



# CX of Individuals with Complex Behavioral Health Needs

A study of 27 individuals living with Serious Mental Illness,  
Substance Use Disorder, and co-occurring SMI & SUD

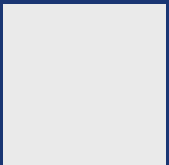
June 9th, 2023



# 01. Executive summary

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# Introduction

In Q1/Q2 of 2023, we interviewed **27 people living with SMI, SUD, and SMI & SUD**. Through their personal stories, we gained an understanding of their **lived experiences**. These included challenges in **navigating diagnoses, accessing care, receiving ongoing treatment, and managing co-occurring conditions**.

After understanding participants' overall BH experiences, we delved into specific topics: **access to care, service experience, navigation, and digital experience**. Participants were generous with their insights, and this report serves as a reflection of what we've learned. Finally, we offer recommendations for how to elevate the behavioral health insurance experience to best support these individuals and others like them.

# Abstract

Distinct challenges unique to behavioral healthcare resound through the voices of the individuals we spoke to, namely, that **every day requires attention and careful management**. So often their journeys are lifelong efforts.

Our conversations illustrate how, more than a diagnosis or acuity level designation can, the **social, vocational, and financial aspects of the individual's life shape their experience and inform us of their needs**. The influence of these personal complexities on care needs demand an effort to rethink how the insurance experience interfaces with, collaborates with, and ultimately understands its members.

**Continuity of care emerged as a pillar of success in the effort to understand a members' unique needs.**

We observed a general lack of support during a frightening and fluid **diagnosis process**, further necessitating a personalized approach to care.

This neglected moment in the BH experience, as well as a lack of trust and engagement with the digital tools offered by their insurance provider for finding care and education, provoke a resoundingly negative perception of their insurance experience.

Through **(1) receiving a rewarding continuity of care experience, (2) explicitly measuring and addressing discontinuity, and (3) creating welcoming digital experiences for BH members**, we see a major opportunity to move towards personalized care, and critically to **(4) provide support and education during diagnosis** and treatment. Redesign in these areas centers around **(5) creating a collaborative relationship** between [REDACTED] members.

**Creating this welcoming digital environment will require asking some probing questions and present unique challenges.** Namely, as an insurance provider, are we prepared to not only create this environment, but to find ways to communicate and rebrand in order to signal that we are a primary place to find BH providers, find BH care, and ensure continuity of care over the long term?

# Method

In Q1/Q2 of 2023, virtual **in-depth interviews** were conducted by DataArt and held with 27 individuals living with:

- SMI – 11 participants
- SUD – 9 participants
- SMI & SUD – 7 participants

**The primary aim of the study was to identify pain points, unique needs, and Moments That Matter for these populations when accessing and navigating BH.**

## Objectives

- Pinpoint areas of the experience to design / redesign
- Understand experiences, likes, and points of friction when accessing care, the service experience, and navigating care
- Identify Moments that Matter: unique needs, success moments and pain points
- Understand how participant's goals and outcomes relate to a combined treatment of both physical and mental health (not consistently covered)

Two in-depth interviews were held with each participant, each 60 minutes in duration, for a total of 54 interviews.

- Interview 1 – focused on the overall experience of living with SMI, SUD, and/or SMI+SUD
- Interview 2 – covered topic areas, including: access to care, service experience, navigation, and digital experience.

## Insurance representation

- Anthem – 16 participants
- Optum – 6
- Humana – 5

## Acuity representation

- Very complex – 13 participants
- Complex – 7
- Less complex - 7

## LOB representation

- Medicaid – 7 participants
- Medicare – 5
- Individual plans – 6
- Large Commercial – 4
- Small Commercial – 5

# Key Insights

## Digital experiences

Individuals rarely consider their insurance provider's digital tools (apps and websites) as viable methods to find care or resources about their condition and treatments.

Less than 25% of participants consider their insurance providers' digital experiences as their primary method to educate themselves on their condition or to find care.

## Access to care

Across conditions of SMI, and/or SUD, it was seen that an individual's ability to receive necessary care is influenced by several factors, including their family support, employment status, location, cultural values, and personal finances.

## Care continuity

Across conditions, discontinuity creates major friction which is a negative incentive to seeking additional care which increases relapse and additional episodes as well as frustration related to “starting over” with new practitioners.

*For SMI*, continued care with the same provider is crucial to stabilization

*For SUD*, lack of follow-up care, in particular from inpatient treatment, results in discontinuity. Low-income populations receive valuable forms of care continuity in the form of support groups such as AA.

## Diagnosis

Diagnosis is a major MTM that is often neglected resulting in frustration, negative sentiments towards insurance providers, and a disinclination to seek further care. There are many questions that often go unaddressed such as: What does it mean to be diagnosed? What does it mean over time? How does this affect my life? How does it change and evolve? despite individuals' strong desire to explore them with their clinicians.

## Collaborative relationship with insurance providers

While we generally observed a negative perception of the insurance experience, individuals welcomed a more collaborative relationship with their insurance providers.

# Key Insights

## Digital experience

Individuals **rarely consider their insurance provider's digital tools** (apps and websites) as viable methods to **find care or resources** about their condition and treatments.

**Less than 25%** consider their **insurance providers' digital experiences** as their primary method to **educate themselves on their condition or to find care**. "Technology has leapfrogged healthcare." (Daniel H, living with SMI & SUD)

The most common practices for finding care are:

- Calling the insurance company to ask for a list of in-network providers, and then calling those providers one by one.
- Using third party websites to find providers.

Individuals research online and utilize social media and/or online forums to educate themselves on their condition, learn how to manage side effects, and find strategies to cope day to day.

## Access to care

Across conditions of SMI, and/or SUD, it was seen that an individual's ability to access necessary care is influenced by several factors, including their **family support, employment status, location, cultural values, and personal finances**.

There are common criteria that individuals consider when choosing a care provider:

- Time and duration from time of scheduling to appointment
- Distance from home or work
- Amount of interference with employment responsibilities
- Amount of family and social support
- Clinician's alignment with cultural values
- Alignment with physical healthcare

# Key Insights

## Care continuity

Across conditions, **discontinuity creates major friction** including disinclination to seek further care, heightened risk of relapse or episode, and frustration from "starting over" with new practitioners.

There are few condition-specific nuances:

For those managing long-term SMI, **continued care** (with the same provider) is crucial to obtaining long-term stabilization. Care continuity allows members to feel that they're being listened to, better understand their condition, manage side-effects, and educate on strategies to augment or optimize their treatment.

**For SUD, discontinuity often manifests as a lack of follow-up care** after inpatient treatment. Peer support groups like AA are crucial in care continuity for SUD, especially for low-income populations. We can consider these peer groups a baseline of care that should be thoughtfully considered alongside clinical care.

## Diagnosis

**Diagnosis is a major MTM that is often neglected** resulting in frustration, negative sentiments towards insurance providers, and a **disinclination to seek further care**. There are many questions that often go unaddressed such as: What does it mean to be diagnosed? What does it mean over time? How does this affect my life? How does it change and evolve? despite individuals' strong desire to explore them with their clinicians.

## Collaborative relationship with insurance providers

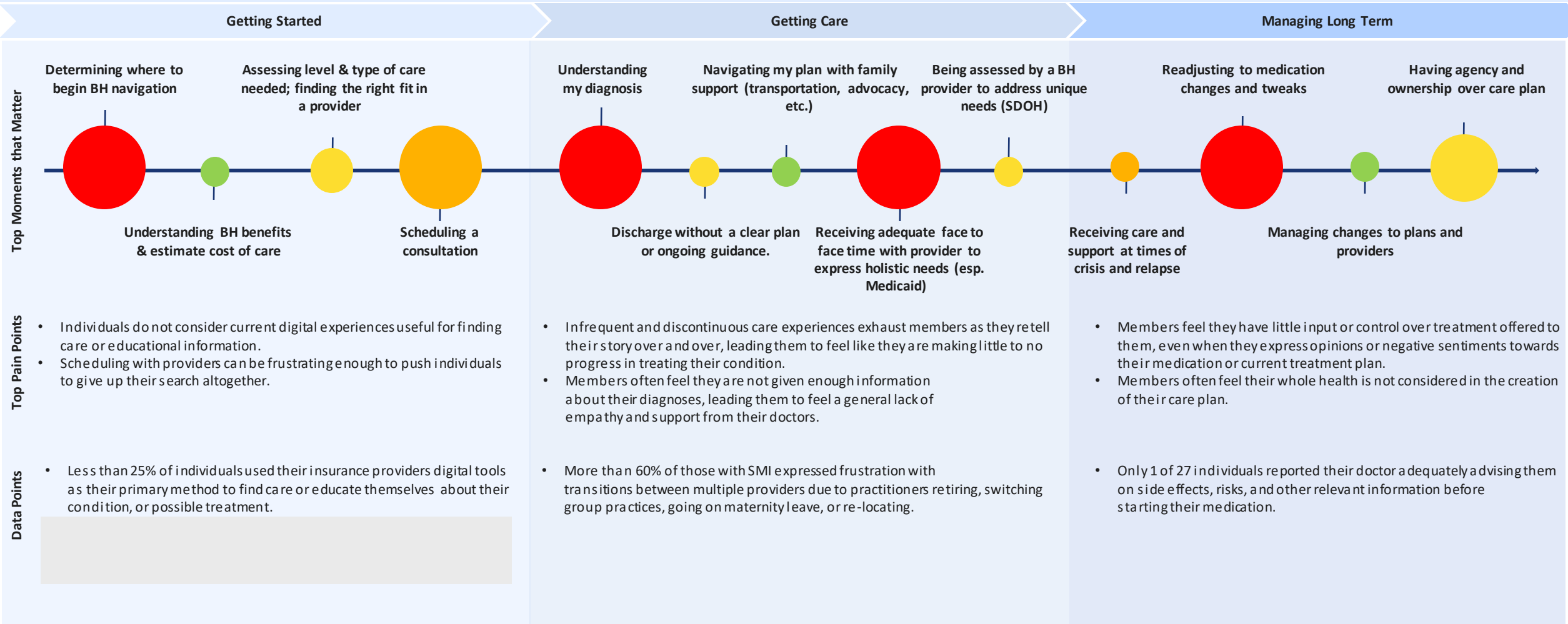
While we generally observed a **negative perception of the insurance experience**, individuals welcomed a more **collaborative relationship with their insurance providers**. "Why doesn't insurance try to understand us?" (Daniel H, living with SMI and SUD)

More than 50% of individuals expressed openness to digital experiences from their insurance provider if they were more personalized and integrated with their clinicians.





# Moments That Matter: Levels of incidence and abrasion



## Concluding remarks

Through first person stories, we have studied the current state of the Behavioral Healthcare industry, as well the impact of these consumer experiences on the lives of individuals living with Serious Mental Illness and or Substance Use Disorder.

**Care continuity** is a fundamental pillar to ensure that individuals living with SMI and/or SUD can live a life according to their needs and expectations, and our strongest recommendation is to **direct our efforts towards ensuring that continuity**.

As we have also learned, mental health conditions cannot be fixed like a broken bone; they require sustained effort from the moment a person is diagnosed until any eventual crisis that may arise due to their condition, so we must actively work to provide services that address what is happening at these moments.

We also have the opportunity to **elevate our digital experience** to meet the expectations and needs of our members and, instead of creating effective and useful products and services that are difficult to access, **be proactive and reach out** through multiple digital channels to offer our members what they truly need, often in the worst moments of their lives.

Another crucial piece of the puzzle are the **non-clinical roles** that assist, support, and guide our members throughout their journey, such as **case managers, care navigators, peer consultants, family members and caregivers**. It is crucial that we conduct further research on these roles to elevate their work and make it more accessible and effective.

In addition to building useful products and services, we as an organization will need to commit to evolving our branding and communications to fully realize the efforts around connecting with the member.