

Appreciating the Unique Characteristics and Needs of High Cost, High Needs Populations using *Personas*

Person-Centered Care

A persona is a research-based “empathy tool” that helps portray the experiences, motivations, goals, and barriers of a patient population too often seen solely through the lens of cost or clinical data.

This whole-person perspective allows us to consider health services and system-level changes that will more closely align care delivery with the underlying behavioral and socioeconomic realities of the human experience.

System Considerations

Personas are useful for identifying gaps in health system performance and design for a given patient population.

With a deeper understanding of the unique needs of key populations, health systems are better able to target and prioritize services as well as develop efforts to reduce costs.

Deep Insights

Instead of viewing a patient as a data point of what might be a short term intervention, personas lend rich insights into the underlying factors impacting a person's total health experience.

Personas convey the consumer's voice and shed light on a population's pain points and needs.

Patient vs. Person: How Their Concerns Differ

Patient

Access to services
and resources

Provider
relationship

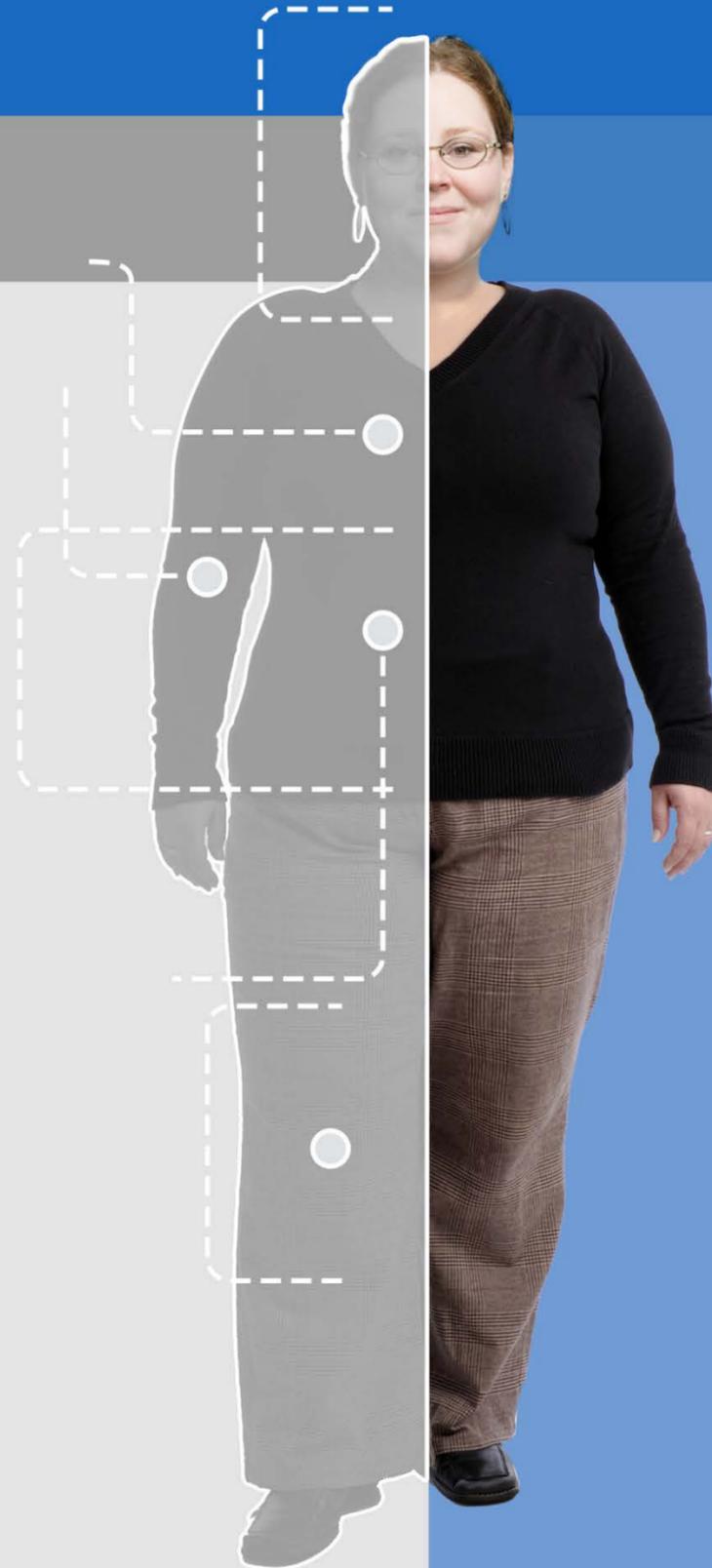
Care
coordination

Invisibility of disability

Patient-centered care

Confidence in diagnosis
and treatment

Pain



Person

Paid and loved-
one support

Outlook

System friction

Skills for dealing
with disability

Home
environment

Acceptance of my
disability

Adaptability

Persons with Disabilities Personas

Perspectives of Adults Under 65 Living with Functional Limitations

Hurting Hannah

Patient

- Feel desperate going from doctor to doctor trying to figure out what's wrong
- Resent that it's taken over three months to get my PT approved
- Feel insulted when the doctor says my problems are in my head

Person

- Endure horrible pain and barely function while I wait for a future doctor appointment
- Feel depressed that I'm very sick and I don't know why
- Feel alienated by people who don't understand what I'm going through

Jaded Jasper

Patient

- Feel frustrated that doctors can't do more for me
- Feel disheartened that my insurance sets the number of PT visits
- Forget to take my medicine because I'm down
- Feel anxious about affording the copay

Person

- Feel grief that I don't have a normal life and I have a sickness I didn't ask for
- Hide my sadness from my kids
- Feel embarrassed when I stumble or fall in front of strangers
- Feel like I don't fit in society

Self-Advocating Amber

Patient

- Feel grateful my doctor really cares about me
- Learn how to jump through hoops to get the care I need
- Feel pleased when a social worker fills me in about available programs
- Feel relieved to have a diagnosis

Person

- Decide it's something I have to get used to and work around
- Try to catch myself when I start to wonder, "Why me?"
- Show others they can appreciate daily life even with a disability

Persons with Disabilities Personas

Perspectives of Persons Under 65 Living with Functional Limitations

Hurting Hannah

“ No one seems to grasp what I’m going through.”

“ Sometimes I forget what it feels like to not have the pain.”

“ I’ve been through four different primary care doctors. I get the feeling I’m on the merry-go-round of doctors.”

Jaded Jasper

“ Sometimes you feel like you don’t even fit in society. And that’s an ugly feeling.”

“ It’s very embarrassing...because when I need to rely on somebody, I just feel so weak, so inept.

“ I don’t have the access to my doctor that I think I should have... the runaround that you get put through...No one answering voicemail. No one calls you back. It’s just such a hassle.”

Self-Advocating Amber

“ I was in contact a lot with the Office of Disability Services to make sure that I wasn’t penalized because of my health.”

“ If I’m able to give something back to somebody else, it gives me a sense of purpose and a sense of worth beyond my disability.”

“ If I’m not feeling bad for myself, I don’t need other people to feel bad for me.”

Hurting Hannah

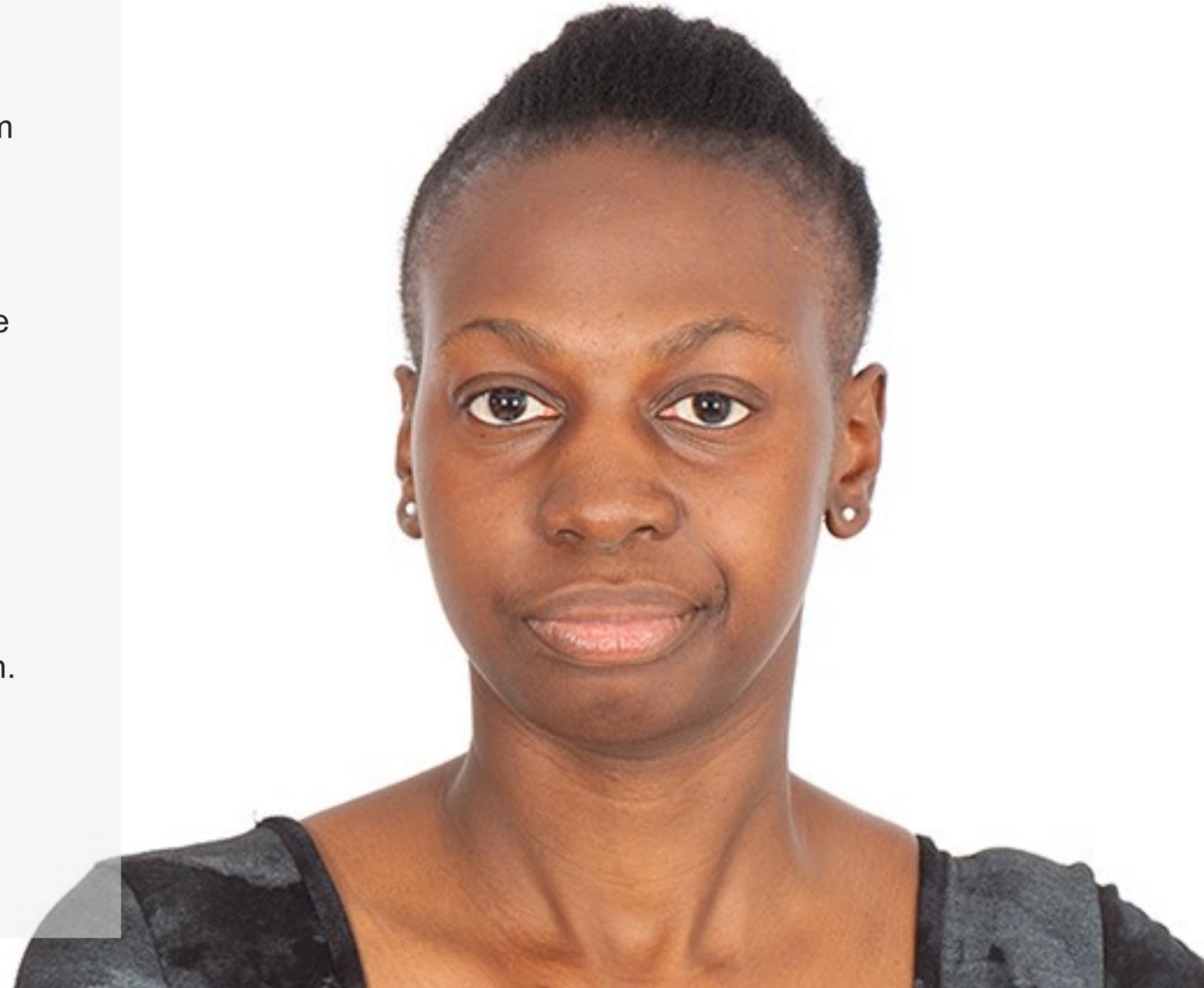
I've been on this doctor-go-round for months now. Although it feels like I've seen every doctor in town, no one seems to have any real answers for me, and this pain and the lack of sleep are driving me to the edge. I'm not sure how much longer I can keep this up.

My doctors make little comments; I can tell many of them think this is simply in my head. I hate being looked at like I'm a hypochondriac. If one more doctor tells me we just need to keep an eye on it, I might lose it.

Things are falling apart at work and, despite my best efforts to keep it under the radar, my coworkers can tell something is up with my health.

It scares me that I'm forgetting what it feels like to live without the pain. I'm not myself lately. No one seems to appreciate what I'm going through. I keep getting told I have to wait several weeks for things to be approved. I just hope I can get to the bottom of this ASAP. Meanwhile, I suffer while I wait.

“It's very depressing when you don't know what's going on, you're very sick, and you can't move much. You get to that point where you feel like nothing is gonna change it.”



Hurting Hannah



Goals

- Figure out why I'm in so much pain
- Stay working/in school as long as I can
- Get my insurance to cover my care
- Get long-term answers over quick fixes

Motivations

- Making the pain stop; not being sick
- Not being such a burden on others
- Not letting pain drive me to the edge
- Finding a way to get some sleep

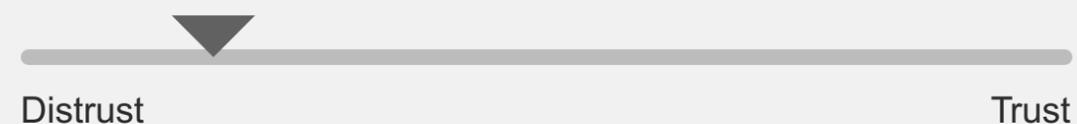
Barriers

- Stress, hopelessness, and depression
- Not finding the right doctor
- Copays for specialists that hurt my wallet
- Difficult-to-diagnose conditions

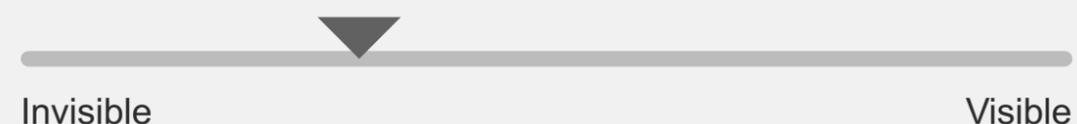
Acceptance of My Disability



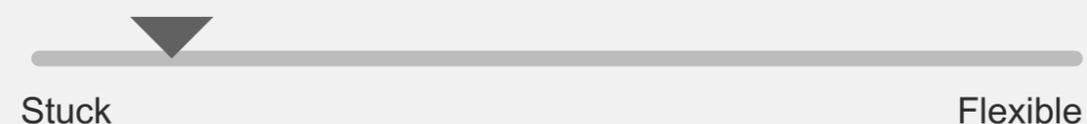
Provider Relationship



Visibility of My Disability



Adaptability



Patient Considerations

- Trust my input; hear me out
- Don't give up on me; don't blame me
- Be willing to admit you don't know
- Cut me some slack; I'm not myself

System Considerations

- Help me off the doctor merry-go-round
- Make it easy to appeal for what I need
- Remove barriers to refer to specialists
- Help me transition to new insurance

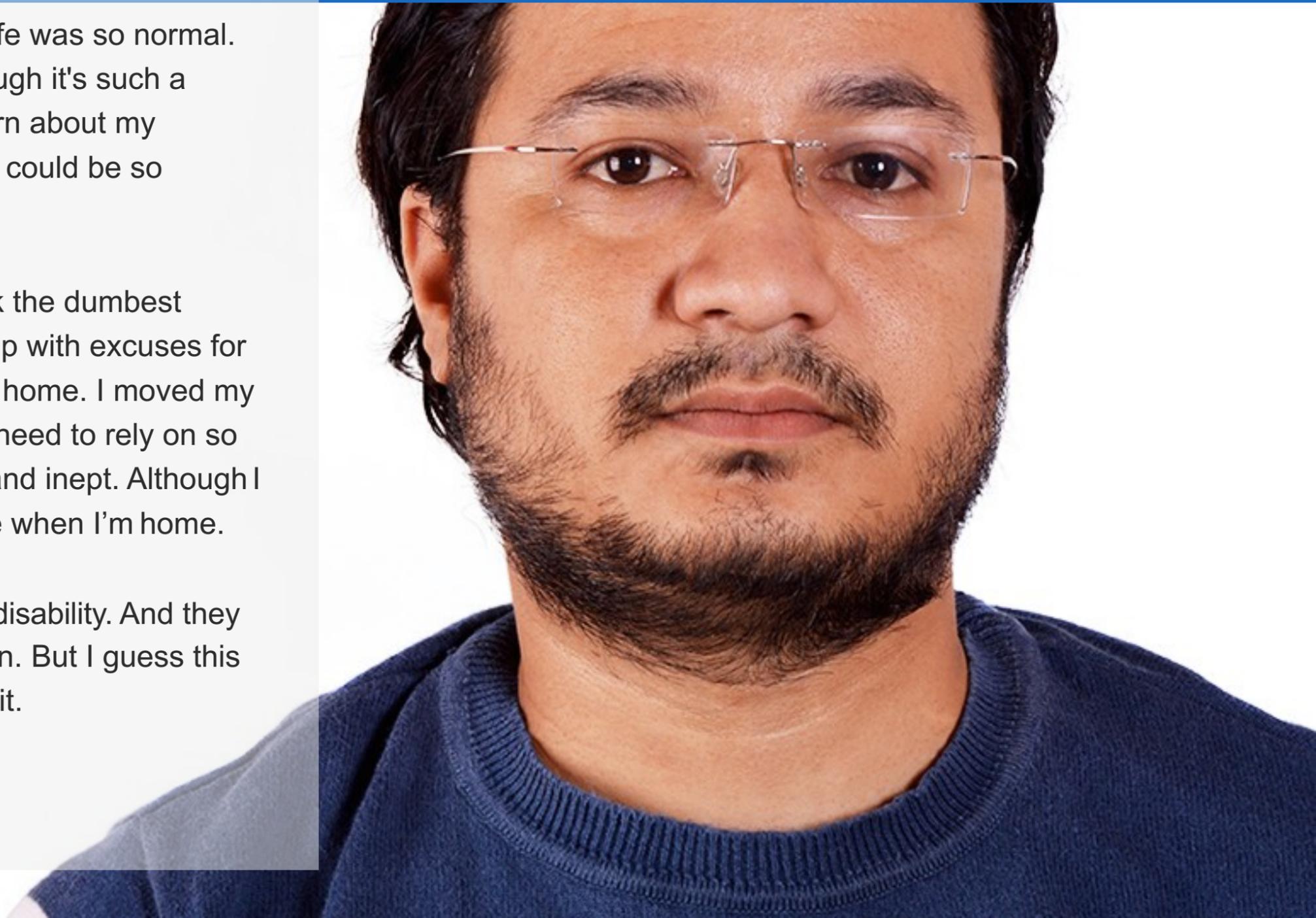
Jaded Jasper

How I miss my old life. It seems like just yesterday that life was so normal. And then came the pain and, finally, the diagnosis. Although it's such a relief to finally know what's going on, it scares me to learn about my disability because the future seems so grim. Who knew I could be so broken. My world has been turned upside down.

Life can just be so unfair sometimes. And people just ask the dumbest questions. It's getting easier and easier for me to come up with excuses for why I can't go out so I can stay in the comfort of my own home. I moved my bedroom down to the first floor last month so I shouldn't need to rely on so much help from others, which just makes me feel weak and inept. Although I often feel down these days, at least everything feels safe when I'm home.

I can't believe how clueless some doctors are about my disability. And they are so quick to add on more and more pills to my regimen. But I guess this is just how it's going to be, so I might as well get used to it.

“ Why do I keep getting sick? Why does this keep happening to me? Why can't I have a normal life?”



Jaded Jasper



Goals

- Carry on with life in spite of my pain
- Avoid thinking about doctors and pills
- Reconfigure my home for my needs
- Avoid triggers; minimize flare-ups

Motivations

- Being as comfortable as I can at home
- Avoiding people's lame questions
- Longing for a normal life
- Hiding my disability and not standing out

Barriers

- Depression, resignation, and bitterness
- Unwillingness to accept support I need
- Lack of jobs I can do from home
- Fear of having episodes in public

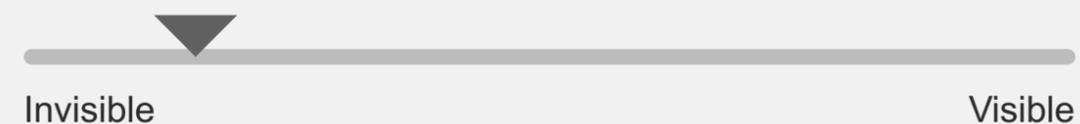
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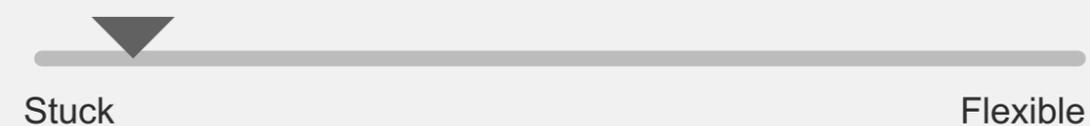
Provider Relationship



Visibility of My Disability



Adaptability



Patient Considerations

- Be knowledgeable about my disability
- Instill confidence in my treatment
- Help me advocate for services
- Help me feel like I'm in control

System Considerations

- Provide emotional triage for my new reality
- Impart skills for dealing with disability
- Increase hope I can function in society
- Help me keep my primary care doctor

Self-Advocating Amber

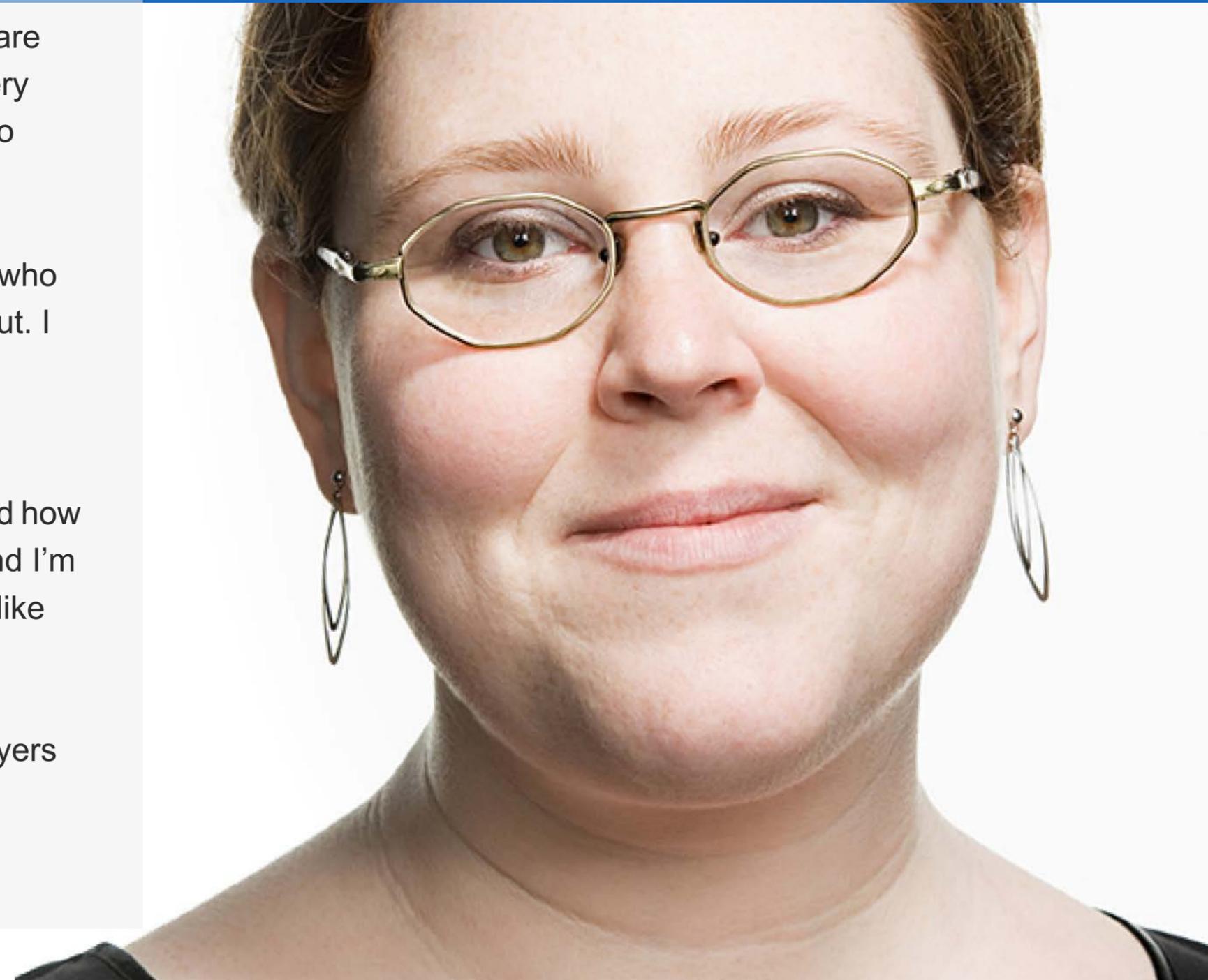
A lot of people make assumptions about people with my disability that are wrong. But I know who I am and I just keep trying to educate them every chance I get. Although it certainly didn't happen overnight, I was able to come to terms with my disability.

I've been very blessed with family and friends, caregivers and doctors who are optimistic about my future, and it's really helped me figure things out. I was really lost for a while there but I'm so relieved now to have some answers and to have things under control.

Sure, there are days where my limitations consume me but I've learned how to work around things and cope. There's too much life in front of me and I'm determined to enjoy it. As I'm learning more about services for people like me I'm encouraged.

I'm getting better about speaking out for what I need. By finding employers who are willing to work with me and caregivers who understand the accommodations I need, I'm moving forward.

“ You can either get upset about it and still be stuck in the situation, and be angry. Or you can accept that the situation is what it is and do the best you can to make the situation better.”



Self-Advocating Amber



Goals

- Function well in life with workarounds
- Jump through the right hoops for help
- Find an employer who accommodates
- Leverage paid and loved-one support

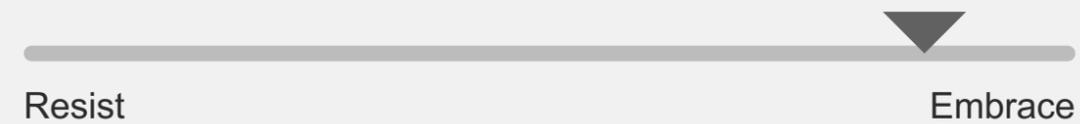
Motivations

- Appreciate life even with a disability
- Be upfront about my limitations
- Many are worse off than even I am
- Help others learn how to help me

Barriers

- Physical and financial constraints
- Insufficient or lack of services
- Inconsistent or ill-trained support
- Inignorance about my disability; stigma

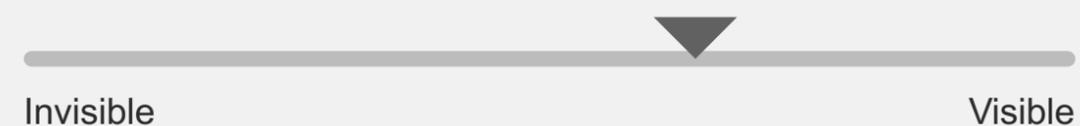
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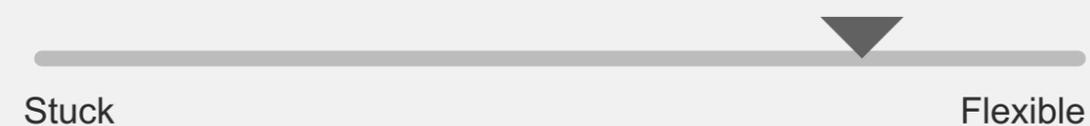
Provider Relationship



Visibility of My Disability



Adaptability



Patient Considerations

- Make it easier to access my doctors
- Help me justify requests for services
- Need your support, not your sympathy
- Bolster my resolve to live my life well

System Considerations

- See beyond my disability; see all of me
- Reach out to me; remove obstacles
- Connect me to resources & services
- Help me advocate for accommodations