

Supporting those with mental illness.

**User Experience Design Intern
Affect Mental Health
Independent Research Project**

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For this project, I studied people with mental illness and their supporters to determine supporter needs. I interviewed 10 supporters and people with mental illness, with some falling into both categories. These needfinding interviews elicited surprisingly unique stories, though most of them were college students. Following the design process, I synthesized findings, insights, and needs that can be used build solutions in the mental healthcare space.

According to NAMI, “approximately 1 in 5 adults in the U.S.—43.8 million, or 18.5%—experiences mental illness in a given year.” These numbers, already alarmingly high, soar even higher when we consider those affected by mental illness - the sufferers and their supporters. Mental illness is extremely prevalent but common knowledge about how to help those dealing with it is minimal. This, feeling responsible for those they are supporting, and suffering the large emotional toll of a loved one going through such an illness are just a few reasons supporting loved ones is intensely difficult. People with mental illness also struggle with reaching out to others for help and sharing their burden. The following are my top findings.

Needfinding Interviews

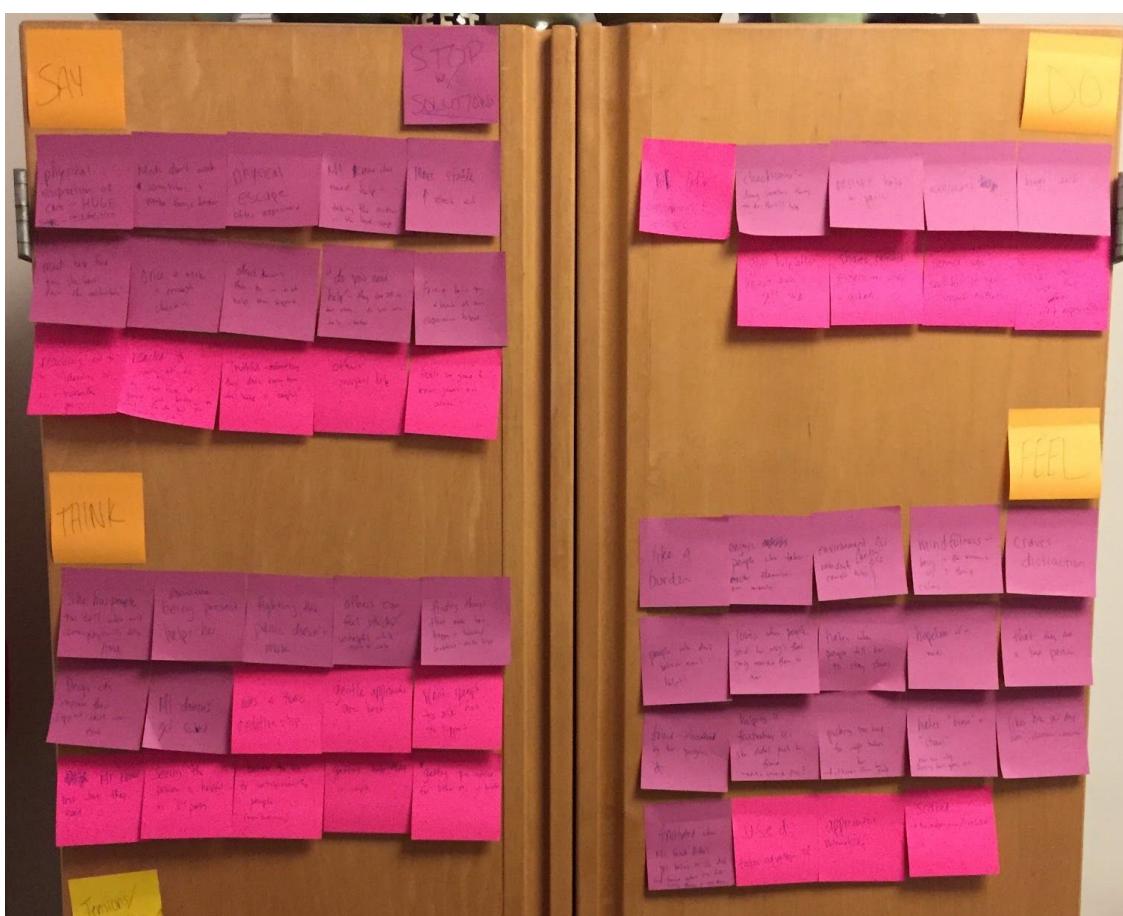
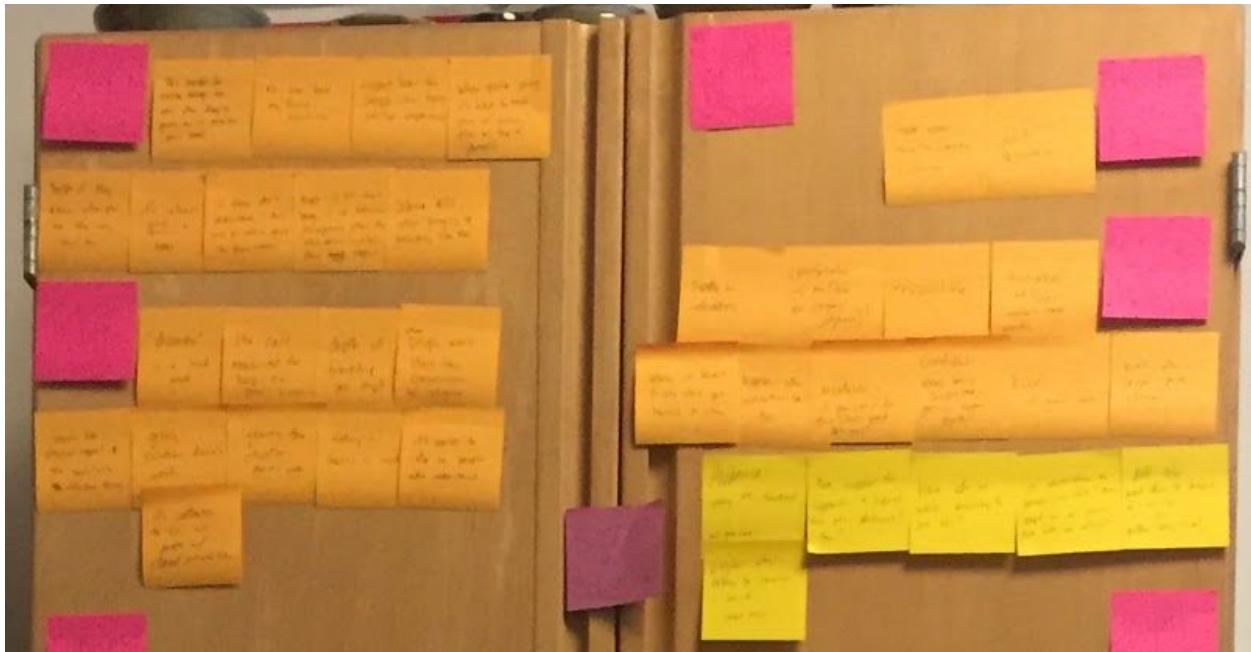
I recruited interviewees through email lists and online communities and talked to people with mental illness, people emotionally supporting those with mental illness, and those that fit into both categories. Overall, I conducted 10 interviews that each lasted 45-90 minutes. I worked to elicit stories, and used the following questions to guide the conversation. Note: “LO” refers to loved one, the person they were supporting.

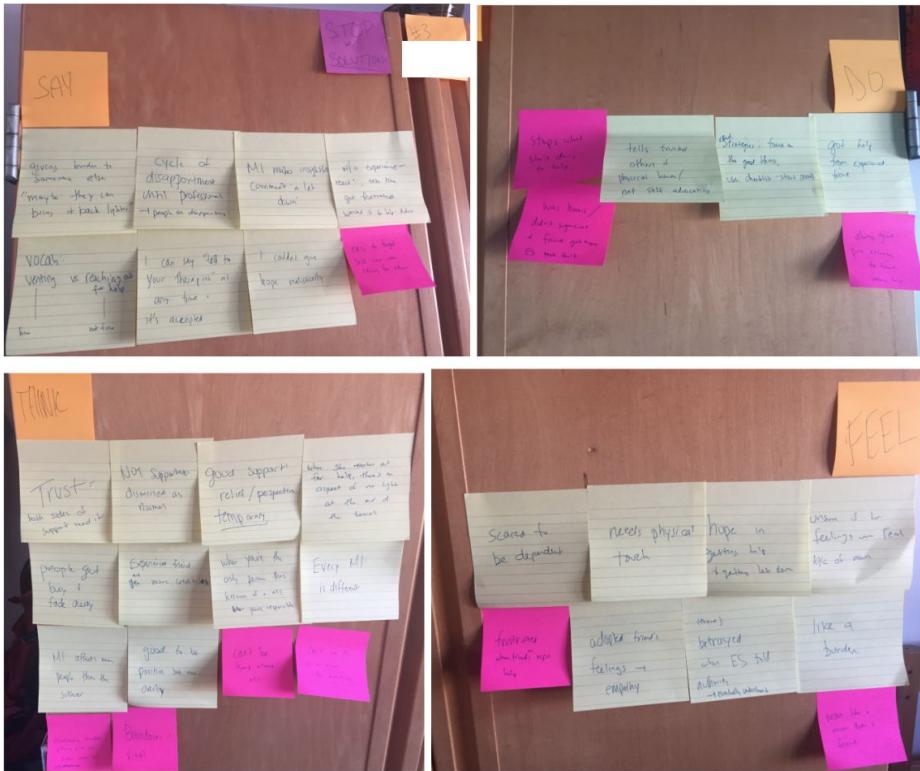
- With mental illness
 - Have you ever felt supported?
 - Tell me about that time
 - Do you feel you depend on others?
 - When?
 - Tell me about a time you felt like you weren't being supported
 - When have you felt loved?
 - Tell me about a time someone tried to help that was disappointing.
 - Tell me about someone who has supported you
 - What did they do specifically that made you feel supported

- Tell me about someone close to you that was not supportive
 - What did they do wrong
- If you could give your friends advice on what could've helped more what would that advice be?
- Tell me about a time you reached out to a friend.
- Without mental illness
 - Relationship to the loved one?
 - Tell me about when you first learned about their MI
 - How did you react to this?
 - Tell me about a time you witnessed LO's symptoms
 - Tell me about a time you felt stressed about their wellbeing
 - Why
 - How does it make you feel that LO has mental illness?
 - How has their mental illness affected you?
 - What does supporting LO mean to you? Tell me about a time you've supported LO?
 - Do you know other people supporting LO?
 - Do you know other people supporting others with mental illness?
 - Have you spoken to anyone about supporting LO?
 - Why or why not
 - What was your worst experience as LO's supporter?
 - What was your best experience as LO's supporter?
 - How do you alter your behavior when you are around LO due to their illness?
 - If you could give yourself any advice looking back, what would you say?

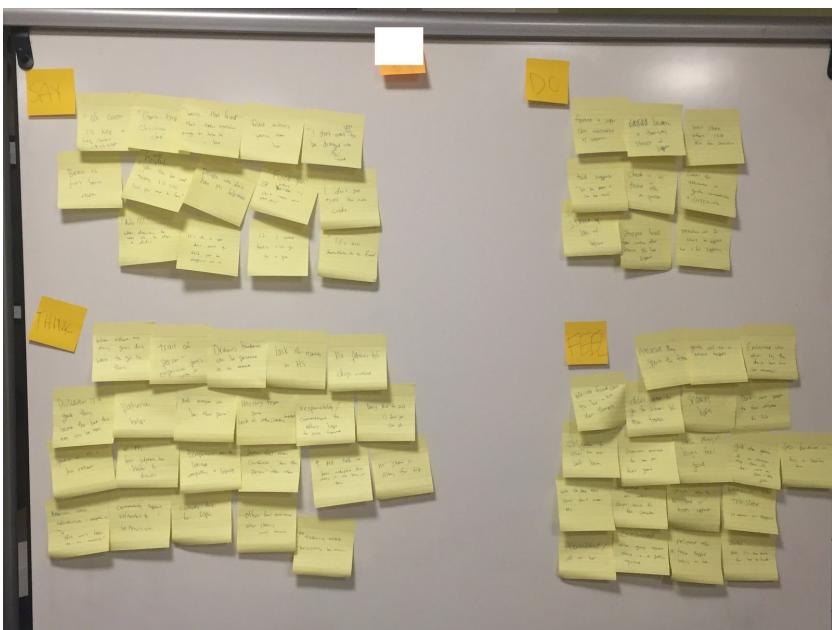
Empathizing

For each interviewee, I created empathy maps to better understand their perspectives. Here are the 10 empathy maps:

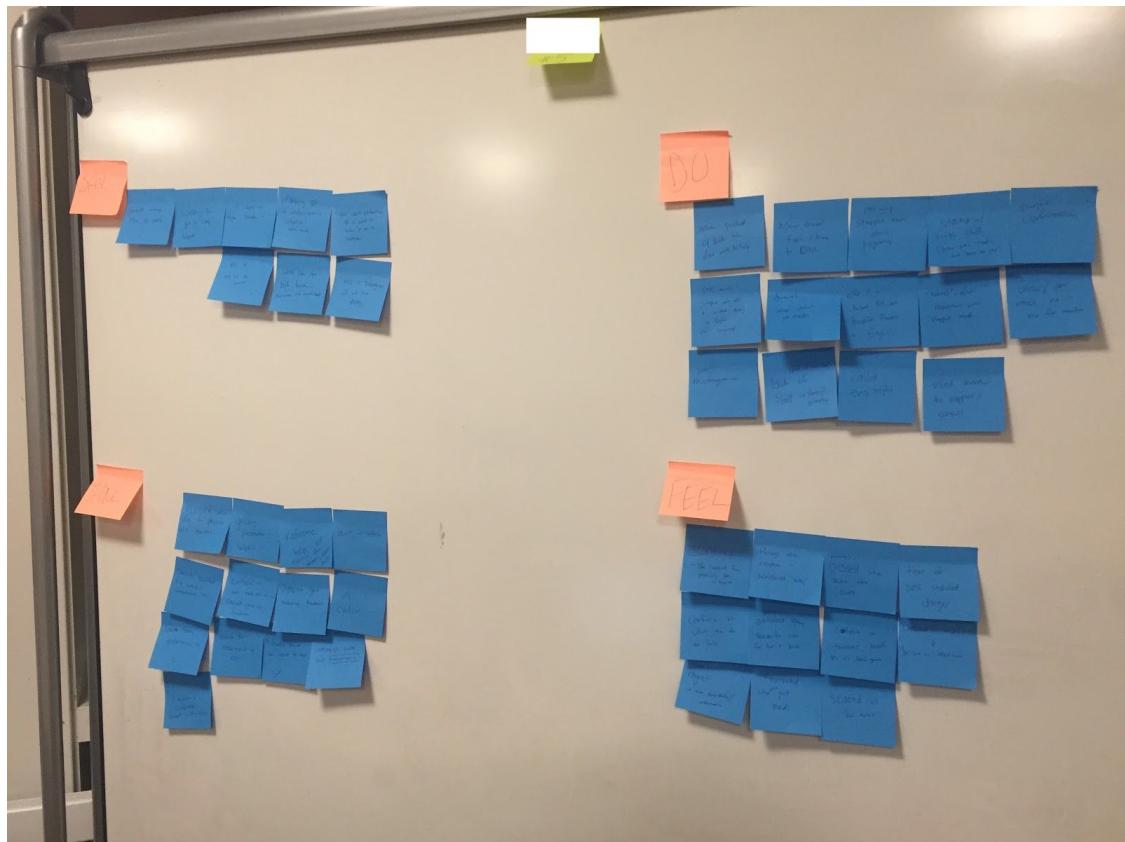




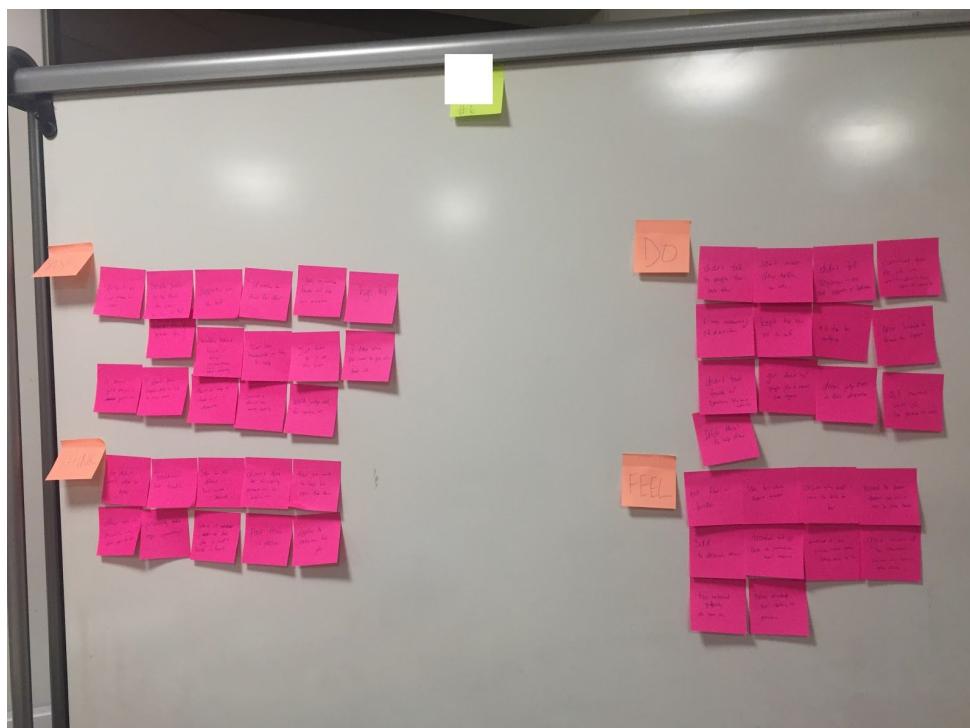
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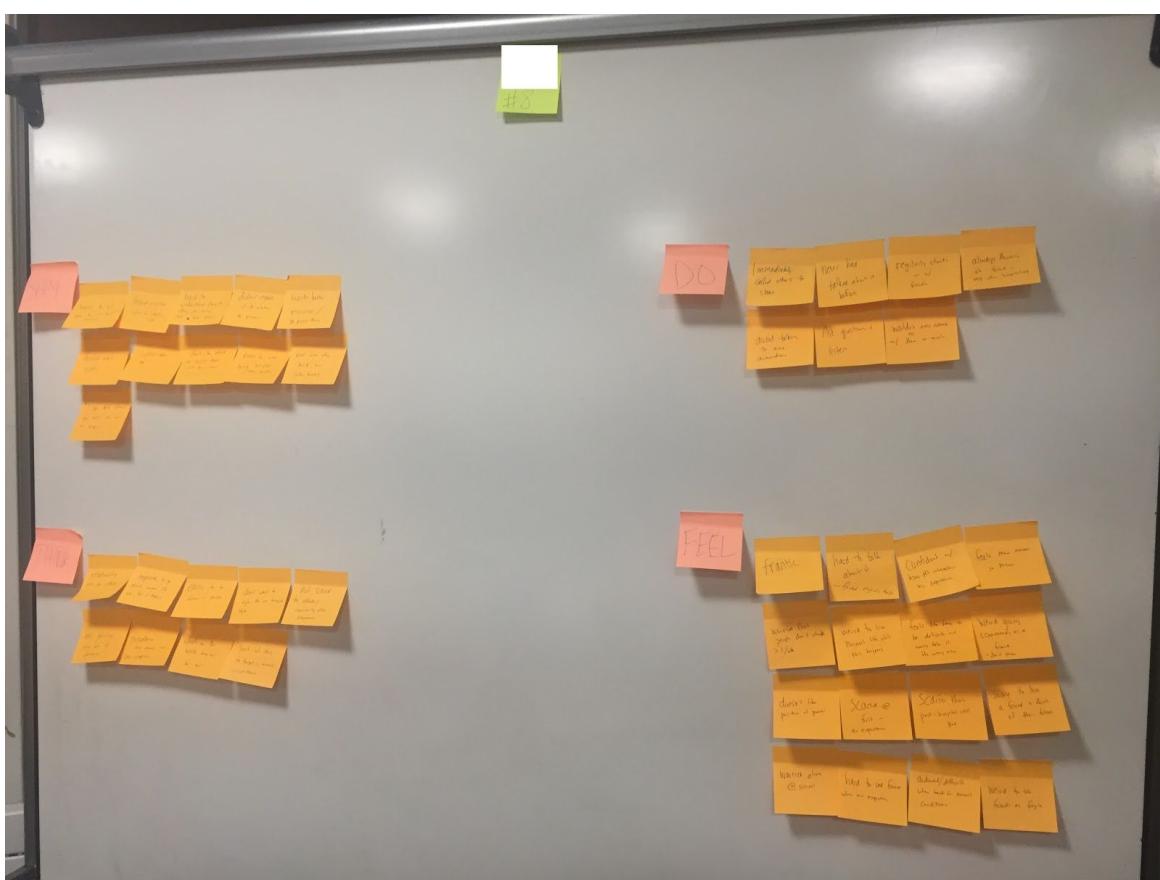
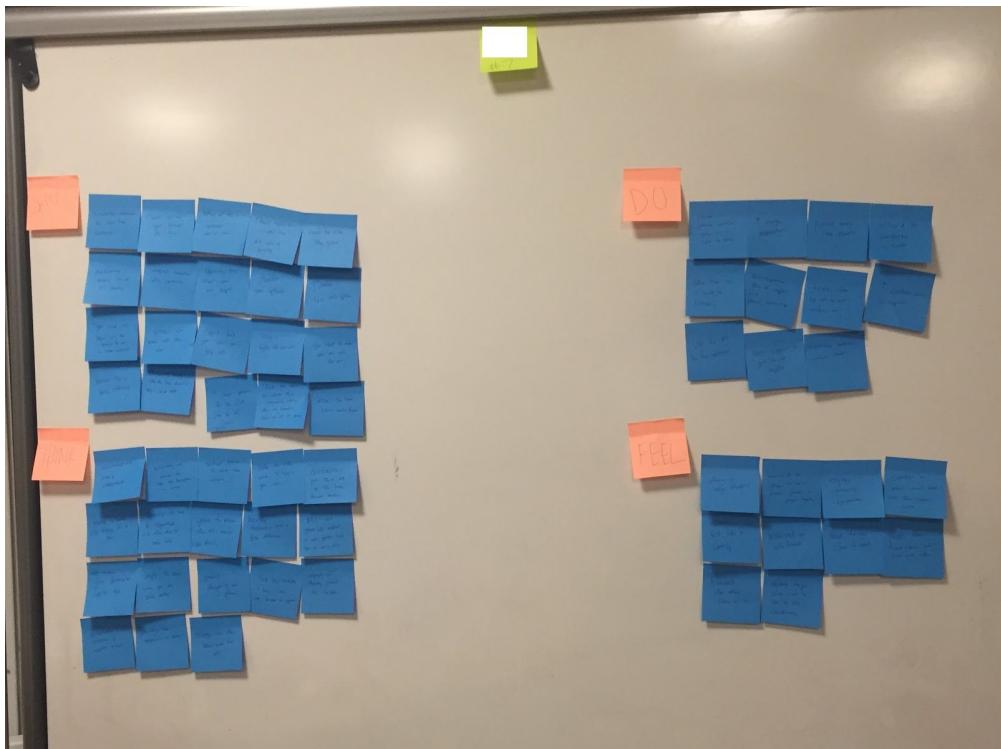
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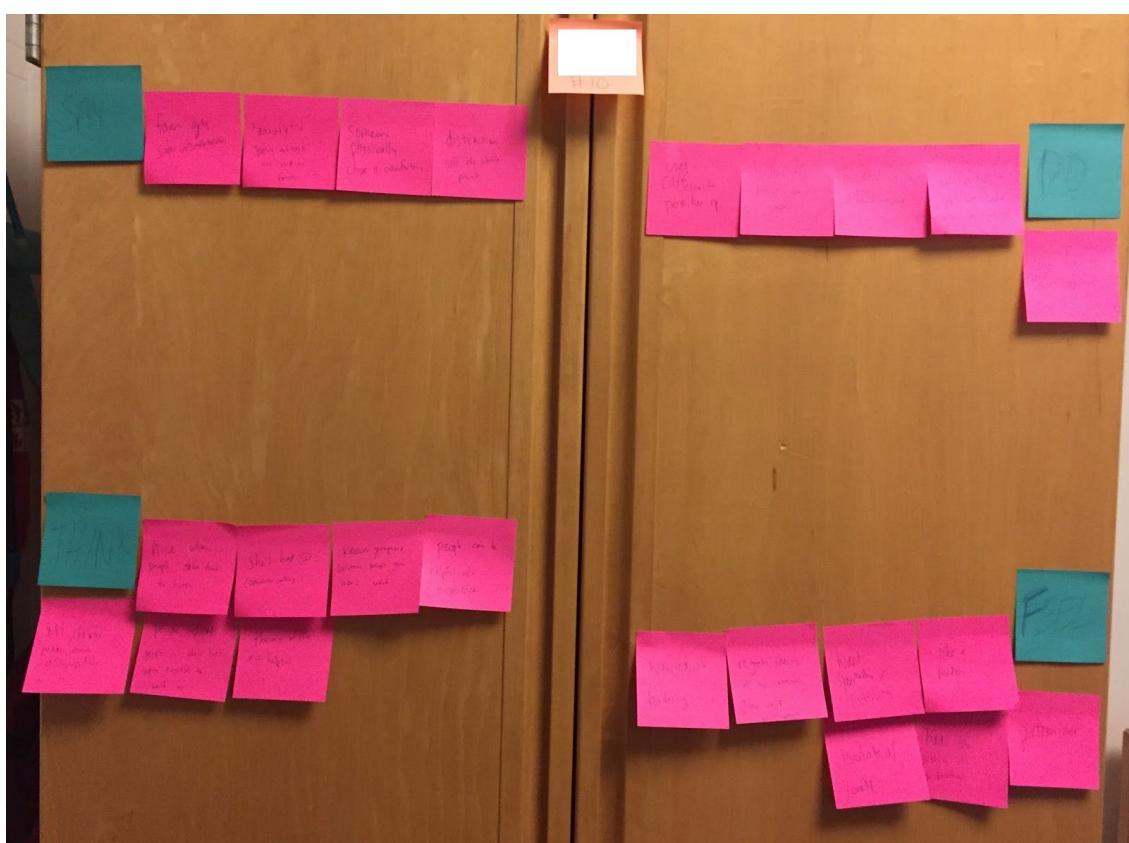


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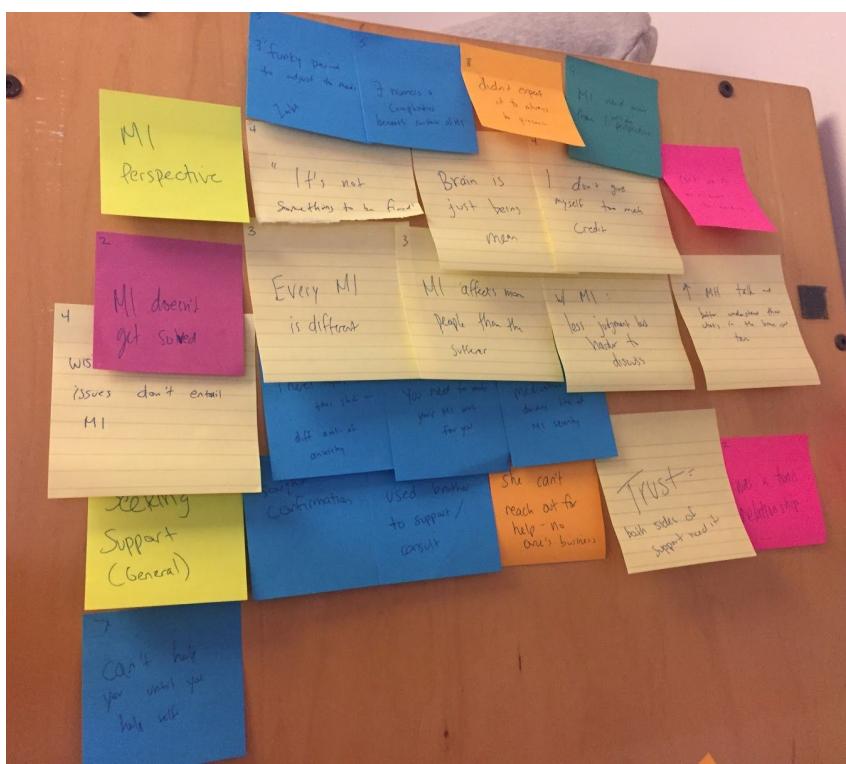
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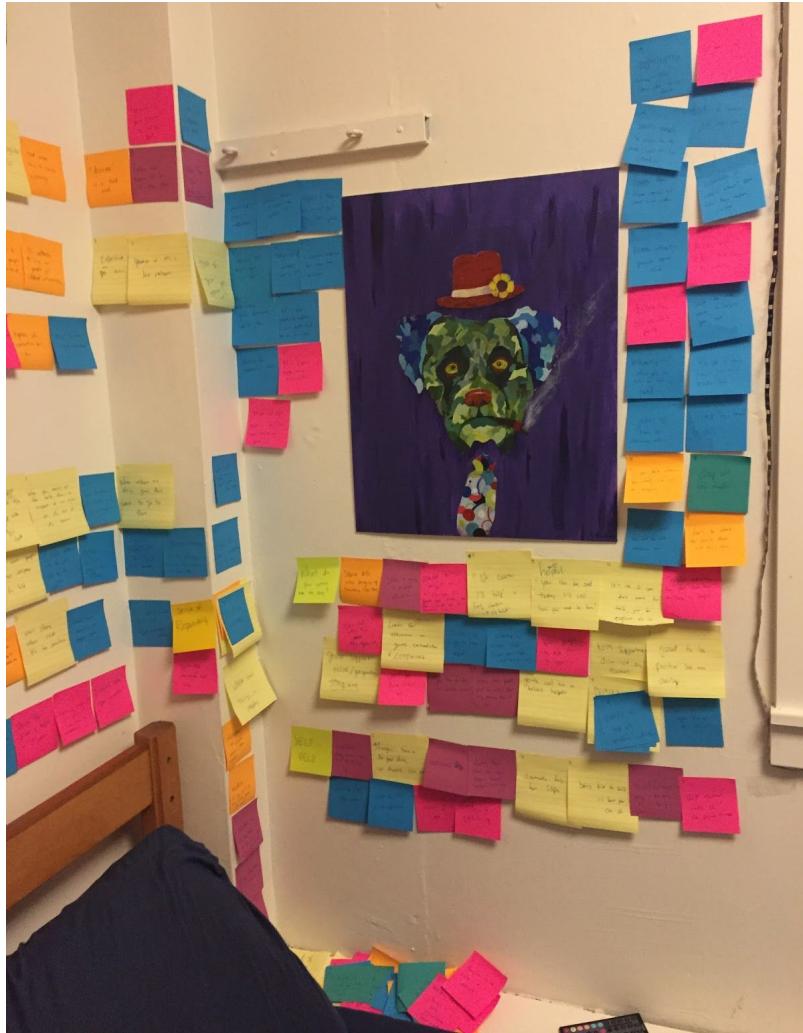




Converging data

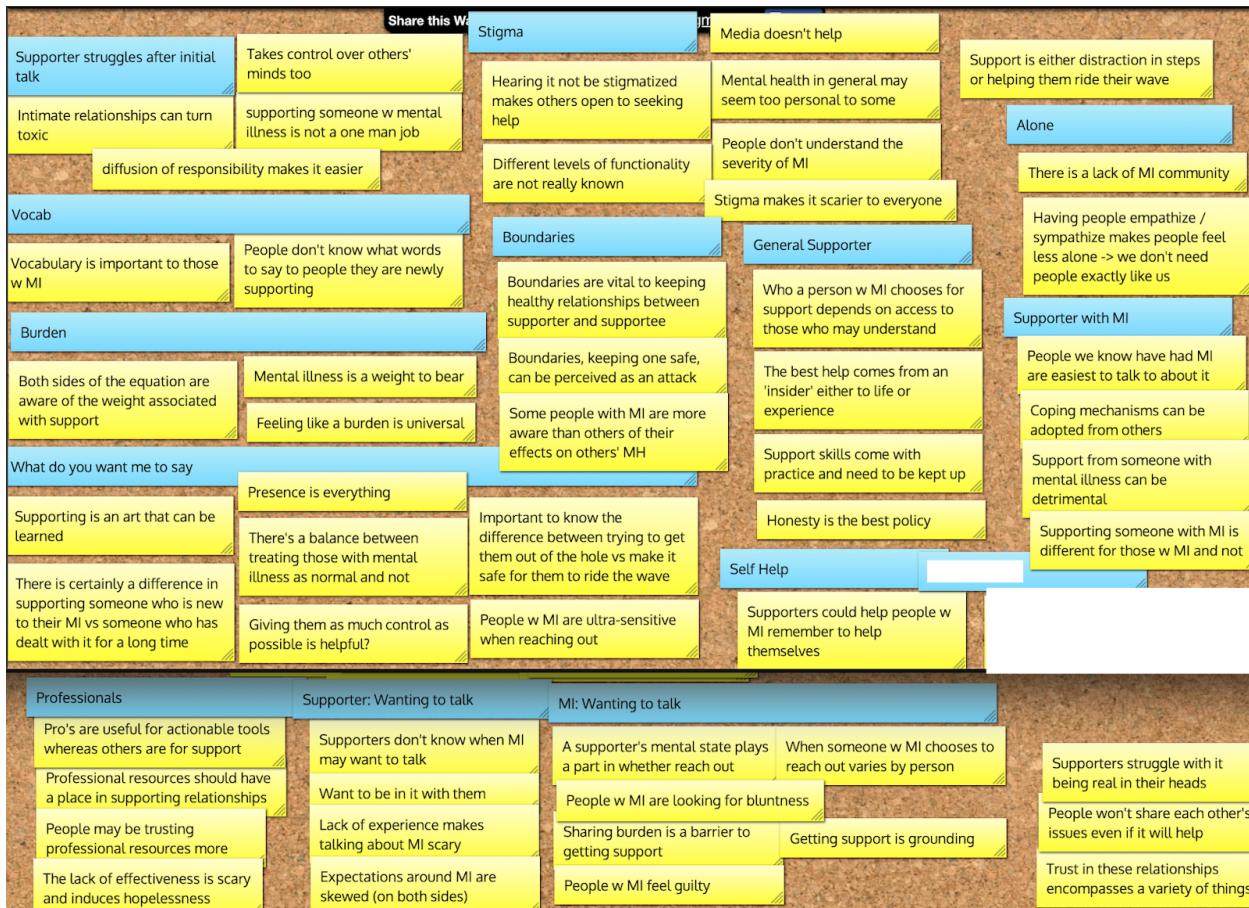
This was the most amount of user data I had ever dealt with, so it was certainly a learning process to condense this. Initially, I noted the contradictions, surprises, and tensions for the first two interviewees. After conducting more interviews and discovering many similarities and interesting differences, I decided to assess the data in aggregate. Once I completed all the interviews and their respective empathy maps, I clustered data points into various themes.



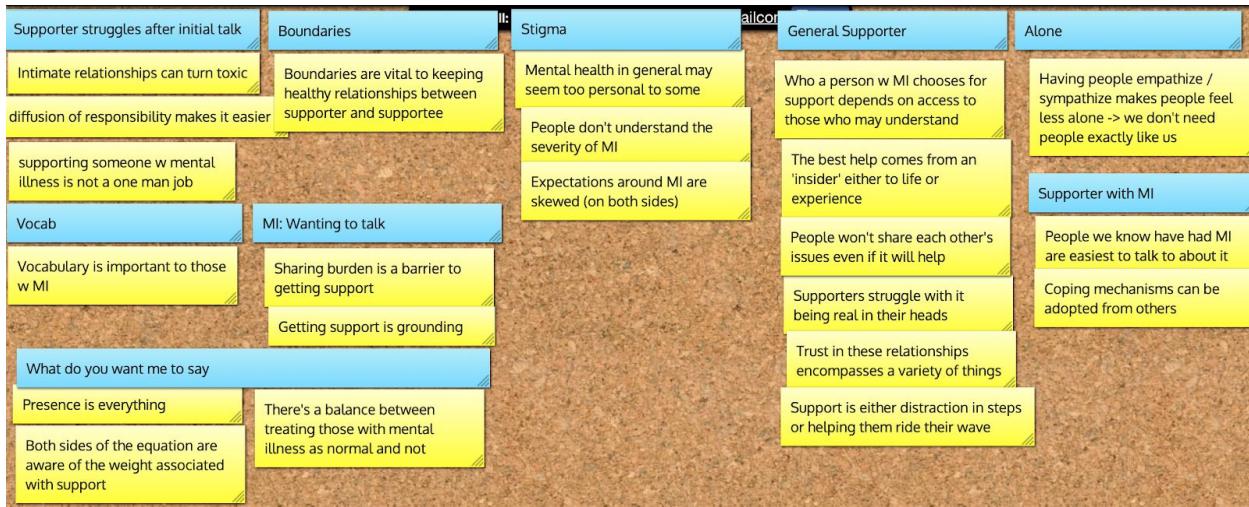


After clustering, I created a document with a variety of data that would be of interest to supporters and those looking to support or get support. This can be found [here](#).

Then, I converged this large amount of data to insights and key findings. I focused on each theme individually, then looked at the themes in relation to one another.



This still proved to be a lot of data, so I condensed this down further.



Key Findings

From here, I moved to picking out top findings:

1. Support is a mixture of carefully inducing distraction or helping them ride their wave.
2. A supporter is a window into reality for those with mental illness when they are lost in their minds.
3. People are afraid their emotions (or symptoms of their mental illness) will be judged or misunderstood as controllable.
4. Supporters can leverage the physical environment to help those with mental illness by moving them to a new location or offering touch. {finding}
5. Supporters feel responsible for others' mental wellbeing, especially when they are the sole supporter.
 - a. (comes from -> Expectations regarding regulating mental health and emotion are skewed for everyone. which comes from -> lack of education and stigma)
6. Who a person with mental illness chooses for support depends on access to those who may understand

Then, I separated these findings by user group.

Findings for the user group 'people emotionally supporting those with mental illness'

- Support is a mixture of carefully inducing distraction and helping them ride their wave.
- Supporters can leverage the physical environment to help those with mental illness by moving them to a new location or offering touch.
- Supporters feel responsible for others' mental wellbeing, especially when they are the sole supporter.

Findings for the user group 'people with mental illness'

- People are afraid their emotions (or symptoms of their mental illness) will be judged or misunderstood as controllable.
- Who a person with mental illness chooses for support depends on access to those who may understand
- A supporter is a window into reality for those with mental illness when they are lost in their minds.

Insights

This project focused on supporters, so the findings regarding people with mental illness can be used at a later point. To reach insights, I asked *why* multiple times for each finding.

1. Support is a mixture of carefully inducing distraction and helping them ride their wave.
Why? Only one of them is not enough | escape or making it more safe is the binary | this is all a supporter can really do to help | distraction is better than suffering and help with the wave makes you feel less alone

Why? There are different times for different types of intervention | | supporters can't solve the mental illness | during time of distraction, people could realize their MI isn't their whole life -> you know someone else cares about you

Why? Mental illness is complex | | mental illnesses are not curable, at least by outsiders and nonprofessionals | small things can give hope x2

2. Supporters can leverage the physical environment to help those with mental illness by moving them to a new location or offering touch.

Why? Physical intervention provides a rope back to reality | certain locations can trigger painful memories | locations can trigger memories of bad habits and self harm | new hope | moving and being touched makes us happier

Why? People with mental illness are locked into their own minds | that's how the brain works... || not attached to a new place so new place new me | getting up and moving releases endorphins, oxytocin with touch

Why? Definitionally || can be anything

3. Supporters feel responsible for others' mental wellbeing, especially when they are the sole supporter.

Why? They think they can save them | if something terrible happens and they knew, they would feel bad for not getting more immediate help | feel like they're expected to care for that person | people know they can affect others' emotional state

Why? Lack of education / they don't understand the severity | they don't know how severe is severe enough to require extra help / they're like witnesses feeling guilt that they possibly could have helped even if not true | culture and societal stereotypes - always can do better / stop at nothing to do something for someone you love | they've done it before

Why? Mental health education is not taught | just how guilt works? | that's love

I then pulled out the insights, and narrowed them down.

Insights:

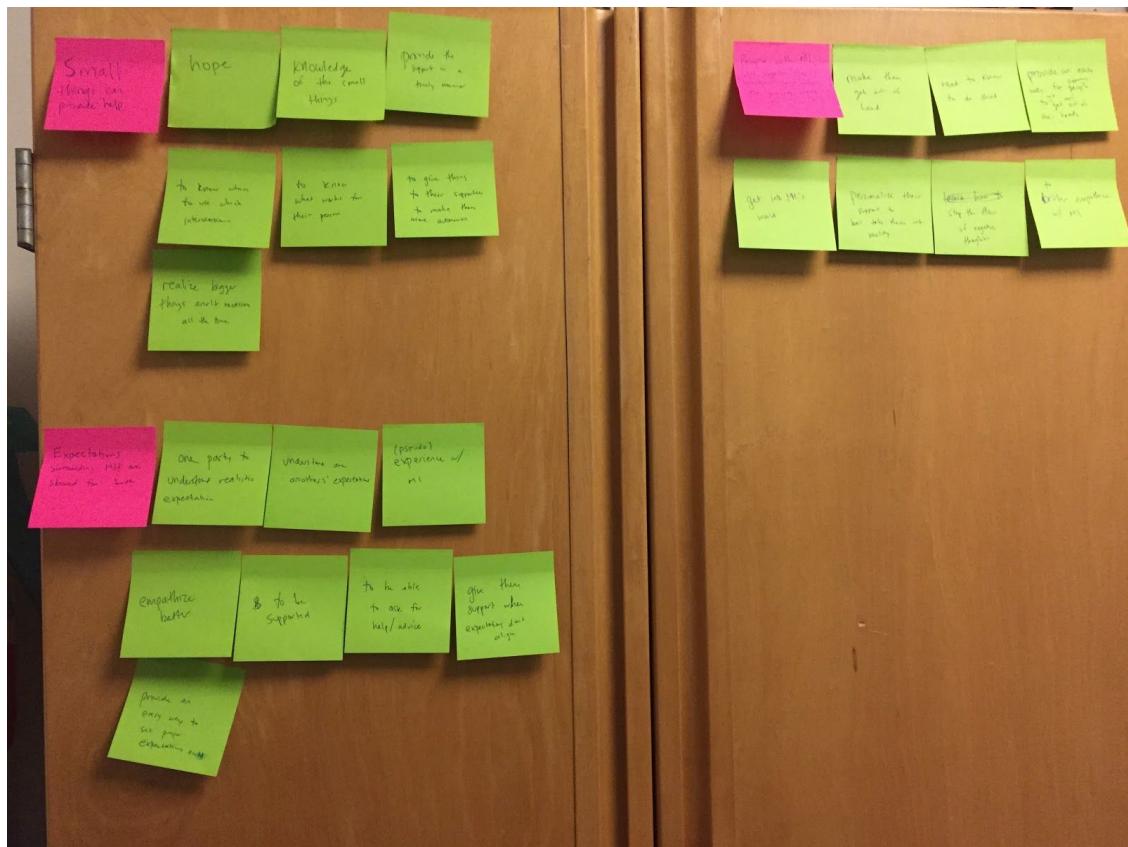
- ~~There are different times for different types of intervention~~
- **Small things can provide much needed hope** (distraction->life is more than their mental illness, riding the wave with someone else -> not alone, physical intervention -> jumpstart brain happier chemicals)
- **People with mental illness are locked into their own minds.**
- Getting out of the suffering spot gives sufferers a new perspective
- ~~Supporters struggle with understanding the severity of mental illness~~
- ~~We think we can affect others' mental states.~~
- **Expectations surrounding mental health are skewed for both the sufferer and the supporter.**
- ~~There exist social and cultural expectations that supporters will stop at nothing to help those they love.~~
- ~~Both sides understand the severity of the emotional toll on the supporter.~~

Top insights:

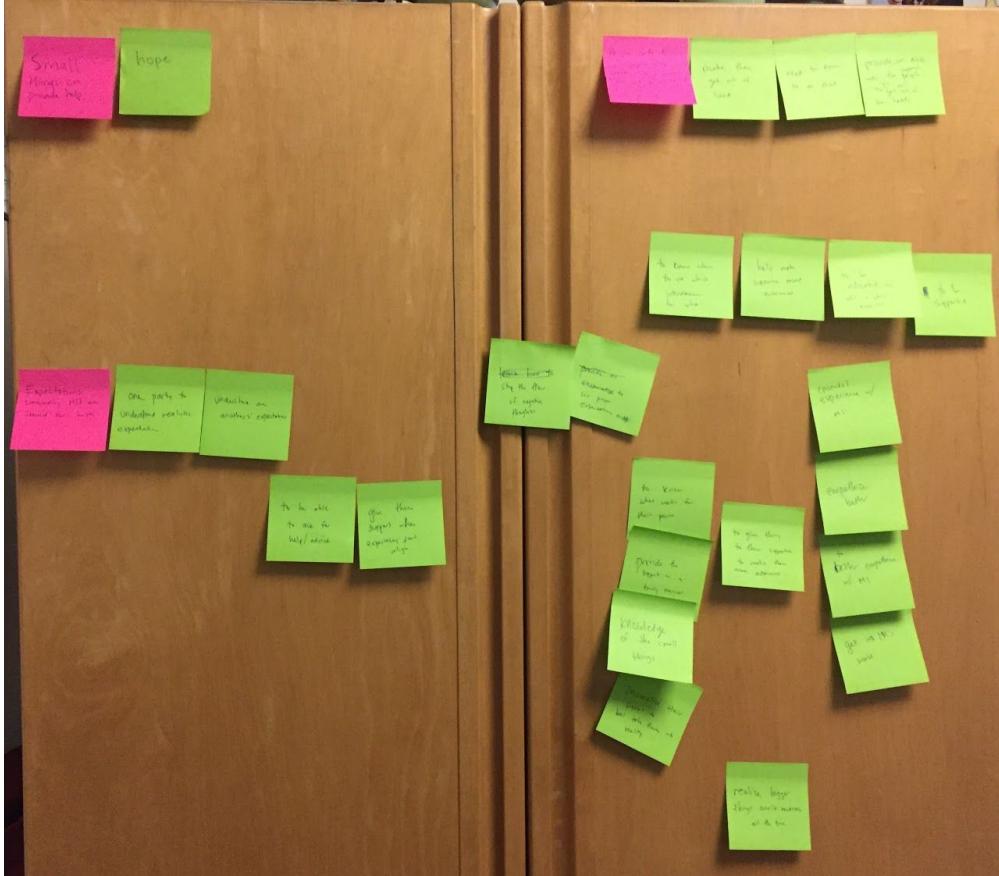
- Small things can provide hope.
- People with mental illness, when experiencing symptoms, are locked into their own minds and can't access the outside world.
- Expectations surrounding mental health are skewed for both the sufferer and the supporter.

Needs

From here, I determined supporter needs through brainstorming.



I narrowed these down as well.



Top needs:

- Supporters need to know when to use which interventions and for whom.
- Supporters need to help make their supportee more autonomous.
- Supporters need to be educated on mental illness and what is generally expected.
- Supporters need to be supported.

These needs can direct future developers to actual user needs instead of designing for what we may think users need. Next I will share the insights and needs in context using point of views.

Point of Views

- We met Julie, a college student with PTSD who freezes up and irrationally fears for her life. We were amazed to realize people with mental illness, when experiencing symptoms, are locked into their own minds and can't access the outside world. It would be gamechanging to have supporters know when to use which interventions and for whom.
- We met Jane, a college student with anxiety who benefits deeply from hugs and distracting adventures. We were amazed to realize small things supporters do can

provide hope to their supportees. It would be gamechanging to help supporters make their supportee more autonomous.

- We met Jordan, an ex-Googler whose family struggled to support her aunt who has bipolar disorder. We were amazed to realize expectations surrounding mental health are skewed for both the sufferer and the supporter. It would be gamechanging to educate supporters on mental illness and what is generally expected.
- We met Nick, a college student who was taken aback by his friend's diagnosis and relied on a group of friends for support. We were amazed to realize expectations surrounding mental health are skewed for both the sufferer and the supporter. It would be gamechanging to support supporters.

Concluding remarks

My hope is that these needs and point of views can be used to reassess the mental healthcare space, and provide supporters with the help they deserve. Supporters are a largely neglected part of the mental healthcare space, yet carry a large burden. With streamlined goals for this user group, proper solutions are possible.

This project was completed independently under the direction of Affect Mental Health. I used the Stanford d.school process to find needs for a user group. I would like to thank Samira Daswani, Katie Neville, and Eric Singh for their collaboration. Please feel free to reach out for more or clearer photos of the process, or with any questions.