

2026

rare
next

SHAPING
THE FUTURE
OF RARE



STIGMA:

**The Invisible
Multiplier
of Burden
in Rare
Disease.**



**Exploring the lived reality of
stigma in rare disease and the urgent
responsibility we share to end it**

HAVAS
Health Network



Contents

- Inside the rare reality 3**
- Research methodology and key learnings 4-6**
- The emotional manifestation of stigma 7-12**
 - #1 Healthcare stigma 13
 - #2 Families and close network stigma 14
 - #3 Community-driven stigma 15
 - #4 Interpersonal stigma 16
- Why emotional experience matters for the industry 17**
- Systemic experience: Uncovering where stigma shows up most 18-19**
- Stigma is a launch variable 20-21**
- Make Stigma the Rare Disease: A call to action for industry 22**





INTRODUCTION

INSIDE THE RARE REALITY

A Havas Health perspective for pharmaceutical and healthcare leaders



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+ **Gemma McCarthy**
Group Strategy Director, Rare Disease Lead,
Havas Life London



Innovation in rare disease is progressing at a remarkable pace. New genetic tools, advanced diagnostics and breakthroughs in precision medicine are expanding what is possible for conditions once considered too complex to treat. Yet despite this momentum, one feature of the rare disease experience continues to slow or even prevent the benefits of innovation from reaching people who need them most: **stigma**.

+ "... innovation cannot compensate for environments where [stigma] persists."

+ Stigma remains deeply embedded across societies and systems worldwide, and innovation cannot compensate for environments where it persists. It is multifaceted and manifests with roots in social interactions, institutional and systemic experiences and barriers, or as internalised guilt and shame.

Anecdotally it is clear that stigma in rare has far-reaching implications impairing access to diagnostics, treatment and participation in daily life, but – as with many aspects of rare – there is very little robust research in the area.¹

We asked the rare disease community, who described stigma as a persistent pressure that shapes their days in visible and invisible ways. They speak of unfair treatment, social exclusion and emotional strain. They describe interactions with healthcare professionals who do not believe them, employers who make assumptions about their ability to contribute and communities that misunderstand their reality.

These experiences compound across a lifetime. Rare disease already brings clinical complexity, but stigma adds a layer of friction that tarnishes every relationship, every conversation and every decision around care.

Understanding this compounded burden is not only an ethical imperative, but a strategic one. When the emotional landscape of rare disease is misunderstood, product launches stumble, engagement falters and trust evaporates. When it is recognised and addressed, meaningful partnership becomes possible, and the full value of scientific innovation can be realised. Stigma is an unacceptable and fundamental barrier to equitable care and quality of life.

+ **At Havas Health, we are amplifying the global community's voice to expose the lived reality of stigma in rare disease, and outline how together we can act to make stigma the rarest disease of all.**





INTRODUCTION

TO SILENCE STIGMA YOU MUST UNDERSTAND IT...

We spoke to more than 250 caregivers and people living with a rare condition.

86% of the people we surveyed lived in 5 markets – United Kingdom, United States of America, Australia, Canada and Germany.

The rest of the sample included representation from Europe, Middle East, South America, Asia Pacific and Africa.





INTRODUCTION



Dataset on classification and frequency of diagnoses in sample





INTRODUCTION

→ While experiences vary at an individual level, we found consistencies across markets on two sides of the stigma experience:

Across all therapy areas we identified negatively-charged emotional responses to stigma – with trends emerging between categories of rare diseases.

These accounts illustrate unacceptable patterns that should be treated as urgent signals, not incidental findings.

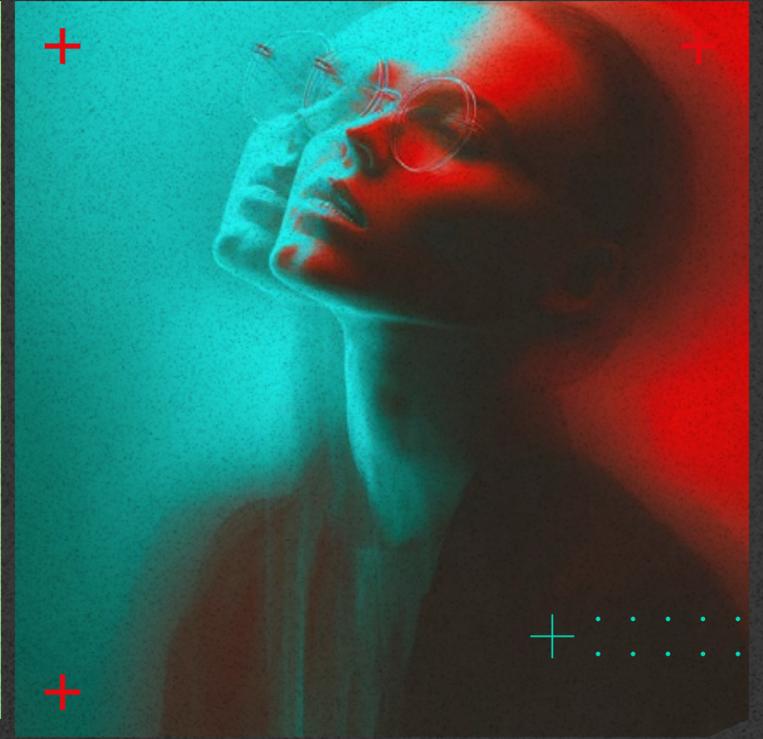


We identified **1,563 pairs** of negatively-charged emotional responses to stigmatising situations

#1

Emotional manifestation:

The emotional landscape and the experiences that drive stigma



#2

Systemic experience:

Uncovering where stigma shows up most and the compound burden it adds to the lives of people living with a rare condition



01.

EMOTIONAL MANIFESTATION:

+ The emotional landscape and the experiences that drive stigma





EMOTIONAL MANIFESTATION

FACING THE UNCOMFORTABLE REALITY THAT STIGMA IS THE NORM

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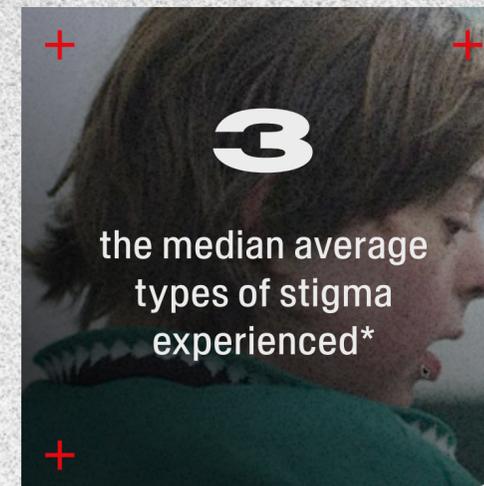


We learnt from people living with, or caring for someone living with a rare condition, that stigma is stubbornly common and unfair treatment is nearly universal.

While the expressions of stigma differ by region and condition, its presence is consistent.



In some countries, stigma manifests as disbelief within healthcare settings. In others, it appears as exclusion in community spaces or discrimination rooted in cultural beliefs. The emotional and social effects follow a similar pattern regardless of geography. People internalise shame, withdraw from activities and modify their behaviour to avoid judgement. The result is poorer quality of life and more complex clinical journeys.



3
the median average
types of stigma
experienced*



Our Rare Next dataset reinforces the global picture with a sharp level of detail. We learned that people have been stared at, mocked, ignored, disbelieved or blamed. Children are excluded from parties, parents are losing work opportunities and clinicians have been dismissing symptoms as psychological. They explain how these repeated moments accumulate into a heavy emotional load that influences how they trust, how they seek help and how they engage with treatment. Stigma is a universal experience whether disbelief, exclusion or shame.



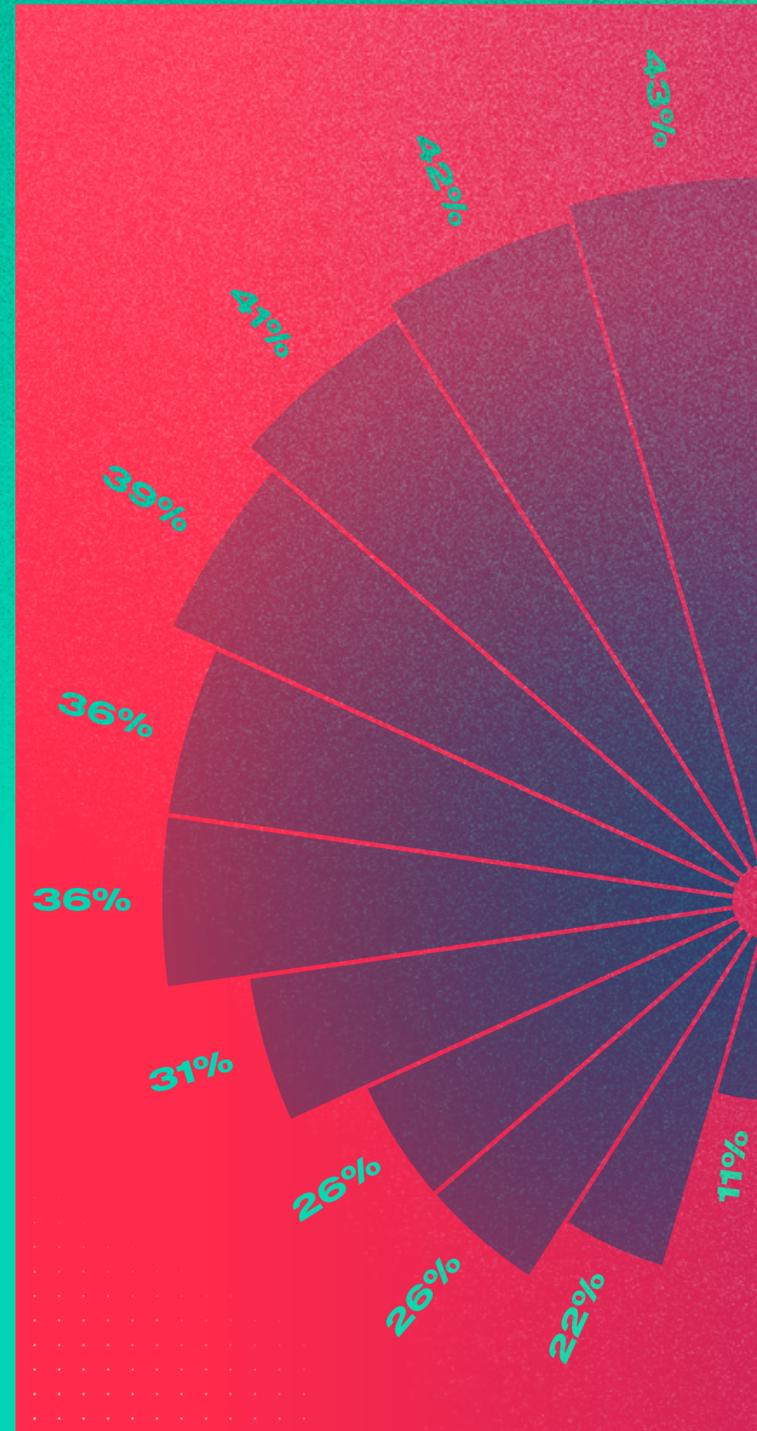


EMOTIONAL MANIFESTATION

Individually, these moments may seem small, but together they form a social environment that never fully relaxes its grip.

Stigma becomes a background hum: present in public settings, in classrooms, in clinics, in workplaces and even within the family home.

It disrupts relationships and expectations. It drains energy. It alters behaviour. It shapes confidence. Over time, it becomes internalised, making it even harder to overcome.



Q:

Has anyone ever treated you or your child unfairly just because of living with a rare condition?

- 43%** said friends stopped inviting them or left them out
- 42%** said doctors or nurses did not believe them or take them seriously
- 41%** experienced the toxic phrase, "You/they don't look sick"
- 39%** reported strangers staring or asking rude questions
- 36%** have had members of the public challenge them
- 36%** have been teased, called names or bullied
- 31%** said people at work or school assumed they couldn't do things anymore
- 26%** said they have lost friends or romantic partners as a direct result of their condition
- 26%** reported family members being treated differently because of their condition
- 22%** hide their condition so they don't feel judged
- 11%** reported that they have lost a job or not been able to find work

+

The experience is not a single event; it is an accumulation and behind every statistic is a human cost.

+



EMOTIONAL MANIFESTATION

THE EMOTIONAL CLIMATE OF RARE IS SHAPED BY REPEATED INVALIDATION AND SOCIAL WITHDRAWAL

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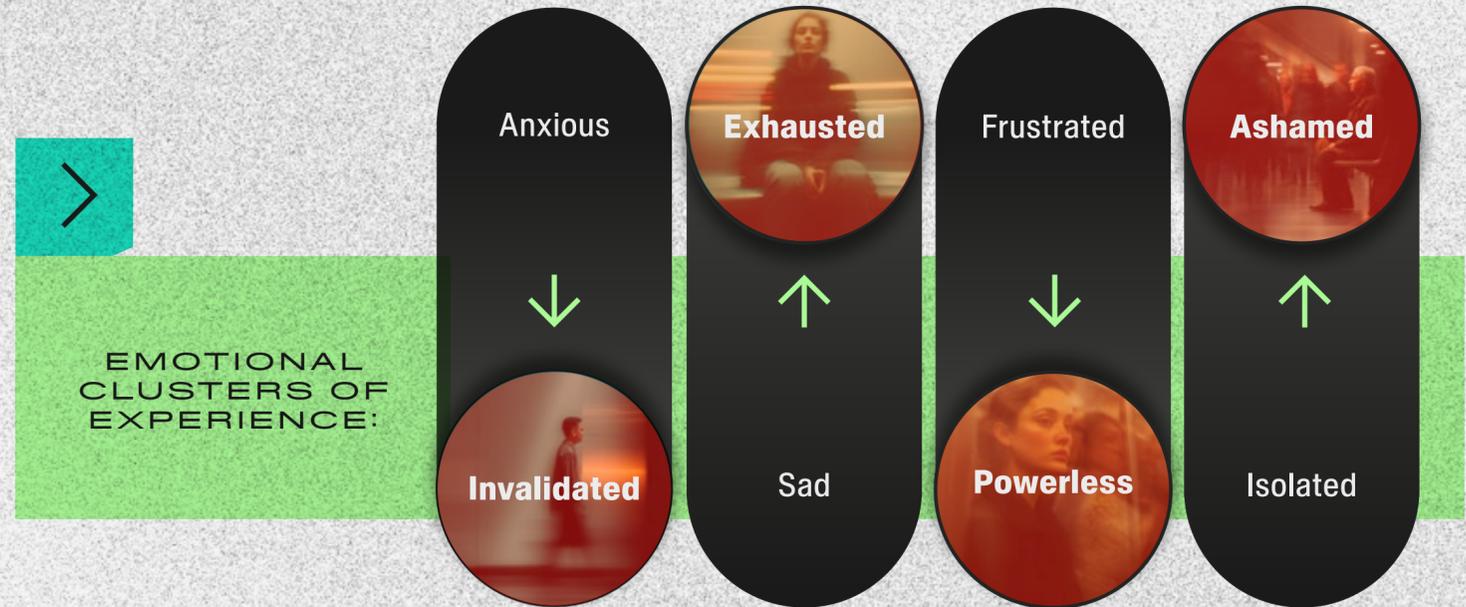


The emotional climate of stigma is among the most profound and least visible aspects of living with a rare condition.

People living with or caring for a person with a rare condition carry the weight of repeated undermining experiences, subtle exclusion and anticipated judgement.

+ *Their emotional world is not dominated by a single feeling.*

+



EMOTIONAL MANIFESTATION

A global pattern of emotional harm.

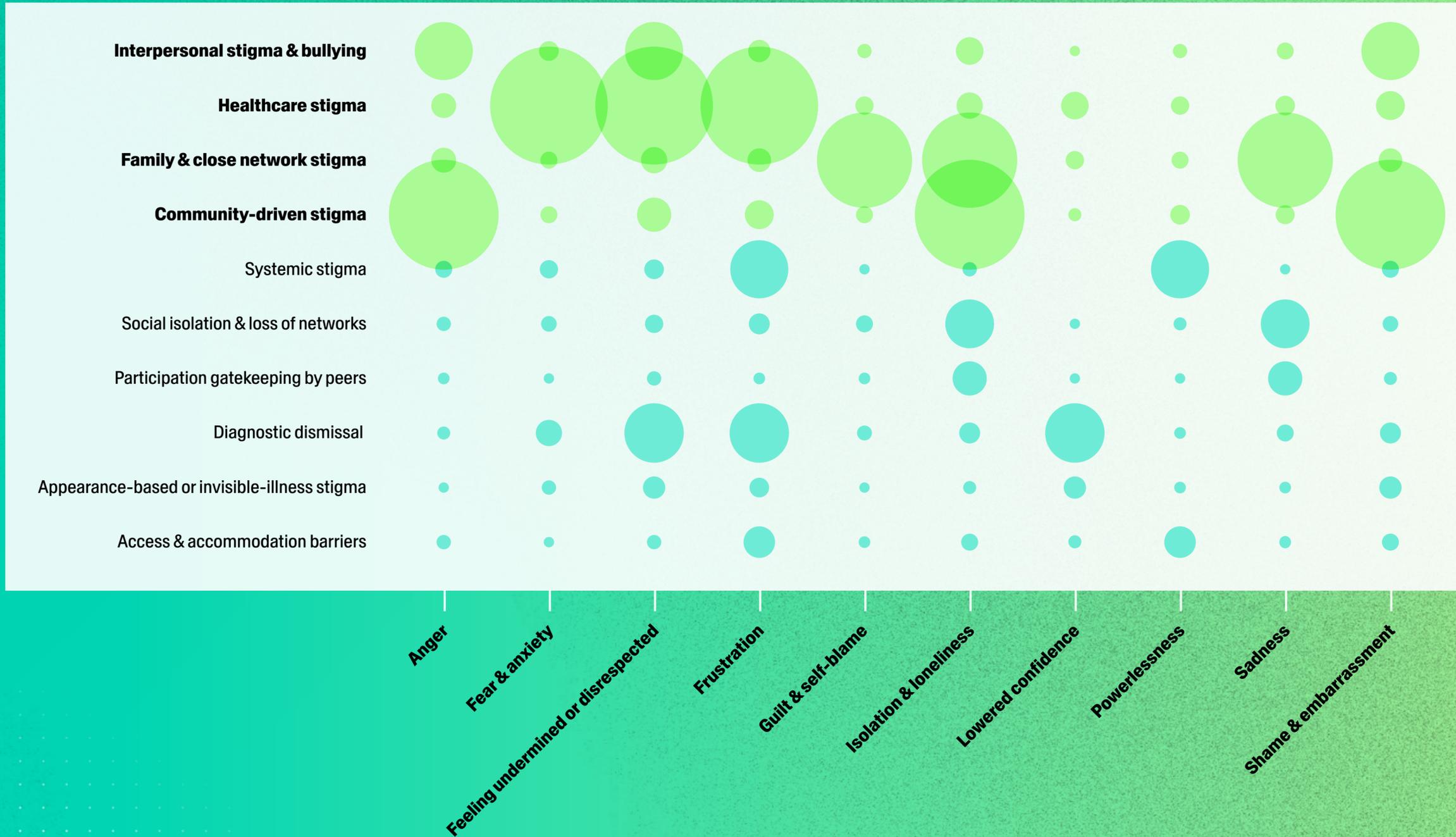
Diving deeper, there are clear patterns linking specific stigma experience themes to dominant emotional responses.

There are profound negative emotional hotspots around interactions with the healthcare system, families and communities, experiences with the community and interpersonal situations.



EMOTIONAL MANIFESTATION

DATASET ON CLASSIFICATION AND FREQUENCY OF DIAGNOSES IN SAMPLE





EMOTIONAL MANIFESTATION

DISMISSAL IN HEALTHCARE LEAVES LASTING SCARS

Clinical encounters shape whether people feel recognised as experts in their own lives or are treated as unreliable narrators. That single pivot sets the emotional tone for everything that follows.

People arrive at appointments having already rehearsed what to say. They bring photos, logs and language they hope will land. Many describe an early moment when the consultation turns from what they had hoped would be the start of a partnership, into a series of platitudes and reassurances that quickly close the conversation.

The effect is cumulative. After enough cycles of dismissal, people start to edit what they disclose and prepare for pushback before they enter the room. Trust has been eroded in a way that cannot be ignored or reversed. Fear and frustration are a red thread through these accounts, but the deepest mark is being undermined and invalidated. Over time, confidence thins and vigilance grows.

When diagnosis is uncertain or symptoms are episodic, disbelief amplifies. Appearance cues lead to “you look fine”, which voices as erasure. Administrative friction compounds the feeling. Referrals stall, letters go unanswered, access to investigations depends on how convincing you are.



Healthcare settings generate the largest incidence of stigma related moments [20%].



This is where powerlessness enters. People learn to work around services and rely on peers to navigate the system.



“My medical records and lab work are very clear but healthcare professionals don’t seem to look at the truth of my situation, but the falseness they have imagined concerning rare or any illness.”

USA, Myasthenia gravis



“Doctors refused to treat me and when I finally got pregnant, they tried to convince me to terminate, because the child ‘for sure’ will be sick. Every conversation and procedure was made in a rude, torturing way.”

Romania, Chromosomal duplication





EMOTIONAL MANIFESTATION

FAMILIES AND CLOSE NETWORKS

The home front is the emotional foundation people rely on for stability and resilience and should be the place where stigma loses oxygen. When belief and practical help fall short here, the emotional cost multiplies.

Families describe two patterns. The first is minimising language: "others have this and they are fine" or "don't make a fuss". The second is refusal to adapt logistics: no safe space for equipment, no willingness to learn routines, limited appetite for overnight care.

People rarely name these moments as hostile, but as tiring. The outcome is quiet grief and a pull toward self-blame. Patients worry that asking for help is making trouble. Adults with rare conditions choose silence to preserve relationships that already feel thin.



75% of family and close network-related stigma was associated with feelings of guilt, isolation and sadness.



When relatives and friends do lean in, the emotional needle moves quickly. A grandparent who masters a medication schedule. A trusted friend who will babysit for the evening.



"His grandmother longs for a real grandchild, he doesn't meet her expectations, which is heart breaking."

UK, Parent of child with chromosomal abnormalities



"My family acts like they know other people that have what I have and they're fine"

USA, Hypoparathyroidism



↘ ↘ ↘
**EMOTIONAL
 MANIFESTATION**

EXPERIENCES WITH THE COMMUNITY

Public space is where private management meets other people's reactions. Small behaviours by strangers, staff and institutions either widen the world or shrink it.

Community is where interpersonal experience and systemic structures collide. One part of the story is the way we shy away from the "norm". The other part is design. Steps where a ramp should be. Chairs that do not work with bodies that need support. "Policy" as a script to say "no" rather than a tool to include. These frictions are rarely one-off shocks. They are drip-feed experiences that teach avoidance. People plan routes to bypass problem venues. They time outings for when crowds are thin.

They choose silence at the moment of difficulty to reduce the scene others might make. Shame and anxiety track closely with these choices.

Community groups and schools are pivotal. Exclusion from clubs, discos or trips is often explained as practicality. The message received is different. It says your presence is too costly to plan for. That message is hard to forget. It changes how children see themselves and how parents see their place in the local network.

+

52% of those who experience community-related stigma feel anger or embarrassment about the situation

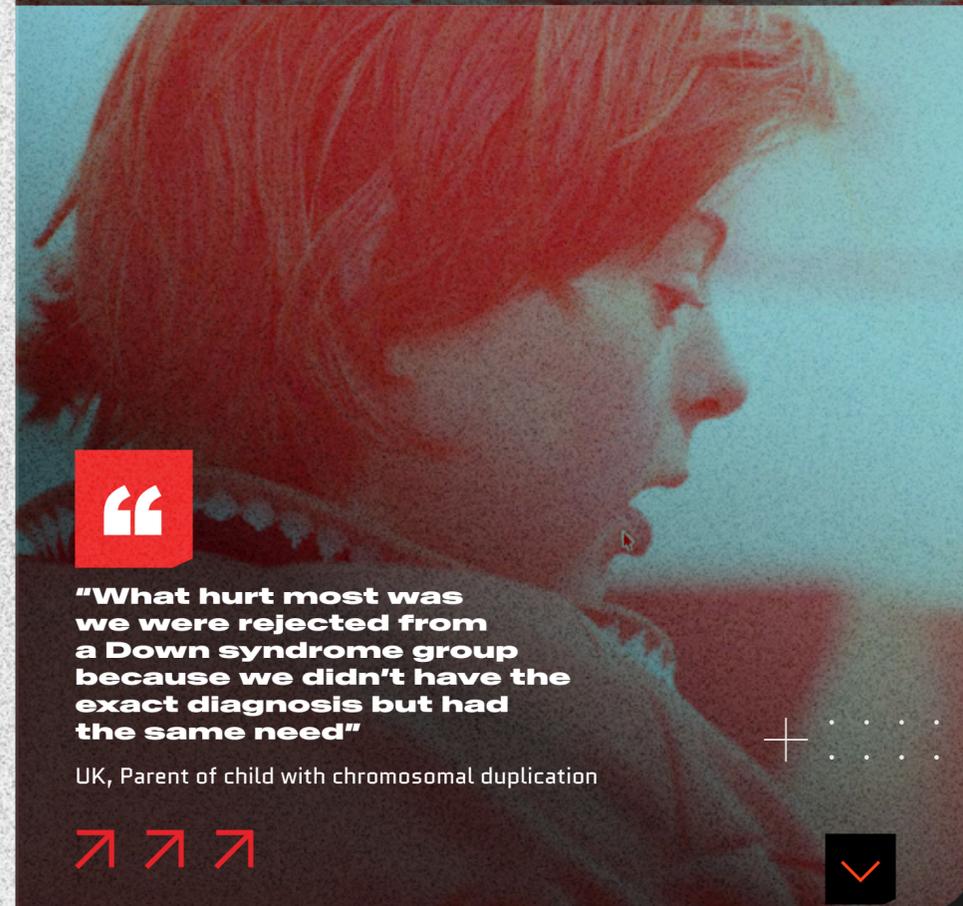
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Exclusion, inaccessible environments, and public judgement should be recognised as unacceptable societal failures, not interpersonal misunderstandings.



"I had to go 16 times into court just to get arranged that my son received education."

Netherlands, Parent of child with chromosomal deletion



"What hurt most was we were rejected from a Down syndrome group because we didn't have the exact diagnosis but had the same need"

UK, Parent of child with chromosomal duplication





EMOTIONAL MANIFESTATION

THE QUIET WEIGHT OF EVERYDAY STIGMA

The moment-to-moment exchange between two people is where dignity is either repaired or damaged.

Even subtle actions can undermine feelings of self-worth and accumulate over time. Bullying, jokes and pointed questions are obvious harms. More common are smaller cuts such as a tone that questions credibility or a 'helpful' suggestion that overwrites the person's own account.

The emotional arc here runs through shame into anger, then often back into withdrawal. People learn to keep information close. They test whether the other person can be trusted before they speak freely.



1/3 of people who endure moments of interpersonal stigma feel undermined and disrespected.



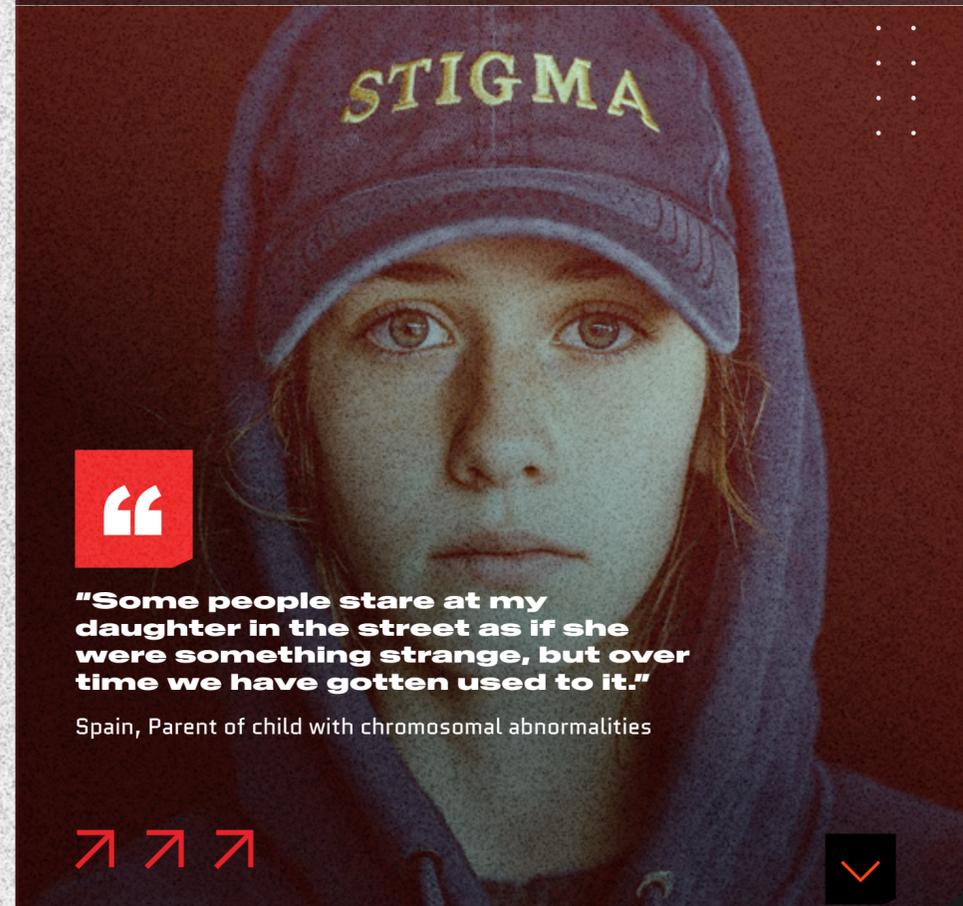
Repair begins with naming what should have happened. *"You deserved respect."* or *"I believe your description."*

It continues with pacing the interaction so the person can keep control. Slowing down and asking what "better" would look like in the next ten minutes gives back a sense of urgency. In workplaces and classrooms, confident interruption of stigma signals safety to everyone watching. It tells bystanders what the norm is.



"Most people don't see my chronic illnesses or my disability-so I get a lot of ableist comments or get cursed at"

Germany, Hypermobile Ehlers-Danlos Syndrome



"Some people stare at my daughter in the street as if she were something strange, but over time we have gotten used to it."

Spain, Parent of child with chromosomal abnormalities

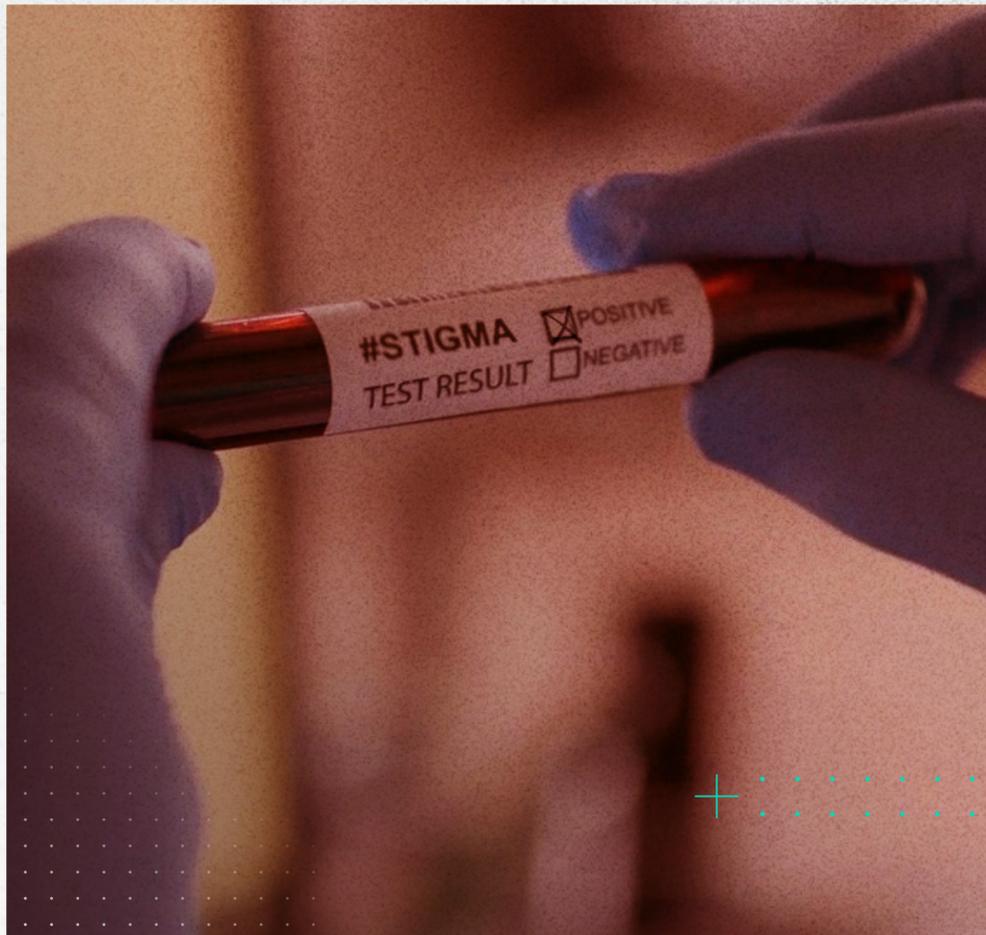




EMOTIONAL MANIFESTATION

WHY EMOTIONAL EXPERIENCE MATTERS FOR INDUSTRY

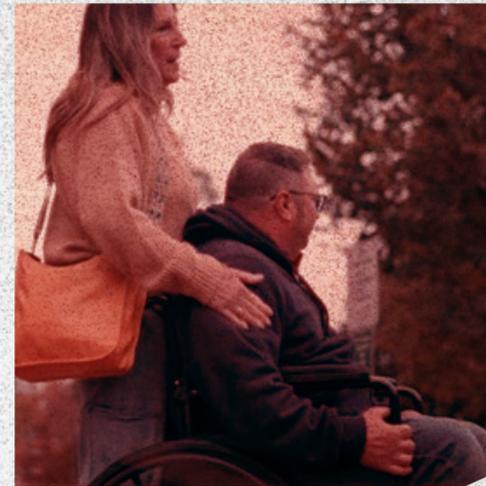
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For healthcare companies and marketers, this emotional context is not incidental. It shapes how families receive information, how much they trust communications and how willing they are to engage with support.

Emotional credibility becomes a foundation for positive corporate reputation and successful brand relationships. If communications inadvertently echo the dismissive tones families have experienced elsewhere, engagement quickly collapses. If activities reflect understanding of these emotional realities, trust becomes possible.

Leaders can support in changing the trajectory from caution to confidence by addressing the first contact in each setting, equipping families to help today and make efforts to interrupt harm in the moment.



Each shift may seem small but together they have a large impact. Together, they turn carefulness from a survival posture into a thoughtful choice, and they give people back the ordinary freedoms that stigma tries to edit out of daily life.





02. SYSTEMIC EXPERIENCES:

- + Uncovering where stigma shows up most and the compound burden it adds to the lives of people living with a rare condition



UNCOVERING WHERE STIGMA SHOWS UP MOST

As we have shown, stigma is not limited to interpersonal interactions, it is embedded within institutions that shape daily life.

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+ Parents describe safeguarding investigations triggered by misunderstanding of symptoms. Adults speak of job loss or career stagnation. Families recount schools lacking the knowledge or confidence to include children with rare conditions.

These failures are not abstract. They intersect directly with emotional experience.

When institutions respond with suspicion or avoidance instead of support, families internalise guilt and shame and feel increasingly isolated. level failures are not abstract. They intersect directly with emotional experience.



WORKPLACES:

Where opportunity narrows

Rare disease doesn't end at diagnosis. It reshapes careers, income, independence and identity, especially for parents and carers.

"There are a lot of medical appointments for my daughter, it requires me to take time off work. My employer gets cranky when I am away."

Australia, Parent of child with chromosomal abnormalities

HEALTHCARE:

Where trust should be highest

One of the most damaging themes is disbelief by healthcare professionals. When clinicians do not listen, stigma becomes systemic.

"I've been gaslighted by people and doctors because I don't look sick, or because I might have one good day-meaning there are no bad days, which was always untrue."

USA, Hypoparathyroidism

EDUCATION:

Where difference becomes exclusion

With 75% of rare diseases diagnosed in children, it's no surprise that schools are repeatedly mentioned as places where stigma first becomes visible.

"My child was denied access arrangements for exams when we had worked so hard outside of school to help him keep up."

United Kingdom, Parent of child with a chromosomal deletion



LAUNCH EXCELLENCE

STIGMA IS A CRITICAL RISK FOR LAUNCH



Stigma is not only a social issue. It is a behavioural driver that influences whether people are receptive to disease education, support programmes and commercial communication.

Strategies that ignore stigma risk misalignment with audience reality. For our industry, the implications are profound. Addressing stigma is not an ancillary responsibility.

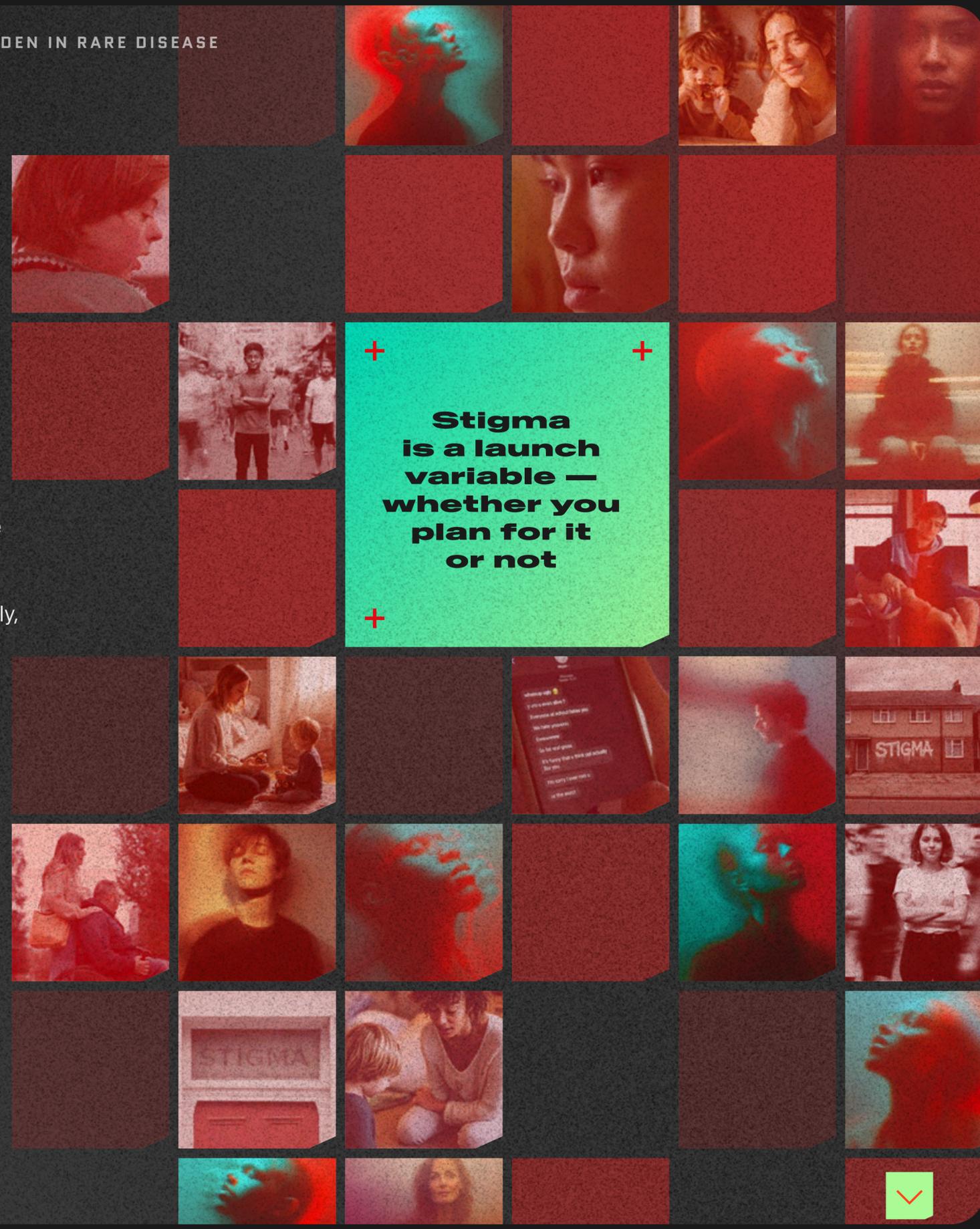
It is central to delivering meaningful health impact and achieving successful commercial outcomes.

A 'stigma aware' strategy strengthens brand credibility, accelerates uptake and promotes sustained engagement. It builds trust that lasts far beyond launch.

When stigma is ignored, even the strongest clinical innovation can struggle to gain traction. When it is understood and addressed early, it becomes a lever for better strategy, stronger brands and more sustainable uptake.

Stigma is a launch variable — whether you plan for it or not

+ Sarah Mikhailov
Managing Director, Havas Life London



A FORMULA FOR LAUNCHING IN RARE DISEASE



For commercial leaders, expanding the definition of launch excellence beyond science and access alone is critical in rare disease. It requires a deliberate focus on the cultural, societal and emotional context in which brands are introduced – and a willingness to design for that reality, not work around it.

Ultimately, launch excellence in rare disease is not just about preparing a product for market - it is about preparing the market itself.

Brands that recognise stigma as a launch risk, and design accordingly, are better positioned to build trust, enable confidence and sustain impact over time.

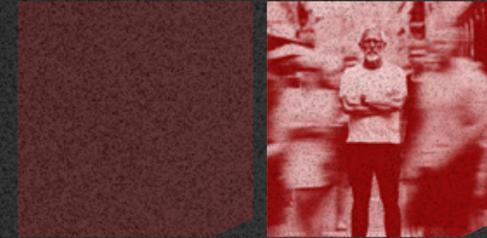
+ **Sarah Mikhailov**
Managing Director, Havas Life London



DISEASE STRATEGY:
Treat stigma as a core disease barrier, alongside misdiagnosis and access, using patient and caregiver insight to reveal where belief breaks down.



STAKEHOLDER ENGAGEMENT:
Engage patients, caregivers and advocates as strategic partners early, shaping disease framing and language before product visibility.



BRAND BUILDING:
Build brands within their cultural context - not just on clinical RTBs - acknowledging how stigma, bias and belief influence perception and choice.

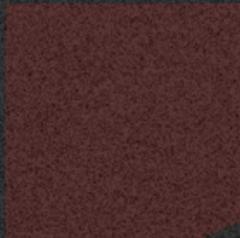


MEDICAL STRATEGY:
Address institutional stigma within healthcare by reframing lived experience as outcome-relevant, not anecdotal.

GO TO MARKET AND SUSTAIN:
Shape markets through ecosystems of support, measuring success through belief, trust and behaviour change, not reach alone.



AWARENESS AND EDUCATION:
Move from awareness to understanding, supporting visibility and plain language tools that reduce friction and emotional burden.





CONCLUSION



A FUTURE WHERE STIGMA IS THE RAREST PART OF RARE DISEASE

The global rare disease community deserves more than scientific progress. It deserves equitable access to care, inclusive social systems and communication that recognises the emotional realities of life. Stigma stands in the way of all three. It distorts clinical pathways, undermines trust and diminishes quality of life. Yet it is also something the industry has the power to change.

By acknowledging stigma as a central barrier and acting with intention to dismantle it, pharmaceutical and healthcare organisations can help shape a future where innovation reaches those it is meant to serve.

A future where rare disease care is not only advanced but also compassionate. A future where people living with rare conditions experience dignity, understanding and partnership.



This is the vision of Rare Next.

This is the work Havas Health is committed to advancing. And this is the opportunity for industry to not only progress, but lead with purpose.



89%

of people living with a rare condition told us they had been treated unfairly as a result of their illness

100% UNACCEPTABLE

THIS IS ON ALL OF US. COLLECTIVE ACTION STARTS NOW.





RARE NEXT SERIES

Innovation in rare disease is accelerating. But innovation alone does not determine impact. It enters systems shaped by belief, bias and lived experience. When stigma is present, it slows diagnosis, weakens trust and limits engagement long before a therapy reaches a patient.

This report is the second point of view in our Rare Next Futures Report series at Havas Health.

Rare Next is built on a conviction: we have the power to shape the future of rare disease. That means shaping not only how brands launch, but the environments they enter. Stigma is not a side issue. It is a force that multiplies burden across healthcare, education, workplaces and families. Addressing it is strategic.

Through Rare Next, we integrate lived experience into strategy, align science with emotional reality and design engagement that earns trust across markets. When stigma is confronted directly, innovation moves further and faster.

The future of rare disease will be shaped by those willing to see the full picture. We intend to lead that work.

+ **Afshan Hussain**
Global Rare Disease Lead,
Havas Health





STIGMA: THE INVISIBLE MULTIPLIER OF BURDEN IN RARE DISEASE

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+
**Make Stigma
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SHAPING
THE FUTURE
OF RARE

