

Change-Making: Designing Empathetic & Quality Care for Neurodiverse Patients

Change-Making

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creating change

creating change



Human-centered health design and design thinking are approaches that rely on different strategies and tools to facilitate change in healthcare. Key to achieving change is identifying and addressing areas where the needs of users, such as patients, are not being met. For change to be truly successful, design solutions must reflect an awareness that users are diverse groups.

For example, patients are users with different backgrounds, needs, and challenges. One difference that distinguishes patients is neurodiversity. The concept is used to refer to the different ways that people's brains work, but is also associated with conditions like autism, ADHD, and learning differences. Estimates are that neurodiverse individuals make up approximately 15% of the population. While neurodiverse individuals are not a monolith, many delay health appointments because of feelings of anxiety in health settings. Waiting rooms are frequently pointed to as particularly anxiety-provoking.

In the pages that follow, I explore how human-centered health design and design thinking can be used to create designs solutions for waiting rooms that mitigate patient anxiety and offer a blueprint for designing other neuroinclusive health environments.

Introduction

03

Neurodiversity

Neurodiversity embraces the inherent variations in brain function among all individuals and acknowledges that people perceive and engage with the world in diverse ways. It is not uncommon for neurodivergent individuals to have difficulties processing their environments, including health environments. They are particularly vulnerable to different sensory stimuli that are part of the healthcare landscape: light, noises, smells, and temperature. Neurodivergent patients may also feel overwhelmed by unfamiliar or uncomfortable social interactions, including interacting with staff or sitting next to a stranger in a waiting area. While these sensory and social factors may have only a minor effect on neurotypical patients, they can incapacitate neurodiverse patients and create significant barriers for health access.

A neurodiversity-oriented approach to healthcare entails contemplating how healthcare systems can strategize to promote access to care and treatment. One of the most impactful avenues for improving health access, in addition to enhancing healthcare experiences, is the redesigning of healthcare environments, like the waiting room.

opportunity area



Opportunity Area

OPPORTUNITY AREA

How Might We?

How might we create waiting room designs that reduce anxiety experienced by neurodiverse patients?

04

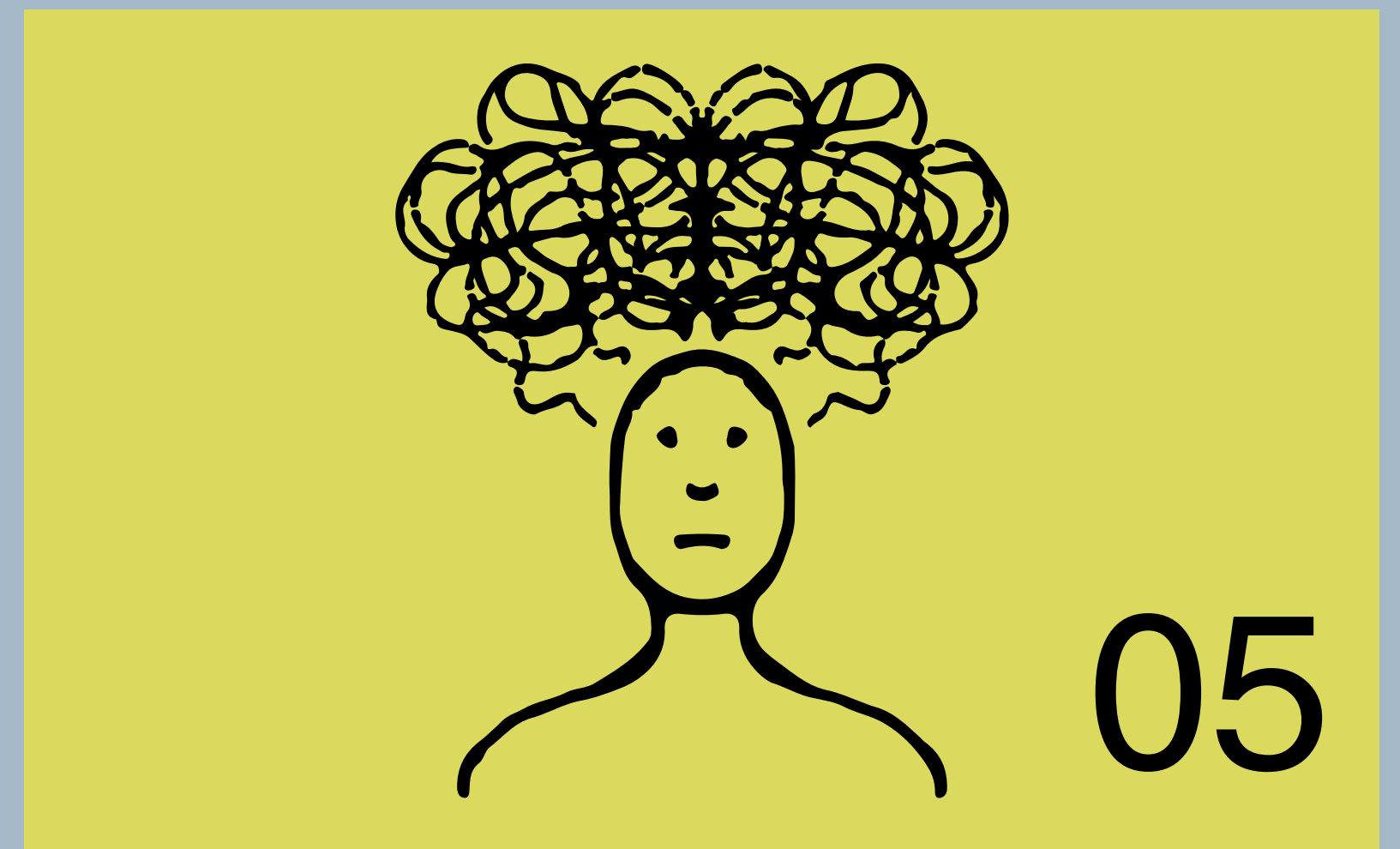
Understanding the Problem

01 neurodiversity and healthcare

02 chronic health issues

03 quality of care

05 support and information

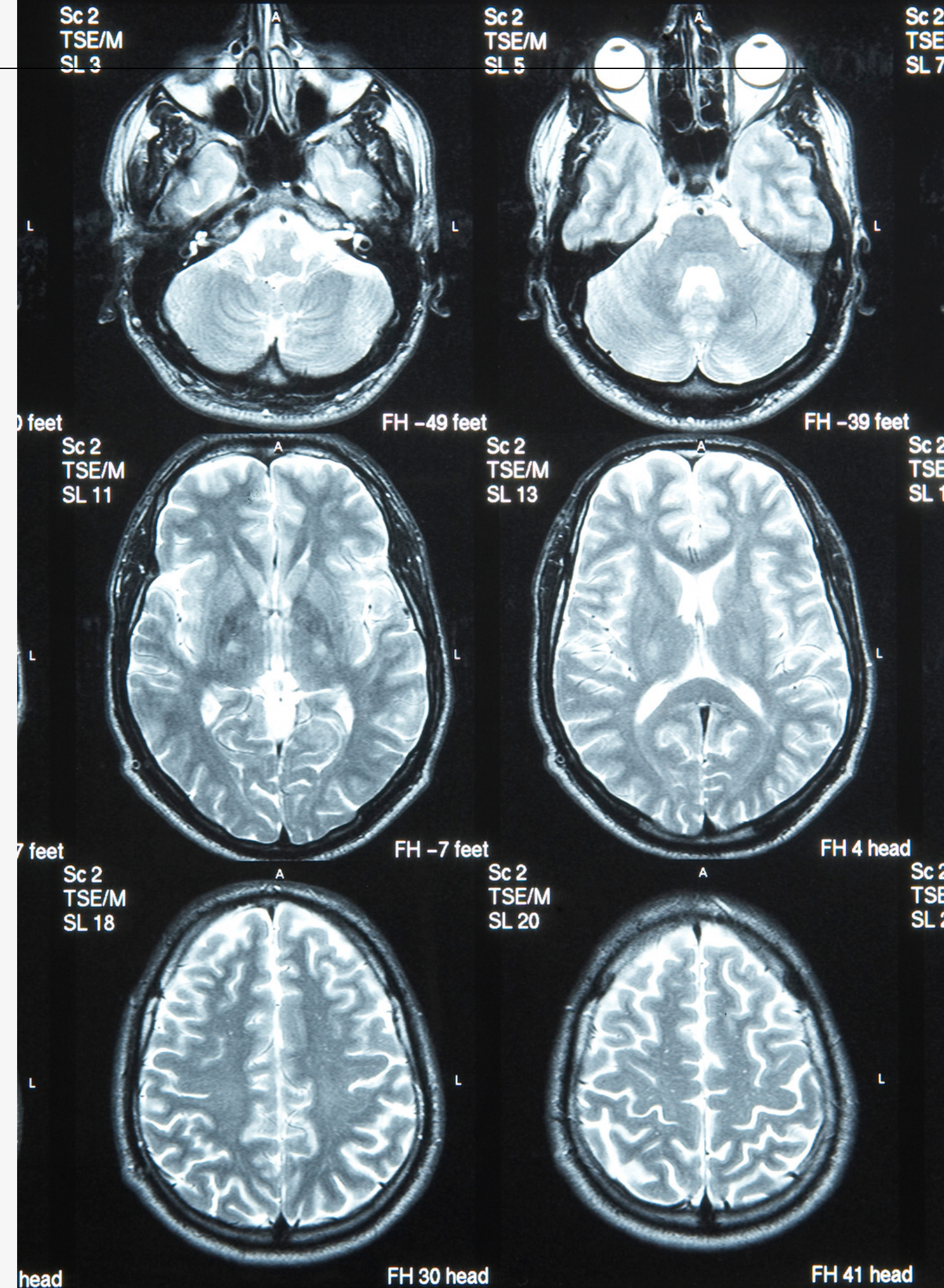


KEY ISSUES

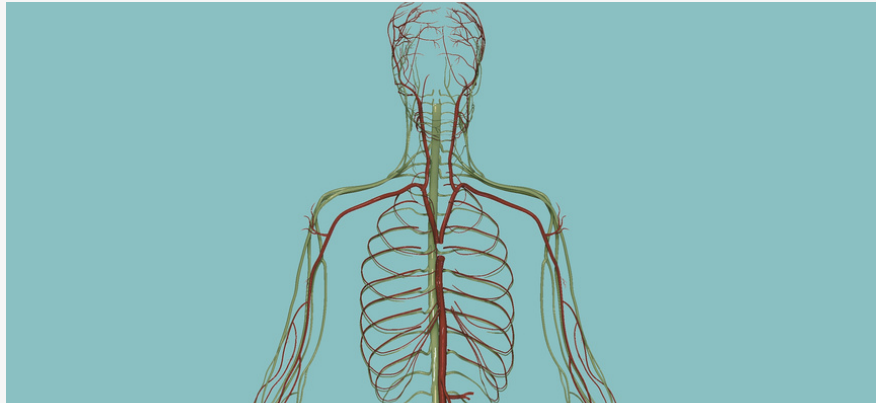
Neurodiversity & Healthcare

NEURODIVERSITY AND HEALTHCARE

06

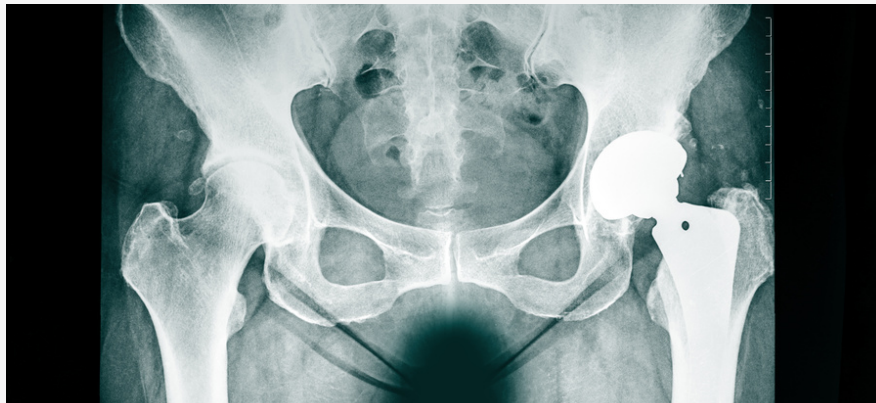


chronic health issues



01

Neurodiverse individuals have higher rates of chronic health issues than the general population.



02

Neurodivergence, especially autism, is linked to concurrent physical health issues, increasing the risk of pain and hypermobility.

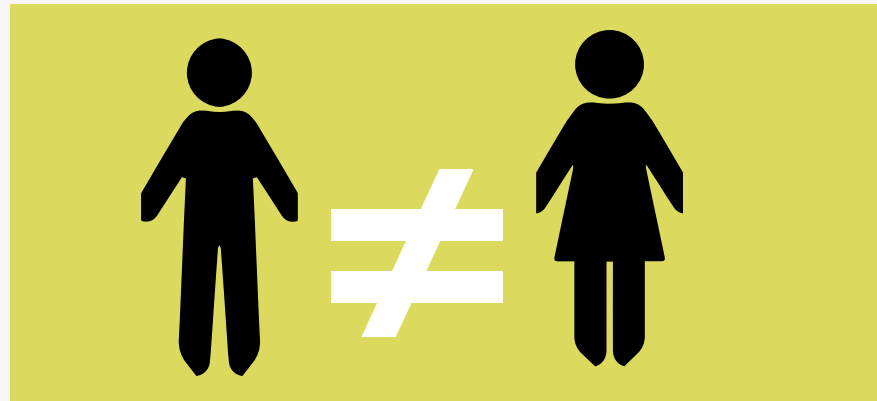


03

These conditions are often missed; getting a formal diagnosis is crucial for proper treatment and care.

chronic health issues

quality of care



01

Neurodiverse individuals often experience unequal care due to lack of understanding of their needs, including communication differences, and feelings of being overwhelmed.



02

Quality care encompasses safety; unequal treatment exposes neurodiverse patients to risks and injuries by healthcare professionals.

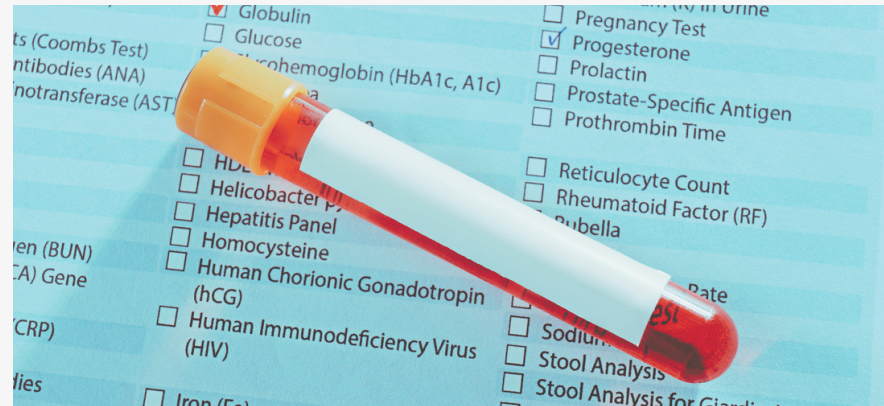


03

Timely, efficient care is essential for positive health outcomes. Neurodiverse patients often delay appointments due to feeling dismissed or mistreated because of provider bias.

quality of care

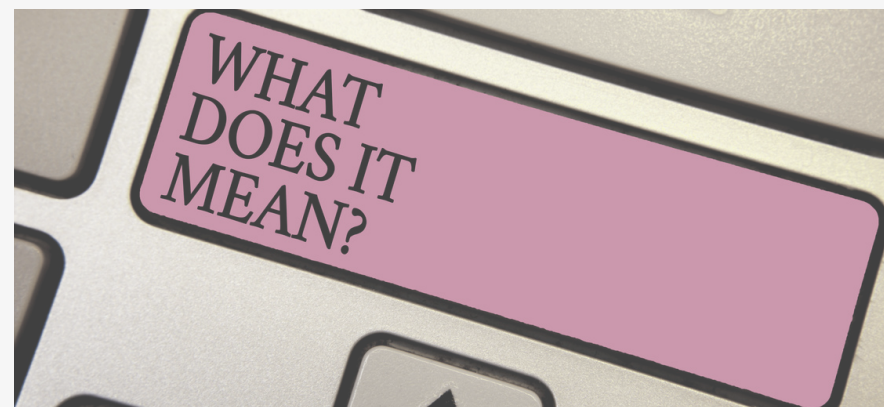
support and information



01

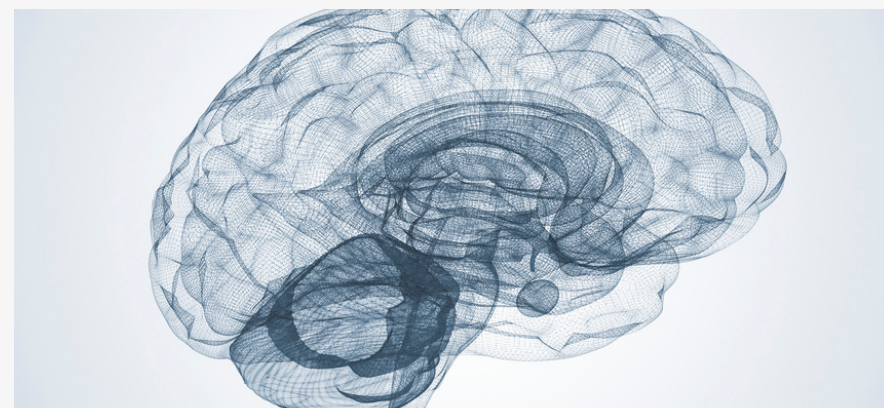
Neurodiverse patients often report feeling uncertain about what to do post-diagnosis.

support & information



02

Many neurodiverse individuals struggle processing medical information that is rapidly presented by their health provider.



03

The relative absence neurodiverse individuals in healthcare settings can hinder efforts to improve their access to support and information.

design lens

applying a design lens

10

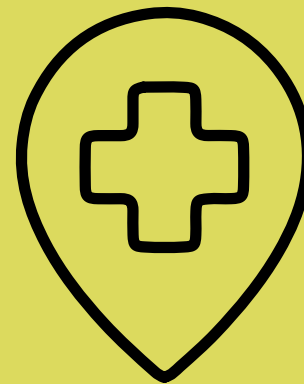
tiers of influence

01



the patient

02



direct influencers

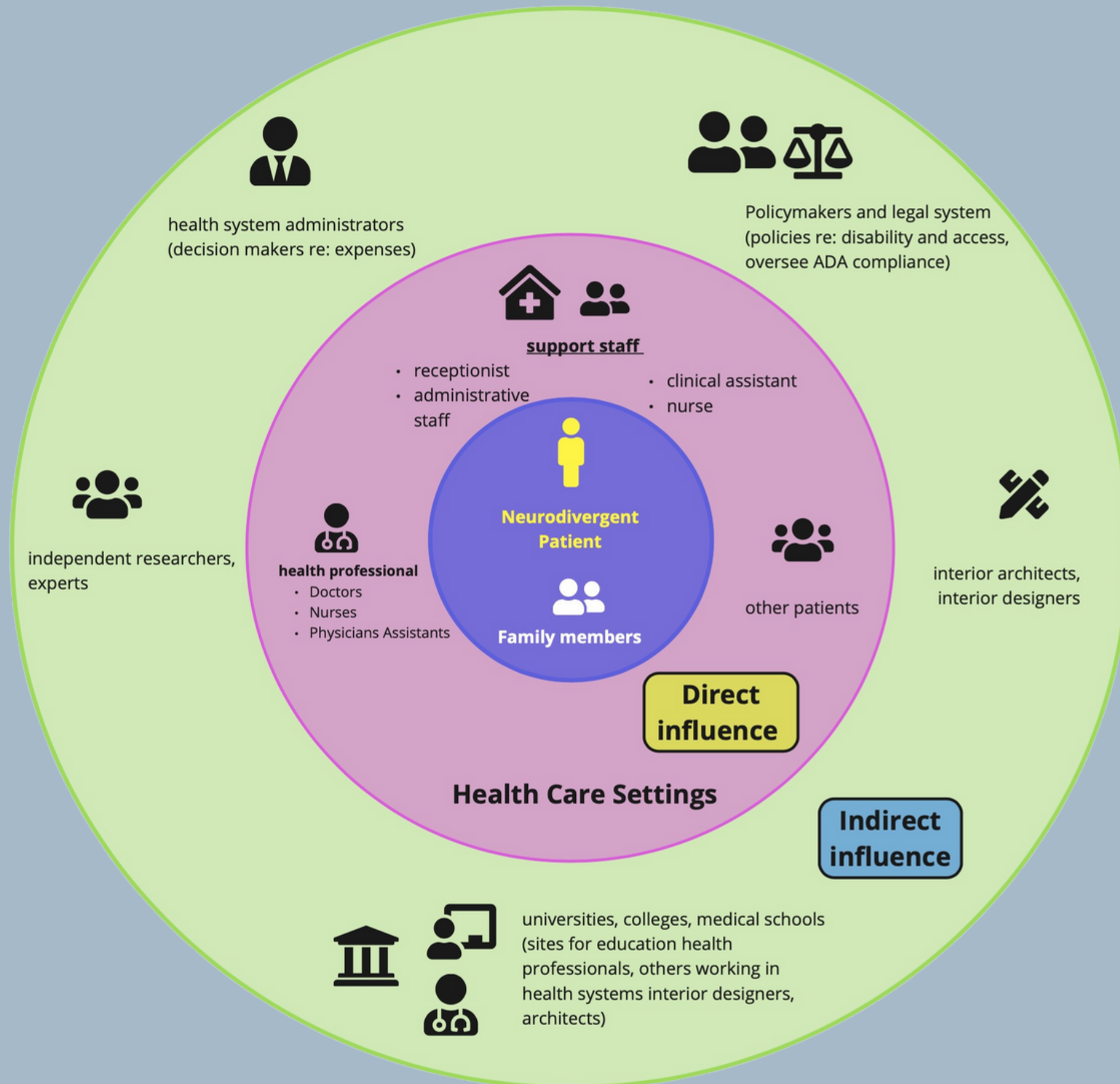
03



indirect influencers

Stakeholder mapping is a valuable tool for understanding and visually representing the various individuals and entities within the healthcare ecosystem, including those with direct influence and those with indirect influence on a neurodiverse patient.

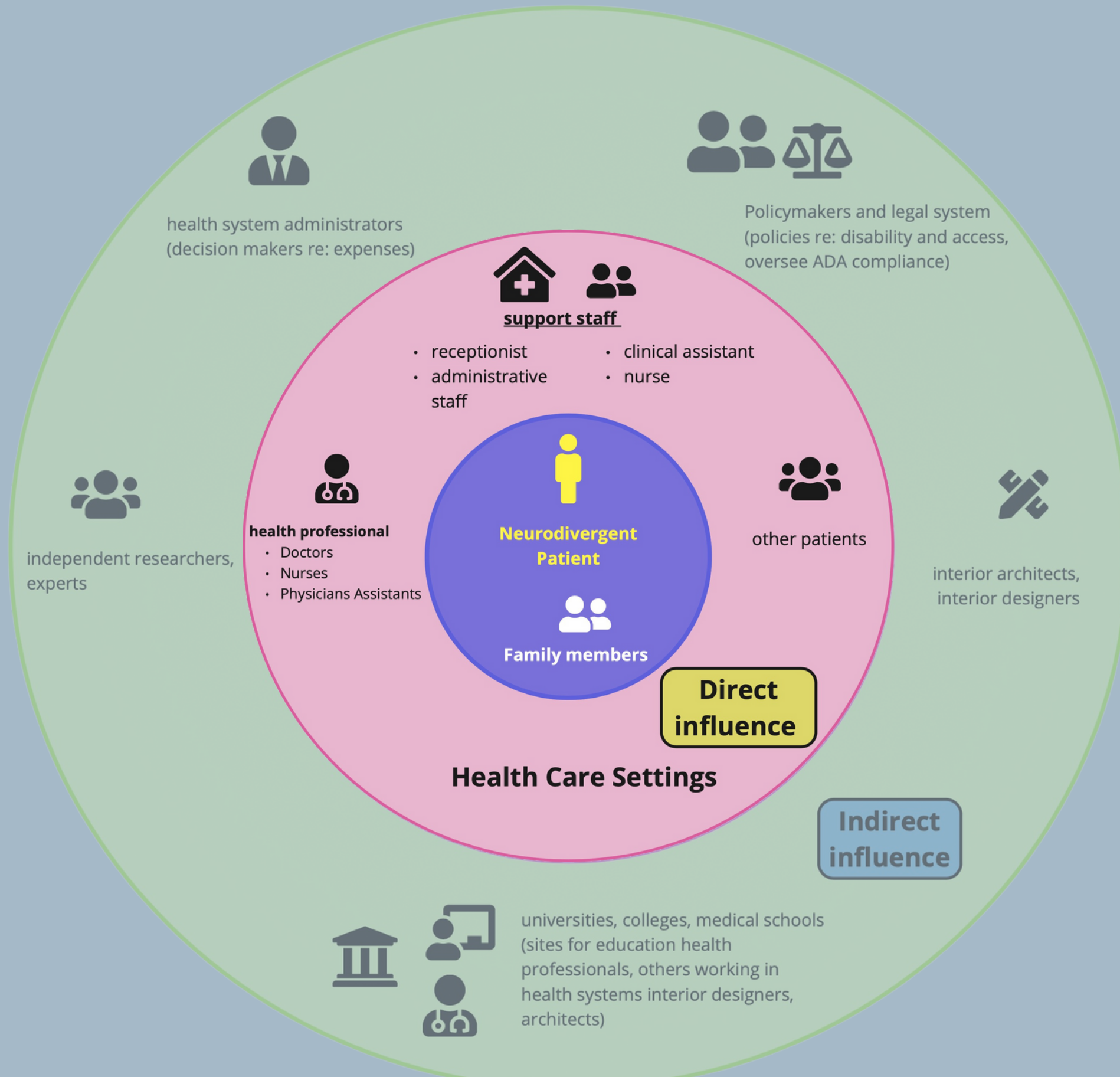
indirect stakeholders



This stakeholder map provides a visual representation of the neurodivergent patient's position in the broader healthcare ecosystem, specifically focusing on their experience in the waiting area. In the outer ring of stakeholders, we find those who exert indirect influence on this experience. This group includes health system administrators, policymakers, legal professionals, independent researchers, experts, universities, medical schools, as well as architects and designers.

While these stakeholders may not have direct interactions with patients in the waiting area, they play pivotal roles in shaping the environment and practices within it. They influence compliance with healthcare regulations, allocate funding, establish educational standards, and make technical decisions, all of which collectively impact the overall waiting room experience for neurodivergent patients.

direct stakeholders



The inner ring of the stakeholder map highlights those who have a direct influence on the neurodivergent patient's experience within the waiting room. These individuals are likely to engage in face-to-face interactions with the patient during their time in the health facility. Support staff, for example, play a crucial role in assisting with tasks such as patient registration and orientation upon arrival. Health professionals may guide patients into examination areas, and the presence of other patients in the waiting area can also impact the patient's experience.

In-person interactions within waiting areas can trigger anxiety for neurodivergent patients, often for various reasons. This includes challenges in conforming to neurotypical communication norms and the necessity of sitting in close proximity to other patients. Given their heightened sensitivity to sensory stimuli, neurodivergent patients may experience discomfort in the presence of others due to sensitivities to sounds and scents, which can compound their existing social interaction challenges and contribute to feelings of unease in healthcare settings.

gaining insight

gaining insight

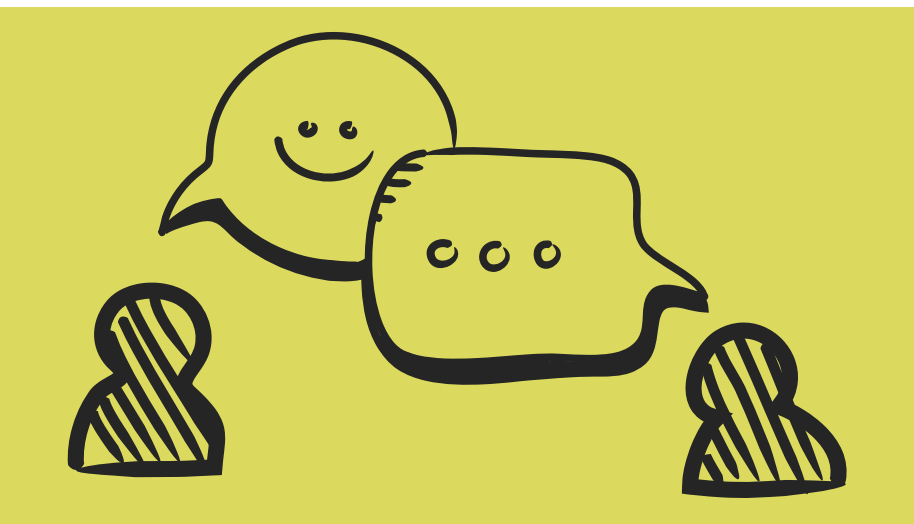
14



There are several effective approaches to gain a deeper understanding of unmet needs among neurodiverse patients. One key method involves conducting interviews to gain insights from their unique perspective.

Various strategies can be used to ideate opportunity areas based on the data collected during interviews. These opportunity areas can ultimately serve as the foundation for developing design ideas.

When we create opportunities to listen to the ***perspectives and experiences*** of neurodiverse patients we can begin to identify where there are opportunities for solutions. Here are some examples of interview questions I used:



Question 01

“Tell me about the most challenging part/s about being in the waiting room before a medical appointment”

Question 02

“How do you typically feel in these situations?”

Question 03

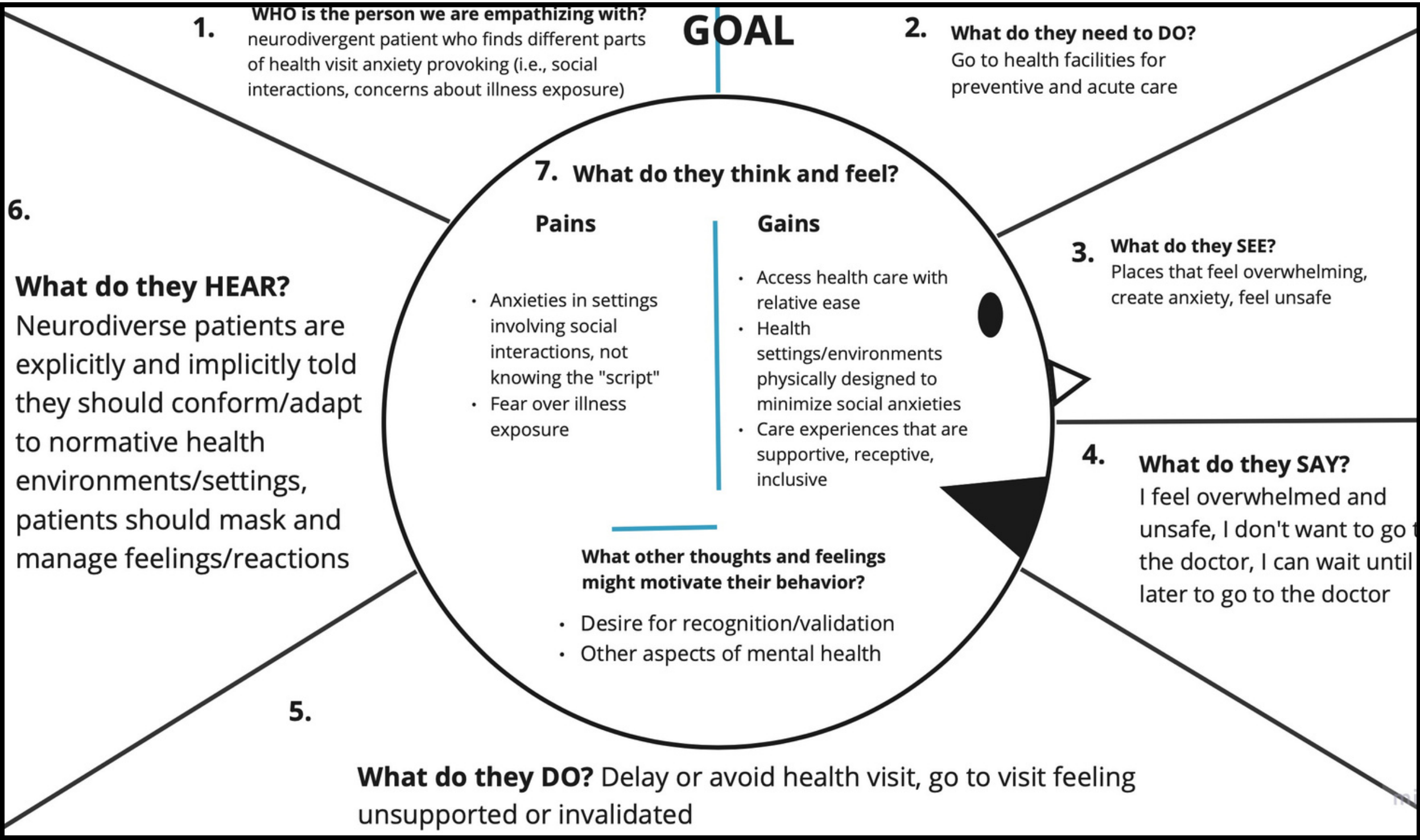
“How often do you go for medical visits?”

Question 04

“How would you compare your experience in the waiting room to other parts of your medical appointments?”

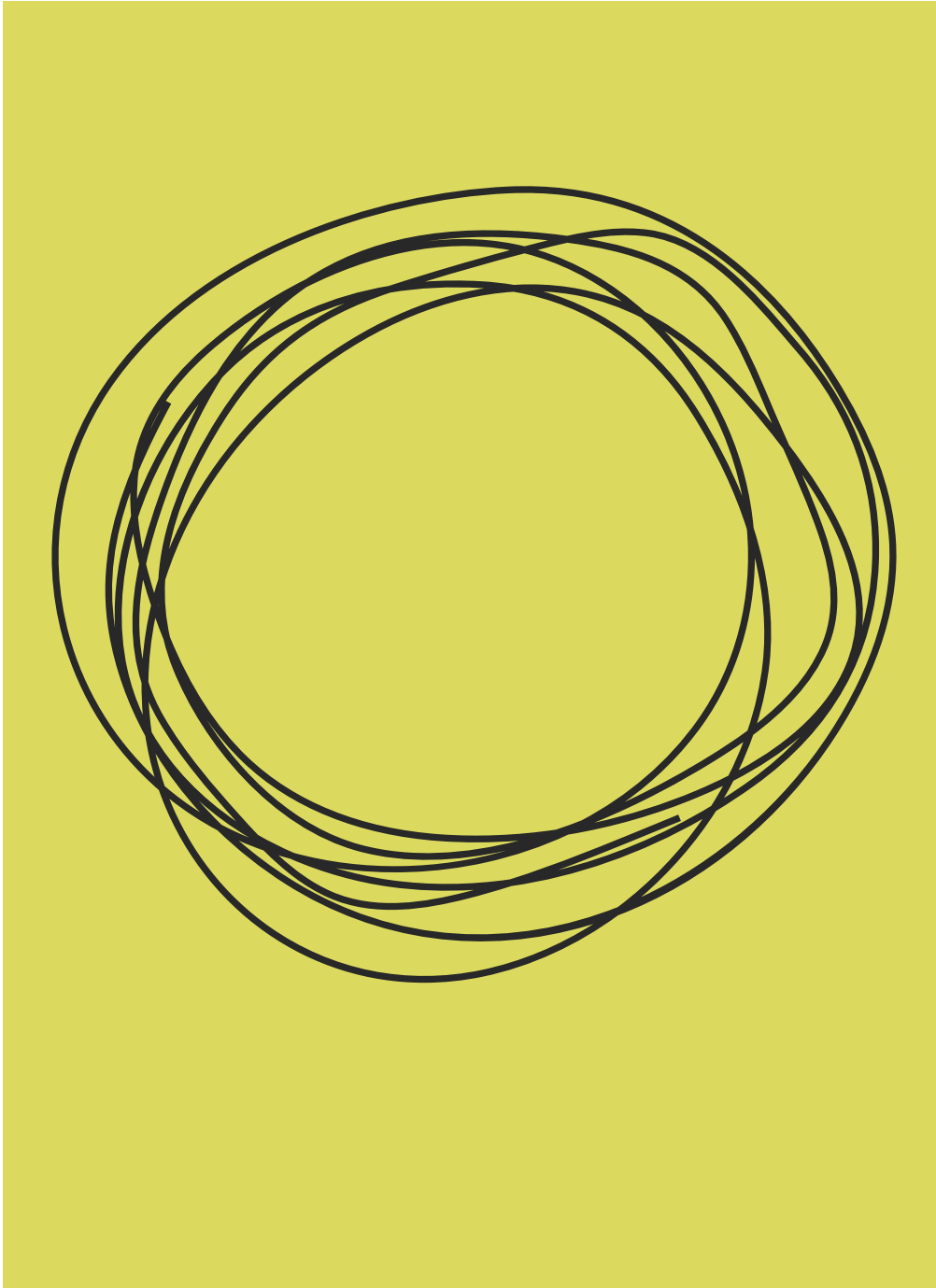
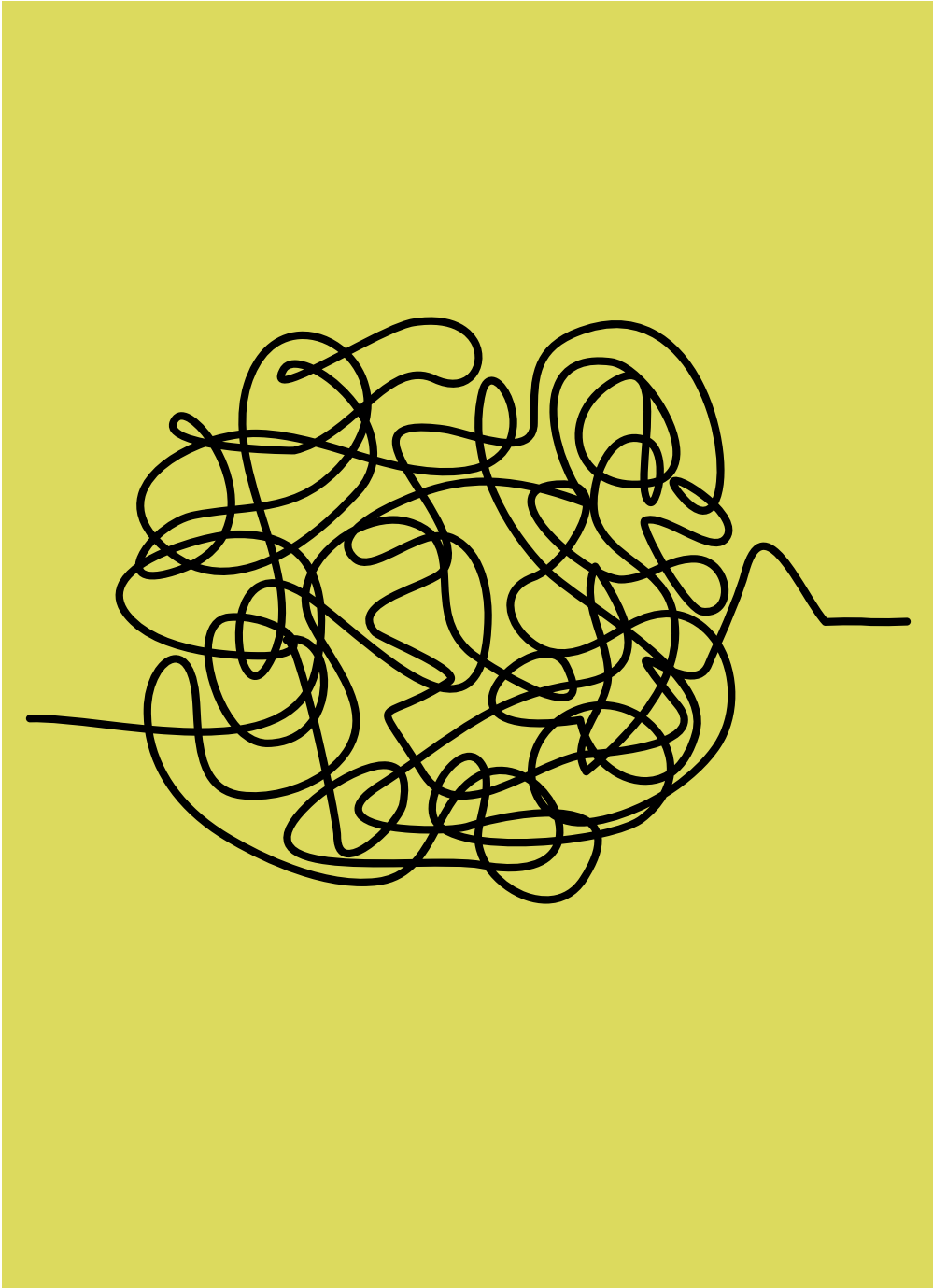
interviewing

empathy mapping














This empathy map is based on interview responses from a neurodiverse patient who shared their experience of feeling anxiety in medical waiting rooms. Their responses immerse us in their perspective, enabling us to envision the various factors that trigger their anxiety both in anticipation of a medical appointment and upon arrival. By gaining insight into the underlying causes of their emotions, aspirations, and motivations, we can begin to identify opportunities to address their unique needs.

from ideas to concepts



IDEATION: How might we reduce anxiety experienced by neurodiverse patients in waiting rooms?

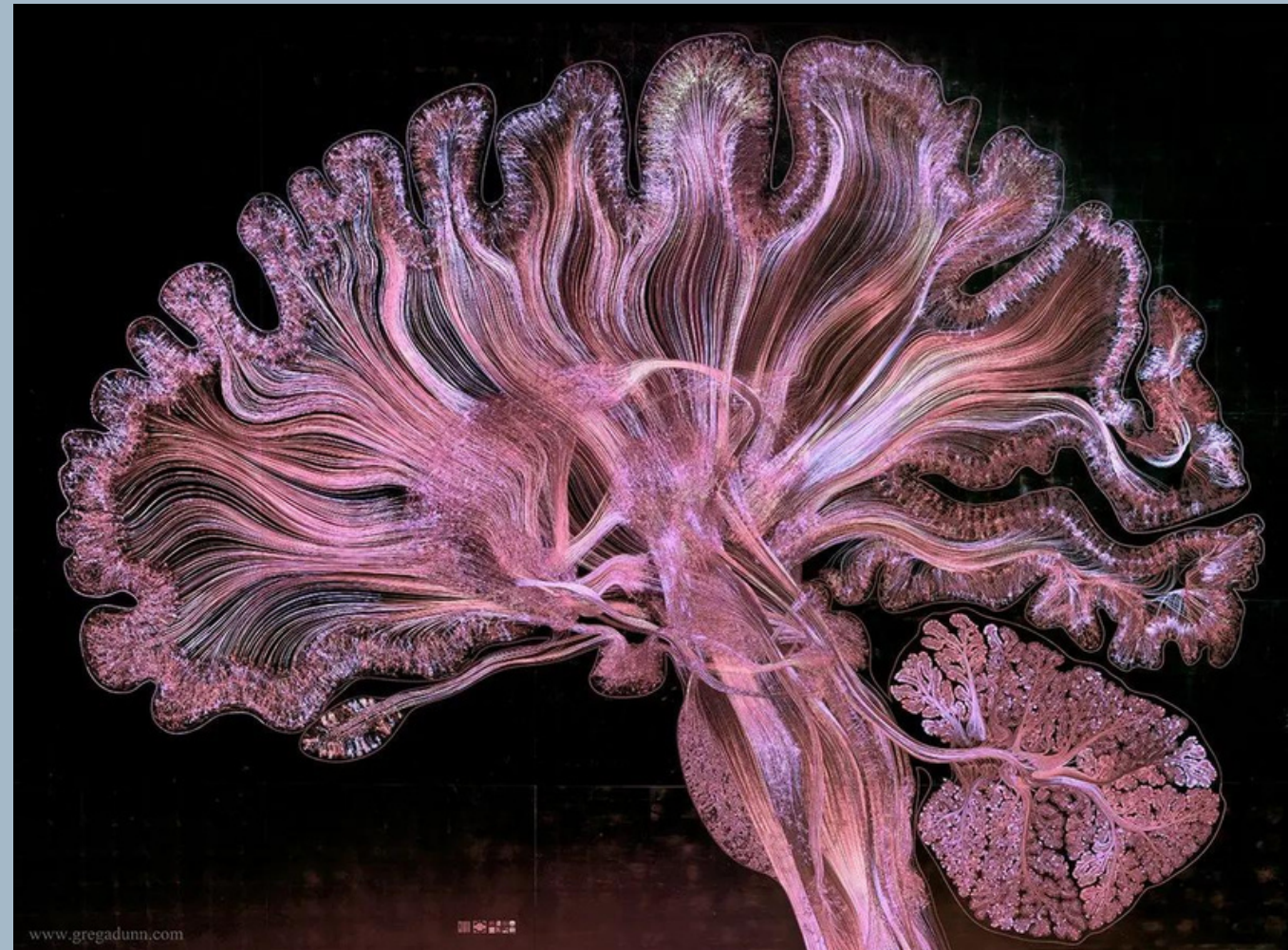
idea 1	idea 2	idea 3	idea 4	idea 5	idea 6	idea 7	idea 8	idea 9	idea 10	idea 11
<p>create separate low sensory waiting areas</p> 	<p>provide tools and resources to mitigate stress/anxiety (i.e., light, noise canceling headphones, etc)</p> 	<p>offer dedicated time blocks only for neurodiverse individuals during the week</p> 	<p>Offer low stress way to enter waiting areas, including alternate entryway or self-check in</p> 	<p>Design waiting areas with adaptive features (including furniture that can easily be moved, lights that can be adjusted and that are not harsh)</p> 	<p>Hire neurodiverse staff</p> 	<p>emphasize training for staff and health providers on neurodiversity (including on implicit bias and healthcare challenges neurodiverse individuals face)</p> 	<p>Communicate with patients in advance to tell what to expect</p> 	<p>Have designated staff available to help patients</p> 	<p>Survey patients to find out their preferences</p> 	<p>test different combinations of these ideas to find which is most desirable</p> 

The figure above shows some proposed design ideas based on the original challenge: ***how might we reduce anxiety experienced by neurodiverse patients in waiting rooms?***

The proposed ideas are based on insights from interview data and various ideation strategies. Some are directed at enhancing the waiting area itself, while others concentrate on staff recruitment, training, and responsibilities. There are additional suggestions aimed at providing support to patients before they enter the waiting room. Some ideas are centered around improving communication with patients and providing avenues for collecting valuable feedback from them.

ideation

stories of change



credit: "Self Reflected," Greg Dunn

Design ideas form the basis of design concepts and a stories of change. These are the stories that help us build on opportunity areas and allows us to see a neurodiverse patient having an improved health experience.

stories of change

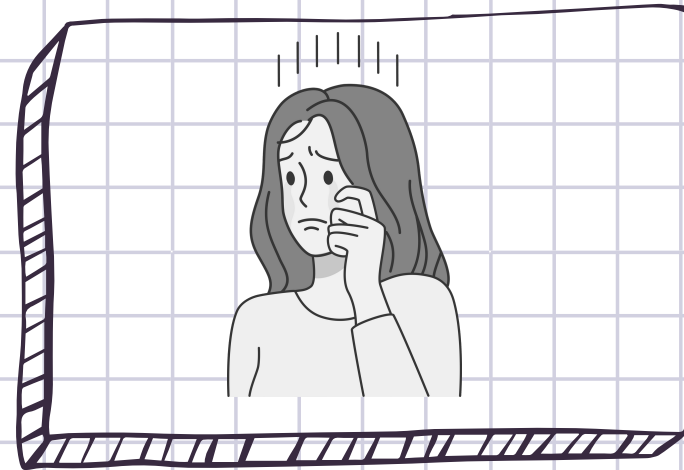
a new story for neurodiverse patients

An updated solution will integrate a number of the design ideas to create a redesigned waiting room experience focused on prioritizing the comfort of neurodiverse patients before they reach a health facility. These updates change the script, or story, of the waiting room experience.

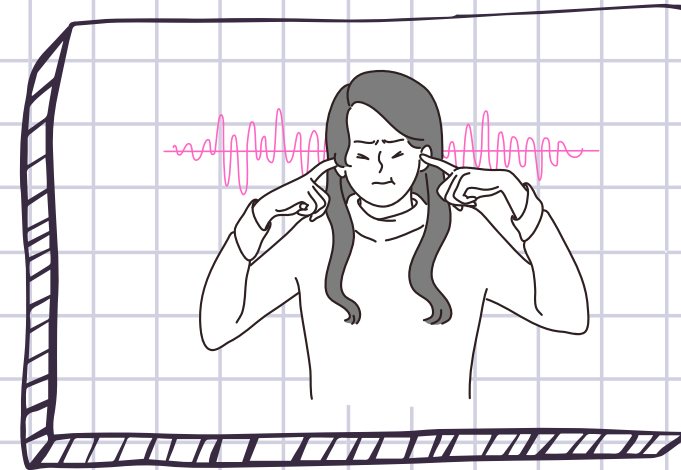
Story of Change: *Neurodiverse individuals often avoid medical appointments due to the overwhelming nature of healthcare settings and the lack of necessary support. The presence of multiple sensory stimuli, particularly in waiting areas, exacerbates their anxiety. What if healthcare systems reimaged the waiting room as an experience, ensuring that patients are welcomed and informed from the moment they step into a healthcare facility? By prioritizing the comfort and well-being of neurodiverse patients before they even reach the waiting area, healthcare systems can significantly enhance access to care and improve health outcomes. Imagine a visual contrast: one side depicts a neurodiverse patient overwhelmed in a typical waiting area, while the other portrays a neurodiverse patient accessing this redesigned waiting area experience. In the latter scenario, the patient remains calm and composed, thanks to advance notifications, supportive staff, a low-sensory waiting environment, and the assurance that their health concerns are valued and understood.*

The story of change as a storyboard

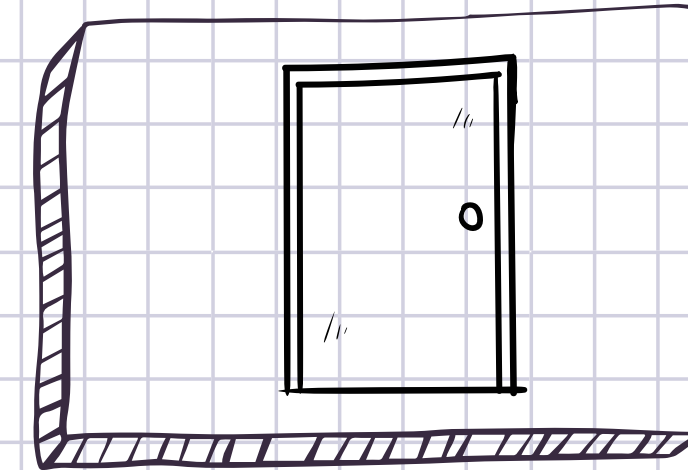
This format offers the opportunity to visually depict the story



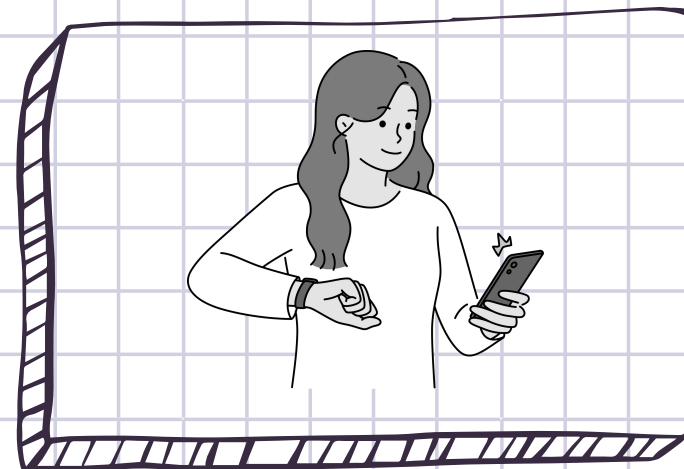
1 Neurodiverse individuals often avoid health appointments because healthcare settings feel overwhelming



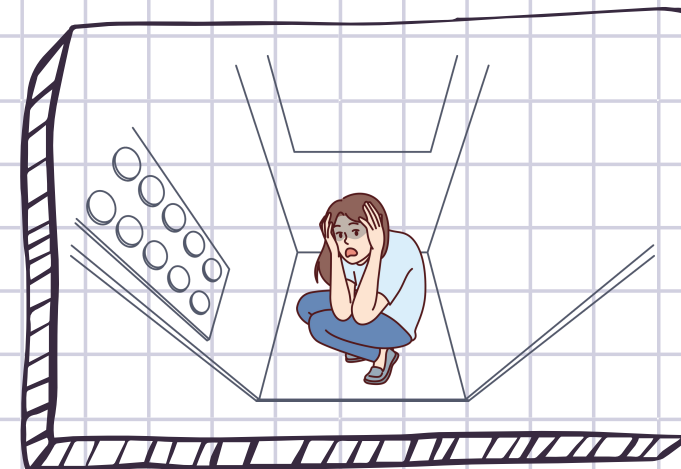
2 The presence of multiple sensory stimuli in waiting areas exacerbates their anxiety



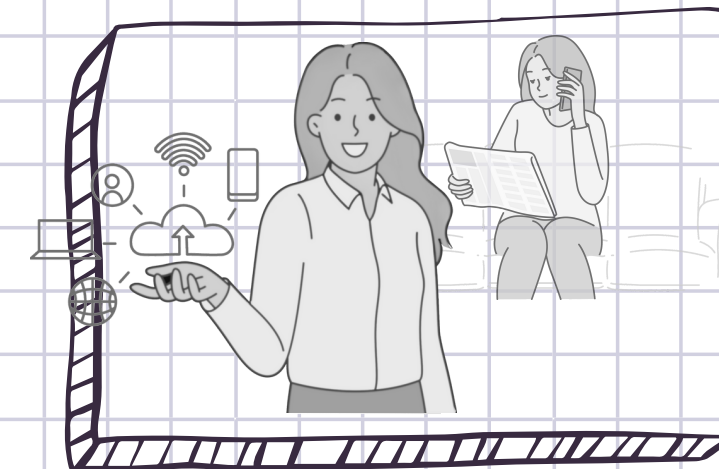
3 What if healthcare systems reimaged the waiting room as an experience that makes them feel welcomed even before they enter a health facility?



4 Prioritizing the comfort and well-being of neurodiverse patients before they even reach the waiting area can significantly enhance access to care and improve health outcomes.



5 Imagine a change from a neurodiverse patient being overwhelmed in a typical waiting area,



6 In to the patient calm and composed. They have received advanced notifications, the staff is supportive staff, and new waiting room is low-sensory. They feel like their care matters.

considerations

The next pages identify key considerations for implementation of these recommendations, measures for assessment, and potential challenges

some

considerations

24

Successful implementation
will be based on:

- Clearly identified project goals & objectives
- Success criteria
- Project deliverables
- Resource plan
- Risk analysis
- Implementation timeline
- Implementation plan milestones
- Team roles & responsibilities
- Implementation plan metrics

Implementation

To assess the impact or success of the updated waiting room experience, the opinions and feedback of patients, health providers, staff will need to be consulted.

Patients.

- Surveys
- Interviews
- Focus groups

Health Providers and staff.

- Surveys
- Interviews
- Internal discussions
- Community discussions

Assessment

Some challenges to anticipate during different stages of implementation:

- Budget constraints
- Miscommunication
- Priorities misaligned with patient needs
- Stakeholder disengagement
- Insufficient training of staff
- Lack of accountability

Potential Challenges

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Thank you!

