jessica Saner
Peer Support Director, ASH
Travis County



41. Dr. Tracy Asamoah, MD
Pediatric & Adolescent Psychiatrist
Travis County



42. Robin Peyson
Executive Director, Communities for Recovery on ASH campus
Travis County



43. Terry Scoggin
CEO, Titus Regional Medical Center
Travis County



Conduits to Care: Law Enforcement, Judicial System, Crisis Providers

We sought the perspectives of those who serve as connections to care or interim care providers in the mental health care system. These include sheriffs & jail administrators, judicial entities, crisis and emergency centers, and community groups.

CONDUITS TO CARE ROLES AND DEFINITIONS

Below we provide descriptions of the many different types of conduits to care we interviewed and observed, which includes sheriffs, judicial system, and crisis provider roles involved in intervening in crisis and getting people to care.

Crisis Call Center

A service provided through various organizations that offers a line staffed by qualified mental health professionals (QMHPs) who have been certified to manage crises and assist with mental health needs. QMHPs triage calls, handle crisis situations, and contact on-call staff at partnering organizations when necessary. Calls requiring immediate attention will be directed to on-call staff, EMS, law enforcement, or other services.

Emergency Detention

An emergency detention warrant may be issued by a judge to obtain a medical assessment to determine whether a patient needs court-ordered hospitalization. The warrant is carried out by law enforcement.

Jail Administrator

A person who oversees correctional facilities including every aspect of staffing and inmate well-being. A jail administrator also writes and implements operational procedures for all areas of their facilities to ensure the safety of workers and inmates.

Judge

Judges are able to issue an Order of Protective Custody (OPC) and/or an Emergency Detention Warrant (EDW) that would result in a mental health commitment. In Travis County, this is done through probate court.

LCSW-S (Licensed Clinical Social Worker Supervisor)

A licensed, master's level social worker who may provide all social work services, including clinical services such as diagnosing mental, emotional, behavioral, developmental, and addictive disorders, developing treatment plans, and providing psychotherapy. This social worker has also completed additional training to be a supervisor.

LMSW (Licensed Master Social Worker)

A licensed, master's level social worker who may provide the clinical services of an LCSW only under the supervisions of an LCSW-S, licensed psychologist, psychiatrist, LMFT (Licensed Marriage and Family Therapist), LPC (Licensed Professional Counselor), or a physician in an agency setting.

MCOT (Mobile Crisis Outreach Team)

A team made up of mental health professionals who help adults and adolescents having a mental health crisis. The goal of MCOT is to assess and help individuals in a crisis as effectively and efficiently as possible and in the least restrictive manner. MCOT connects people with other programs through a local mental health authority (LMHA) for ongoing care and recovery support. MCOT works with police and EMS.

Probate Court

The probate court establishes the validity of the wills of deceased persons, declares the heirs of deceased persons who die without a will, establishes guardianships for incapacitated persons and minors, supervises court-ordered involuntary mental health commitments, and administers all eminent domain cases initiated in a state county.

Prosecutor

A lawyer who conducts the case against a defendant in a criminal court.

Public Defender

A lawyer employed at public expense in a criminal trial to represent a defendant who is unable to afford legal assistance.

Sheriff

County sheriffs are often on the front lines of stabilizing, detaining, and transporting people in the midst of a mental health crisis. They may issue POEC (peace officer emergency detentions) to start the process of hospitalization, wait with someone at an emergency room until a facility has been identified to provide care, and transport the person to the designated facility. Often, sheriffs have individuals in their jails who need mental health care but who are unable to get a commitment to a hospital or other treatment facility.

Conduits to Care Interviewed and Observed



44. ASH Town Halls

**Facilitated by Mike Maples, HHS Deputy Executive
Commissioner of Facilities**

Travis County



45. Amanda Flores

System Planning Specialist, State Hospital System, HHSC

Travis County



46. Allen Pittman

**Project Manager, State Hospital Redesign,
Office of Transformation, HHSC**

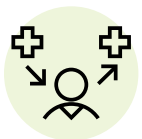
Travis County



47. Ellen Richards

Chief Strategy Officer, Integral Care

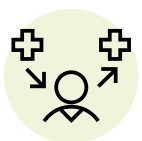
Travis County



48. Dawn Handley

Chief Operations Officer, Integral Care

Travis County



49. Taylor Cook

Technology and Innovation Fellow, City of Austin

Travis County



50. Pete Valdez
**LMSW, Court Administrator, Downtown Austin
Community Court**
Travis County



51. Jennifer Sowinski
**LCSW-S, Clinical Case Manager Supervisor, Downtown Austin
Community Court**
Travis County



52. Sheriff Rodney Watson
Hill County



53. Sheriff Gerald Yezak
Robertson County



54. Sheriff Jesus “Jess” Ramos
Lampasas County



55. Sheriff Jeremy Shipley
Freestone County



56. Sheriff Calvin Boyd
Burnet County



57. Sheriff Sally Hernandez
Travis County



58. Sheriff Dennis Wilson
Limestone County



59. Captain David Turrubiarte
Limestone County



60. Judge Nancy Hoehngarten
Travis County District Court, Law #5



61. Melissa Shearer
Public Defender
Travis County



62. Jason Steans
Prosecutor
Travis County



63. Judge Dan Prashner
Associate Probate Judge
Travis County



64. Janie Harwood
CEO, Avail Solutions, Crisis Call Center Services
Nueces County

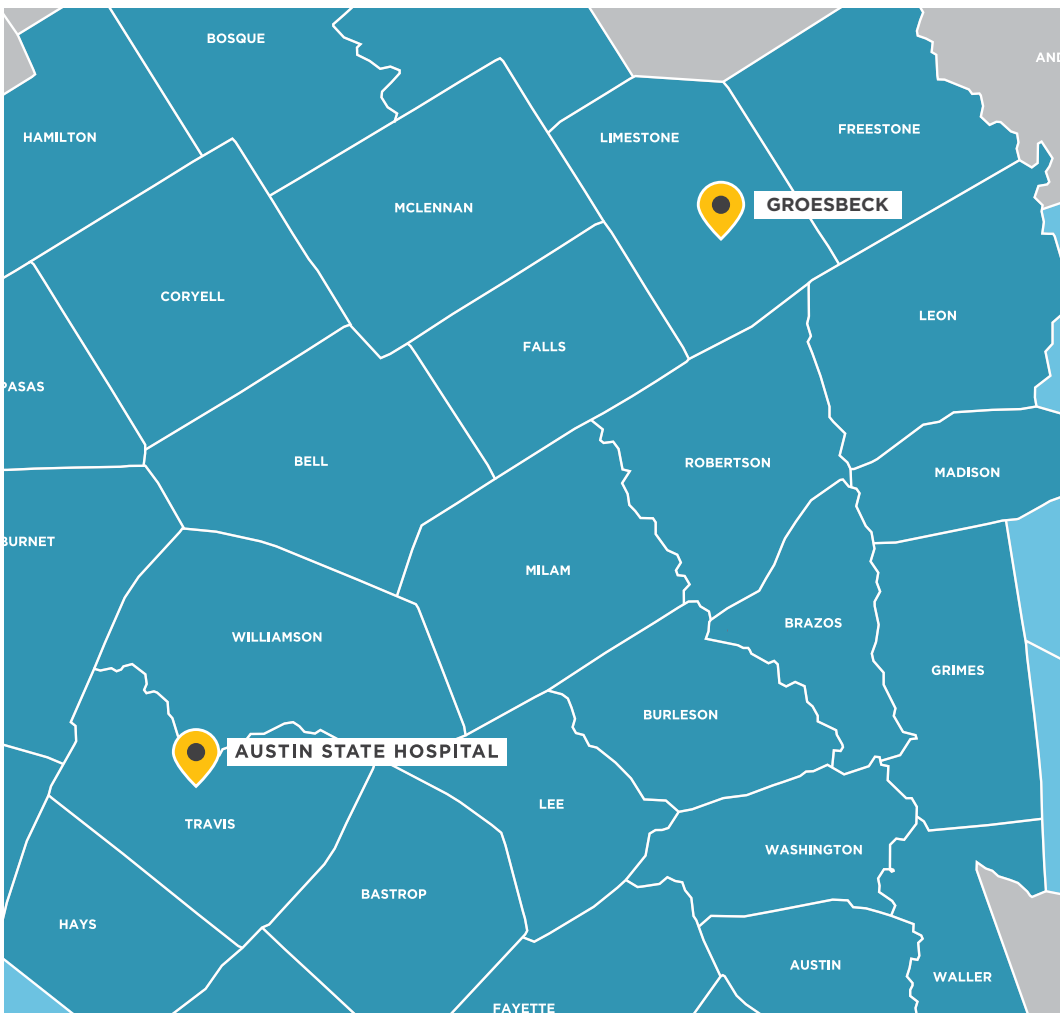


65. Susan Winters
Mobile Crisis Outreach Team (MCOT), College Station
Brazos County



Field trips and Observations

We spent time in the field at a few places to get first-hand experience of the spaces in which people are providing and receiving care.

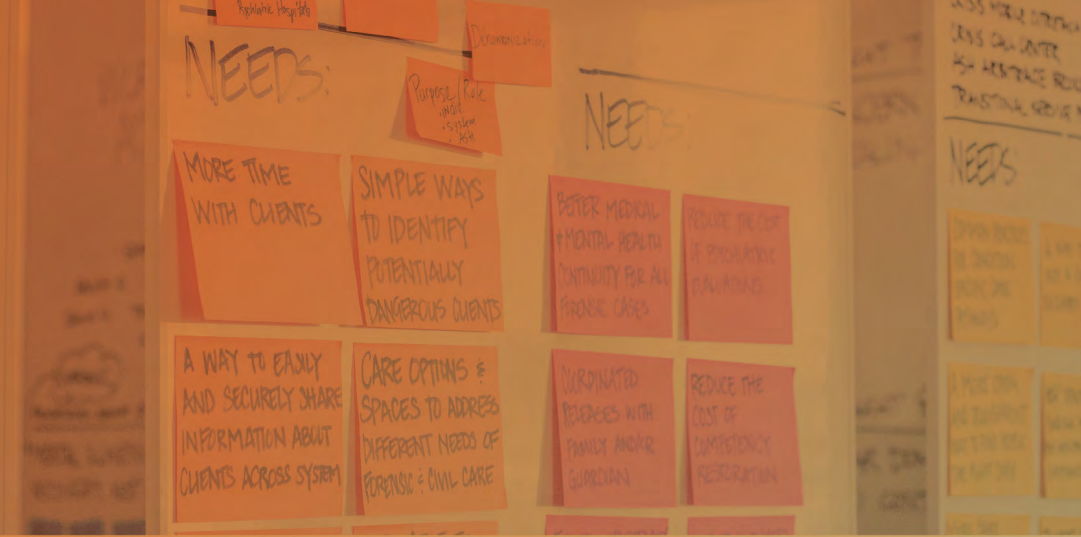


AUSTIN

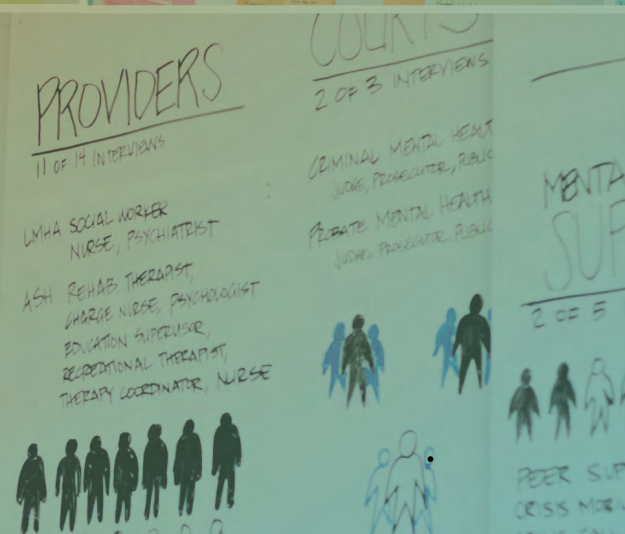
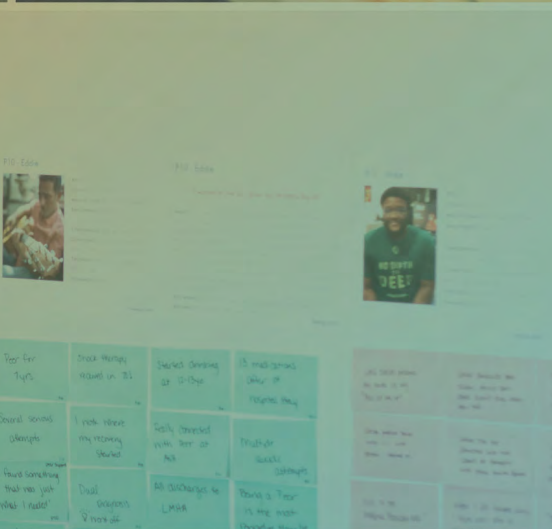
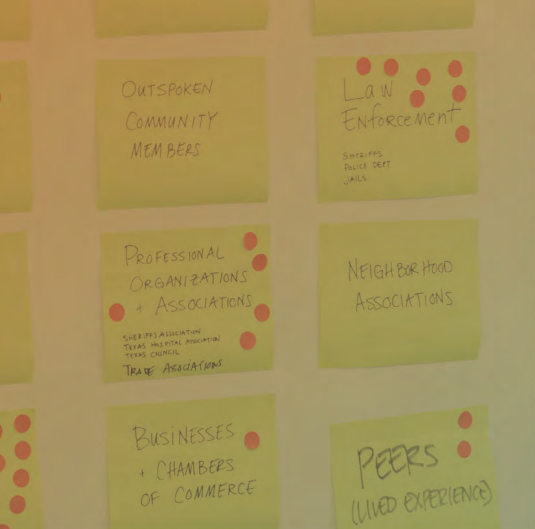
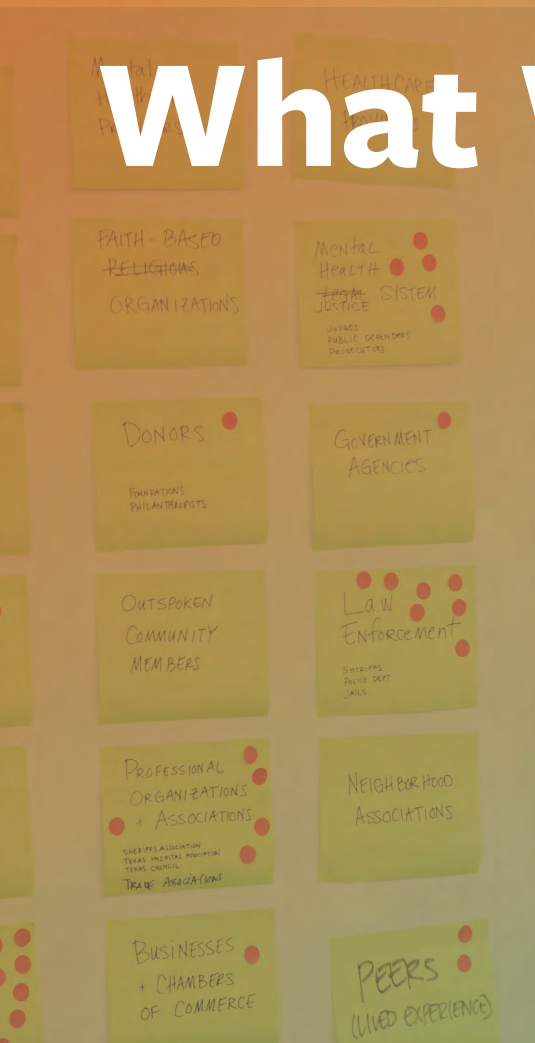
- ASH Probate Court: commitment/probable cause hearings at ASH
- ASH all-day unit observation in adult unit
- Communities for Recovery on ASH campus

LIMESTONE COUNTY

- Jail visit in Groesbeck, TX



What We Learned



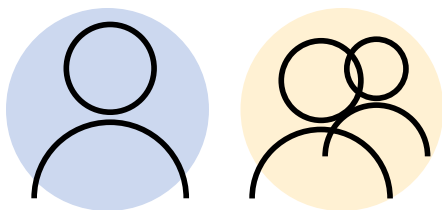
What We Learned

I. Needs

Building empathy for people is at the core of our qualitative information gathering methodology. Our diverse approach to qualitative field work provides the framework for us to build empathy for people who serve or are served by the mental health system. We listen and observe for patterns of needs, some of which are explicitly articulated and others that are expressed through actions, emotions, and understanding. This part of our qualitative methodology surfaces the pattern of needs that were expressed to us across different points of view and a visualization of the work flow across the current system.

We processed the notes from all of the interviews and observations to identify pain points, needs, desires, and motivations from people who actively interact with and experience the mental health care system. We grouped similar data points to expose and amplify the “voice of the person”. The result is a collection of needs that is a broad representation of what patients, caregivers, providers, law enforcement, the judicial system, and conduits to care either currently lack or depend on in the system.

For each cohort, we identified an anchor that represented pervasive needs that people mentioned time and time again. Each anchor need is supported by more detailed needs that we have phrased in the people’s voices as “we need” statements.



PATIENTS & CAREGIVERS NEED environments that support healing and recovery

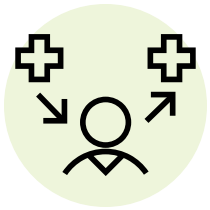
- We need to know what we are getting into when we begin treatment. – *patients*
- We need treatments, plans, and approaches to be tailored to our individual needs (rather than a “one-size-fits-all” approach). – *patients*
- We want to be able to connect with loved ones and visitors in a space that is inviting, comfortable, and allows privacy. – *patients, caregivers*
- We want access to a variety of therapies that engage our minds, bodies, and spirits. – *patients*
- We want to be in a space that is comfortable, visually attractive, clean, light-filled, and familiar. We want to feel like we’re home, not in prison. – *patients*
- We need to be able to safely retreat when we need alone time. – *patients*
- We need to feel safe at all times. – *patients*
- We want to have trusting relationships with the staff and providers. – *patients*
- We need the system to value us as human beings and help us to strengthen our sense of identity, autonomy, and self-worth. – *patients, providers*
- We want to contribute to the community. – *patients, providers*
- E.g. through job training or on-campus work programs
- We need to regain our dignity through avenues that allow us to make our own choices – *patients, provider*
- E.g. “token store”, “clothing store”
- We need space to stretch out – it makes us anxious when we are confined. – *patients*
- We need more options for recreation and exercise. – *patients, caregivers, providers*



PROVIDERS NEED

a way to easily and securely share information about patients across all providers and throughout the system.

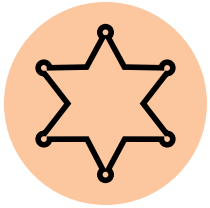
- We need to be able to access treatment plans from any point in the system. – *providers*
- We need a centralized system for referrals. Right now, every program has its own intake process and it's a mess. – *providers*
- We need a better way to learn about and stay on top of different care plans from different providers. – *providers*
- We need an easier way to see a person's full history in context. – *providers*



CARE CONDUITS NEED

more care venue options and a way to meet potential patients where they are in order to effectively triage their needs.

- We need more locations that can provide mental health emergency services and reduce the load on traditional hospital EDs and jail. – *crisis call center, sheriffs*
 - E.g. The Burke Center in Lufkin, TX
- We need safe, neutral spaces where law enforcement, families, and people in mental health crisis can meet for evaluation to determine next steps. – *crisis call center, sheriffs*
- We need a way to connect a variety of qualified mental health professionals to patients so that they can anticipate and treat needs before they become crises. – *crisis call center*
- We need to make it easier for people to connect with mental health resources early on so they don't have to get into crisis before they get into service. – *crisis call center*
- We need to build relationships with people so they will allow us insight into their lives and thus allow us to serve them better. – *peer support*
- We need comfortable, familiar, and nurturing spaces that will reduce anxiety and aid in the healing process. – *peer support*
- We need better ways to connect with providers and partners (inside and outside ASH) so that we can help ease the transition for people as the move from care to the community. – *peer support*



SHERIFFS NEED

the ability to quickly move people with mental illness to appropriate care, not jails.

- We need a less resource intensive way to get people evaluated and placed in treatment. – *sheriffs*
- We need a cost-effective way to move patients out of jail and into better treatment. – *sheriffs*
- We need financial support for the role we play in housing, transporting, and treating mental health patients. – *sheriffs*
- “We understand what the needs are but we don’t have the checkbook.”
– *Sheriff Dennis Wilson, Limestone Co.*
- We are not equipped or properly trained to provide the mental health care that people need. – *sheriffs*
- We need to eliminate “inmate clumping”, where a civil person ends up in jail because there’s no place available for him or her to receive treatment. – *sheriffs*
- We need partners with local knowledge to step in and provide options for care that meet the specific needs of the community. – *sheriffs*



COURTS NEED

a way to better transition people back into the civil community after release from jail or ASH.

- We need to create a comprehensive system that will provide mental health support to adults who are transitioning out of the jail system (probation or parole) by providing mental health screening, medication, therapy, life skills training, job training, transportation aid, and help navigating the benefits system. – *judges, providers*
 - E.g. Integral Care’s ANEW and The Mental Health Bond Project programs
- We need a better way to address underlying issues – such as homelessness and substance use – when we seek possible recovery paths for people on the verge of release from jail. – *judges, providers*
- We need transitional spaces that allow people leaving ASH or jail to gently reintegrate into the community. – *judges*
- We need to remove the roadblocks that people encounter when they are trying to get care after being released. – *judges*

What We Learned

II. Supporting Needs

We have cataloged supporting needs that show a pattern of need across cohorts. The following needs serve as scaffold to support the anchor needs.



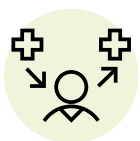
PATIENTS AND CAREGIVERS NEED:

- Respect and dignity
- An understanding of his or her condition
- Information that details options for available care
- Person-centered recovery plan and goals
- A way to help see the plan and progress
- Guides throughout the treatment and recovery process
- A way to modify the care plan based on what works and what doesn't
- An uninterrupted care experience that is consistent across facilities
- Simplified pathways to find care
- A community that accepts and supports him or her
- Connection to peer mentorship
- Programs to aid in rehabilitation and reintegration (“step-down” or “wrap-around” services)
- Work training and placement services



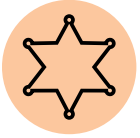
PROVIDERS NEED:

- More time with patients to foster meaningful connections
- Private and safe places to connect with patients
- Places to meet as a team
- Simple ways to identify potentially dangerous patients
- Care options and spaces to address the different legal needs of forensic and civil patients
- To be able to communicate easily with a patient's whole team across their continuum of care
- To be able to communicate easily with a patient's family or support team
- All roles on care team valued, including peer support
- To be able to bring in partners to transition a patient's care to them
- Help connecting patients to other social services
- Help enrolling patients into services regardless of funding sources
- A coordinated recovery plan



CONDUITS TO CARE NEED:

- Common practices for condition specific care pathways across providers
- A more open and transparent way to find people the right care
- More care venues that are easier for patients to reach
- Help streamlining funding and payment for mental health and substance use disorder
- A way to plug into a patient's recovery plan



SHERIFFS NEED:

- To spend less time at the patient's home or at the hospital
- Less time transporting the patient
- More options to restore a person's ability to stand trial for a growing forensic population
- More continuity/communication across different care venues
- Transparency of the criteria used for ASH admissions and discharge
- A way to plug into a patient's recovery plan and history.



COURTS NEED:

- Ability to quickly move people with mental illness to appropriate care (not jails)
- Better medical and mental health continuity for all forensic cases
- Coordinated releases with family/guardian
- Reduce the wait times for competency restoration
- Transportation solutions to appointments (court and therapy) for poor and homeless population
- Housing solutions for homeless patients
- Increased standards for group homes and half way house environments
- Reduce the cost of accessible and affordable psychiatric evaluations
- Reduce the State's cost of competency restoration
- Better/more out-patient rehabilitation services
- A way to plug into a patient's recovery plan

What We Learned

III. Insights

The goal of our qualitative information gathering is to gain clarity around the needs, motivation, and themes that underlie every experience. Building on the patterns of needs, we form insights. Insights are the synthesis of all the qualitative data. They emerge when we begin to see patterns of needs across a diverse group of people and elevate their individual expression to be representative of a greater shared experience. Insights identify themes that exist at the person level, the cohort level, and at the system level. Insights often provide the essential reframing of the situation, even if only a slight shift, that helps us see the problem in a new light. Insights clarify which problems to focus on solving. Insights help designers understand why things work the way they do and shape a point of view on how tensions or conflicts within current experiences can be reframed as new opportunities to spur new ideas.

Below we identify eight insights, noting the first insight is one we consider to be foundational to all subsequent insights. For each, we've included a sampling of verbatim quotes that provide further depth and context.

INSIGHT 1

Mental illness is lived through the process of recovery, not quick fixes

Recovery is a lifelong journey, and ASH's current role is a minor blip in the continuum of mental health care. Today, ASH is focused on competency restoration (forensic) or discharge (civil), which are inconsistent with the expectations of the people who enter care. Recognizing that new treatments and cures for these brain diseases may one day exist, care today needs to offer people a path to recovery that spans a lifetime, where wrap-around social services, outpatient care, and ongoing sustaining therapies are core elements of how the system responds.

“What didn't work is [ASH] limited my time with the treatment. After a while you can only have so much time...and then you're kind of kicked out of the system... after that I felt, what am I supposed to do now...then I would have setbacks.”

– Camila

“If we can do a work rehab program in the hospital and get the community on board, that would be great.”

– ASH provider

“I don't want narcotics. I want medicine that's going to help me.”

– Lori

“My husband sat me down and talked about the quality of life, and that I had none. That maybe I didn't feel depressed, but I felt nothing else as well and I was not living my life. That thus began the odyssey of trying to find something that worked, which lasted several, several years.”

– Regina

INSIGHT 2

Individual people cannot be the only bridges to the continuity of care

The component parts of today's mental health system are siloed and only tacitly connected. Perspectives, information, motivations, and needs are faceted across the whole system. Everybody is doing their part, but the parts are not hard-wired, hand offs are missed, information is immobile, progress is lost, and there is a missed opportunity for alignment around a shared plan that enables people to get and stay healthy. Consequently, the system appears to work only when a 'healthcare hero' steps up to force it to do so; when the hero tires and quits, the system collapses.

"It takes 120 days to make a decision about social security, and sometimes the person will have to be discharged to the street before that's in place."

– Public Defender

"The court system is not designed to be a treatment facility. We'll wait months to get someone into ASH on a misdemeanor and jail is not a good place for the mentally ill."

– Judge

"Then when I couldn't find [a therapist], my OB was like, 'I'll just have to do it myself because I don't want to have to be accountable for a pregnant lady taking her life.' That just pissed me off."

– Spring

"I kind of feel like we need to move into that kind of last frontier where we've connected the dots for people like my son who are standing in the middle of that bridge between mental health and developmental disabilities."

– Miranda

INSIGHT 3

Not attending to people's needs outside of crisis is interpreted as a shortage of beds

What appears to be a scarcity of beds is actually a lack of funding and coordination to streamline the process of connecting needs to existing resources beyond people's experience with crisis. The result is an increasing request for more "beds" when someone has a crisis or relapses. Money connects care, but the lack of money limits care options and breaks continuity.

⋮ *"Sometimes, in really dire situations, we tell people that they will be able to get help faster if they threaten to commit suicide."*

– Call Center

⋮ *"[My doctor] turns around and tells me, 'I can't help you right now, you have to wait another five weeks before I can make you pain free because you're a non-paying patient.' You're making me depressed again because I'm a [Social Security Income] patient, it's not my fault I'm sick, but that's how you're making me feel."*

– Camila

⋮ *"I was like, 'Man. Nobody's accepting new patients?' All the therapists were out of pocket. So, you mean to tell me I have to make \$80,000 a year to afford a therapist? It's hard."*

– Spring

⋮ *"I want my client to get arrested to get the treatment they need."*

– Public Defender

⋮ *"Are you going to increase beds? Because we need a place to take them to get help, and we just have to wait for a bed at ASH to open up."*

– Sheriff

INSIGHT 4

The opacity of how we care for people with mental illness leaves everyone in the dark

Mental illness takes away not only your voice – but also your ability to see what’s happening. Patients, families, providers, and those who support them don’t know and can’t see the whole plan to an individual’s recovery. ASH and HHSC are seen as incontestable black boxes. People don’t know what to expect and don’t understand the processes or standards of care, which leaves those involved unable to help guide someone to a next step.

“You’ve seen the other side, I haven’t. I haven’t seen where they take my son.”

– Keira

“ASH - they’re the ones playing the fiddle - you gotta dance to them.”

– Gerald Y, Sheriff

“Just medication. Just medication, and nothing else... Left me thinking, how am I going to fix this, they just said, take this, come back in 30 days, take this come back in 45 days. You know? Then I still wasn’t understanding what was going on, I knew I was feeling different and crying all the time but not getting really the help that I needed until I was in trouble.”

– Camila

“They put in me in a chair, and I don’t know why. They gave me a shot, and I don’t know why. 20 people held me down, and I don’t know why.”

– Samantha

INSIGHT 5

Anticipating and planning for relapse is a better strategy than waiting for crisis.

Trying to address the lifelong mental health care needs of a growing population with a finite state budget has resulted in focusing resources on the most vulnerable stage - crisis. For the majority of people with mental health conditions, relapse is a common pattern of brain disease, and not a failure of recovery. Waiting for a person to relapse into crisis is expensive, with the ultimate cost coming from having people cycle through over and over. Embracing a continuum of care means that we should anticipate the needs of people who relapse and adjust the model of care to help them succeed through more planned interventions.

“I’ve had times of stability. So, it’s been waves. But it was never as bad as it was this last time because I was trying every way to end my life, with all kinds of different things. And, so, I didn’t want to live anymore. Thank goodness I didn’t succeed in that. I did some very serious attempts. Ended up in emergency rooms several times, and each time I’d go to Austin State Hospital. And then, from there, that’s when I first went into Bluebonnet Trails.”

– Eddie

“We see the same people over and over again.”

– Sheriff

“My son has been in the emergency room at least once a week. He drives himself there when he wants to get a few hours of sleep.”

– Keira

“When we release them without a place to go, they end up back here.”

– Court Prosecutor

INSIGHT 6

Without the guidance of a shared plan, the revolving door of fragmented care erases individual progress

Too much change in providers, medications, and therapies stymies the benefits of care. A consistent care team and plan mitigates the impact of turnover as evidenced by the ultimate band aid - an engaged mother - who researches and seeks out the expertise of those with similar lived experience and consistently provides that reference at every turn to drive alignment and engagement around the relevant problem.

“I think the only way to having [all these records and documents] help him is that they know that he has a mother that’s serious and that is going to check behind them. The care he might get at our local mental health authority is going to be different than someone that doesn’t have a mother that knows what to expect.”

– Iris

“My doctor wasn’t even engaged in my appointment. I didn’t feel like he even cared to hear anything I had to say or even much less listen because he was steadily writing the whole time. So, I’m talking to his student but yet, [he’s] supposed to be listening and [he’s] not even paying attention.”

– Lori

“I’m positive that had I not quit working, if I didn’t have the support of my husband, and if I didn’t have the knowledge and the personality that I have, I’m pretty sure my son would be dead right now.”

– Miranda

“They keep switching your psychiatrist, and like I said, they stopped therapy by that time, which I thought was really important especially when you’re bipolar because you always have to maintain your condition.”

– Regina

“I thought I was going to be seeing a person and it wasn’t until my case manager told me, ‘Actually, yeah. We have to do it like this [telepsychiatry].’ I was like, ‘Oh, that’s different, but okay. If that’s what it takes.’”

– Spring

INSIGHT 7

Stigma and fear isolate people, when they most need connection and information

Mental illness isolates, which further exacerbates it. There is a real fear of losing your voice in treatment, of saying too much, of losing your children, of losing your job, of relapse, of being hurt, of the unknown. The collateral damage of mental illness is further trauma, as stigma fills the void of loneliness and detachment. Relationships (not just therapy and medication) are an essential and often unmet need to recovery.

“I don’t want to be this way. I don’t want to feel this way every day. You go try to make friends and they don’t want to be your friend no more after they start hearing shit.”

– Lori

“I can honestly tell you that it’s really hard to be at home 24/7, that’s the worst part, and depression hits hard to see the same walls every single day.”

– Camila

“You are not bipolar. You are beloved.”

– Father Charlie Garza

“But I think mental illness does run in my family. Back then it was kinda just swept under the rug, and we didn’t really deal with it. But, as I look back now, instead of taking the medication, I was self-medicating [with alcohol].”

– Eddie

“I went into a spiraling depression. But I never really was open about it. I never really told my family, friends, out of fear. It got to the point where my body was getting really cold and numb. I was caving into what the voices were saying, saying I was useless, no one loves me. I would get into... I would just feel cold, and I wanted to feel again.”

– Mike

INSIGHT 8

The focus on security during crisis holds back the transition to the healing care necessary for recovery

Security is given a higher priority than dignity. ASH can feel more like a jail than a healing place. People at ASH memorialize their time there as being zombied out on meds, rather than getting better. People in recovery, including providers and family, want a space that is clean, uplifting, creative, quiet and that offers them creative outlets and connections that heal everyone involved.

“One of my greatest fears, as a mother, is that my son will be shot, choked, or tased to death during an emergency call for help. Please understand that Ray is sick – he is not a criminal.”

– Pamela

“This window in the door is great. It allows us to still have a connection with the client but without the risk of them forcing the door open to get in the nurse’s station.”

– ASH Provider

“They start to treat you more like an animal than a person. It’s like all of a sudden we’re a problem to them and we’re a bother to them because we’re there to get help.”

– Lori

“We have a problem with the visitor room. It would be really easy for a client to escape because they just have to get past one door and then they’re out.”

– ASH Provider

“We don’t trust [clients] to go outside on their own.”

– ASH Provider

“They put me on something, and it made me gain 60 pounds in six months. I eventually wound up getting diabetes. The psychiatrist saw nothing wrong with that. I was sleeping 18 to 20 hours a day. I’ve had so many different side effects. It just doesn’t seem like the psychiatrist care. You know, they’re overworked.”

– Regina

Collaborators

RECRUITING

Our partner Human Interfaces handled the screening, recruitment, and scheduling of most of the patient and caregiver participants that either they identified or we supplied to them. Other recruiting help came from The Meadows Mental Health Policy Institute, NAMI Austin, Integral Care, Bluebonnet Trails, Texas Health and Human Services/Austin State Hospital, and Sheriff Dennis Wilson.





Design Team

Beto Lopez

Managing Director, Design Institute for Health
Clinical Associate Professor, Associate Professor
of Medical Education

Natalie Campbell

Designer, Design Institute for Health

Sydney Harris

Director, Mental Health Care Redesign

Katherine Jones

Director of Strategy & Mission, Designer,
Design Institute for Health

Kijana Knight-Torres

Researcher, Design Institute for Health

Lauren Smedley

Design Fellow, Design Institute for Health

Eric Zimmerman

Design Fellow, Design Institute for Health

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THESE FINDINGS WERE PREPARED BY:

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