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The Body,
Spread Out
Into a
Database

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In his earliest memory of being told the things that could not be possible for his life,* Praveen starts in his own head, alongside it, a list of the things that could. The latter, his brother Nishanth assumes, must be much smaller than the former, a running joke between the two as they grow older.

*I'm not sure anyone ever thought you would make it to—
and through—school, Nishanth says one day, at least half-serious.*

*I'm counting that as a thing I thought I could do, Praveen jokes
back, because there's no way they'll stop me if they don't
know I'm disabled. And I don't think they'll ever need to know.
I think I can get by.*

He can and he can't, as it turns out. A few months before he is scheduled to take his final examinations at the end of the school year, the last set of exams he hopes he'll ever take, his father receives a call from the school.

*We'd like to see an updated version of your son's disability certificate,
the voice on the other end says, so that he is able to get the
accommodations he needs in advance of the exam.*

*There is some silence, a lot more confusion—
isn't the certificate something they already
turned in to the school a few years ago?*

The certificate says Praveen has multiple disabilities, yes?

Yes, they nod, wondering what this sudden phone call is for.

(And more since then, Praveen jokes to Nishanth.)

* Although not the first time he has been told what he might never be able to do, he realizes, with some exhaustion—people never tire of reminding his parents that life in a disabled body is something of which to be frightened.

But it also says that these are temporary disabilities.

*On the other end of the phone, they look at each other—
what is temporary about multiple sclerosis?
About retinal detachment?*

*What this really means is that until you have a new certificate,
that is valid right now, that says he has all these disabilities,
and will have them at the time of the exam—until you have all
of this, Praveen won't be able to take these exams.*

*A new certificate could take months—Maybe longer, even.
His exams will have come and gone by then.
Please consider the old certificate if you can.
This whole process is so long.
He may not get another certificate.*

*Nothing we can do about this.
It's a requirement that the central board has.
If we show a disability certificate that is expired,
then he won't be considered disabled at the time of the exam.*

The phone call ends with no further negotiation.

When Praveen and his parents talk to a friend's family that evening, the friend reminds them: *it isn't just the disability certificate any longer, it's a little more complicated now. There's the unique disability ID card. I've heard it takes months to get.*

What's different about this card?

*It's kind of like the disability certificate, but this one is supposed
to be more efficient—you can use it across the country, not just
in the state you receive it. And there's one other thing—it's supposed*

to help create a kind of national database of disabled people. So, it ties in to your Aadhaar card, that way your ID is linked everywhere.*

(This is a little ridiculous, Praveen thinks, given that I haven't been able to get an Aadhaar card yet. So many of us can't.)

Praveen's parents explain: *An Aadhaar card is quite difficult to get for people with different kinds of disabilities. And Praveen's vision has become worse since the last time we tried to get the certificate, so maybe we have to do a whole other assessment—*

(But I also haven't changed that much, Praveen counters— why would I need yet another assessment, and multiple visits to the doctor, just to confirm that I am still disabled?)

The process of being certified runs on (mis)trust, a dialogue between the medical examiner and Praveen's father that pushes forward, attempting to measure what it means to live the way Praveen does. A photo must be taken first, he is told before the certification, an exhausting process in itself as his father tries to hold his head up. There are four tries before the photographer seems satisfied.

When they are waiting to be evaluated, the doctor steps into the room, and then steps out just as quickly, stating that he has another patient who is more urgent to attend to, and leaving the form he will be filling out for the disability certificate.

* Since 2010, the Unique Identification Authority of India (UIDAI) has attempted to uniquely identify every Indian through their biometric and demographic information. Aadhaar is colloquially used to refer both to the database in which citizens have been enrolled, and to the physical card that they receive as a proof of their identity. In this instance, the reference is to the latter.

This is to certify that I have carefully examined Shri/Smt/Kum _____ Son/wife/daughter of Shri _____ Date of Birth _____ (DD/MM/YY) Age _____ years, male/Female _____ Registration No. _____ permanent resident of House No. _____ Ward/Village/Street _____ Post Office _____ District _____ State _____ Whose photograph is affixed above, and am satisfied that he/She is a Case of _____ disability. His/her extent of percentage physical impairment/disability has been evaluated as per guidelines (to be specified) for the disabilities (to be specified) and is shown against the relevant disability in the table below:-

S.No	Disability	Affected part of the body	Diagnosis	Permanent physical impairment/mental disabilities (in %)
1.	Locomotor disability	@		
2.	Low vision	#		
3.	Blindness	Both Eyes		
4.	Hearing impairment	\$		
5.	Mental retardation	X		
6.	Mental-illness	X		

(Please strike out the disabilities which are not applicable)

(When the doctor steps out of the room, Praveen asks,
*What's written on the certificate?
What does it say? About me? To the school?*)

His father reads it out to him, telling him that his photo will eventually come in the top right-hand corner of the certificate. That for now, it says, "This is to certify that I have carefully examined Shri/Smt/Kum _____ [*your name will go here, Praveen*] son/wife/daughter of Shri _____ [*and my name will go here*] Date of birth _____ Age _____ years, male/female _____ Registration no. _____ [*what number is this? Praveen wants to know—I'm not sure, his father says, we can ask them?*] permanent resident of house no. _____ ward/village/street _____ post office _____ district _____ state _____ whose photograph is affixed above, and am satisfied that he/she is a case of _____ disability. His/her extent of percentage physical impairment/disability has been evaluated as per guidelines (to be specified) for the disabilities (to be specified) and is shown against the relevant disability in the table below."

Have the guidelines not yet been specified?
Praveen is curious.

*No, I'm sure they have been, his father says,
the doctor must know even if we don't.*

*OK, Praveen says,
what are the disabilities in the table?*

When his father reads them out: locomotor disability, low vision, blindness, hearing impairment, mental retardation,* mental illness, Praveen interrupts—where is multiple sclerosis? His father isn't sure either. I think it's one of the new disabilities that is counted, he offers, this form just seems old.

**Praveen, again:
... and what if I have many disabilities?
Does this form have a place to mark all of them?**

**His father hesitates, and he can hear it, before he adds,
I'm not sure about this, the doctor will know.**

*So does the certificate tell the school that I will need different
types of help during my exams?*

Praveen asks.

Not yet, no, his father says, just the percentage of your disability.

What does this percentage mean?

Praveen is still unsure.

*The percentage of your impairment, his father reads from the form,
which I think means how much functioning you have lost,
what things you can no longer do because you are disabled.*

* This term is no longer legally acceptable in India and is not used as a category for certification following the 2016 Rights of Persons with Disabilities Act. It was, however, used prior to this Act.

*That's a hard thing to say, Praveen pushes back a little,
maybe I could do more things if the school
was actually willing to support me.*

Praveen's ears burn as the doctor asks upon entering the room:
*But what do you want this certificate for? Is he doing badly
in his exams?*

*No, so that he can enroll for the exams,
his father responds.*

*Difficult to assess today, maybe come back another time.
Hard to tell if he is really disabled.*

Most of these parts Praveen blocks out. He returns another time, and then another. As his father predicted, the months pass. He still does not have the certificate. The suspicious doctor from his first visit is replaced by a neurologist, and then others after him, also wondering if multiple sclerosis is really a disability that you can be certified and confirmed for.

*I don't think the government counts
this disability, one medical officer says on the fourth visit.*

*THEY DO. His father is livid.
THEY DO. IT IS PART OF THE NEW LAW.*

Sitting next to the medical officer is another person whose designation they are not sure of. She chimes in: *We also don't have a field to enter this into the computer, sir. How will we record all these disabilities in the database if you are saying your son has multiple disabilities? There is only one field for entry.*

*Yes, but what do you want me to do about this?
My son has multiple sclerosis, and now also a detached retina.
It isn't like him or I can change anything about your database.
You need to find a way to record both these things.*

When they are almost certain that they're very close to getting the certificate, finally, after four separate visits to the hospital for evaluation and follow-up evaluations, another phone call comes in, this time from the hospital.

New guidelines, which means we are not issuing disability certificates anymore. You should be applying for a unique disability ID card.*

Is it not possible to take the assessment you did for the certificate and use it for the card?

No, usually we reassess the candidate to determine the nature of the disability.

We just went through four months of assessment at your hospital.

*The unique disability ID also requires an Aadhaar card,† sir.
Your son doesn't have one.*

- * The unique disability ID card was initially envisioned as a replacement for the disability certificate, since the evaluation criteria for the disability certificate varied significantly between states, and since certificates issued in a particular state were not accepted across the country. However, in numerous instances, since its rollout in 2016, the UDID card has not been accepted as a replacement for the disability certificate. As of 2021, applications for both the unique disability ID and the disability certificate are done through the same online portal (as intended in its development for the UDID card alone), and both are issued simultaneously.
- † Aadhaar means “base” or “foundation.” Most commonly, the Aadhaar card is considered as a base/root form of identification, from which other identification documents are issued, and to which they are linked. Although the unique disability ID card is not legally required to be linked with a person's Aadhaar card in India, there have nonetheless been numerous instances wherein those applying for a UDID card are required to provide an Aadhaar card.

*Is an Aadhaar card mandatory for the new disability ID,
or will another form of address proof do?*

*If you want to avoid any problems, sir, just link the Aadhaar card.
You can make one first, then try to get the unique disability ID made.
Many places now want only the new disability ID.*

What about our application for the disability certificate?

*You may need to make a new application—
don't worry, you can find all of this information online.*

*This is not very clear on your website,
Praveen's father starts to say when he hears that
the person on the other end of the line has ended the call.*

Praveen overhears a phone call to the school:
*My son is unable to get a disability certificate—
And is being asked to get a unique disability ID card instead
Will the central board accept this for his examinations?*

*What do you mean you don't know?
Can you check and find out?*

*And a little later:
It's strange to hear the board is only accepting the certificate.
The hospital is only willing to give the unique disability ID card.*

*Praveen doesn't have an Aadhaar card yet.
It has been hard to get one for him.
Providing biometrics is difficult due to his retinal detachment.*

Elsewhere in the city, Rajesh reads the newspaper before a three-hour meeting, hoping to escape all thoughts of work. This meeting, he knows already, will be a difficult one. There will be lots of questions about the unique disability ID cards, and how come many people haven't been receiving them. The cards also don't have the option to enter information for some of the newer disabilities, he's told.

As it turns out, the meeting is less boring than he expected. This time, four disability rights activists have been invited directly to present their perspectives on some of the problems with migrating from a paper-based disability certificate to a digital unique disability ID card, after which they are all going to discuss possible technical solutions. He listens to the presentations, thinks: *all human errors*. One activist is talking about how it has taken months to be able to get people certified for the disability certificate, and how some hospitals are insisting on a sudden transition to the unique disability ID. *Why can't we have both, or at least have either one be accepted till we have fully moved to the unique disability ID*, the activist asks.

The room fills with uneasy laughter.

Another activist offers, *the question of which disabilities are even recognized as difficulties is also a big one. Some of the newer disabilities from the recent Rights of Persons with Disabilities Act, even though it is not so recent—what has it been now? Maybe one and a half years?—are not being recognized for the unique disability ID card.*

A third says, *and to get the disability ID card, even if you have a disability certificate already, you also need an Aadhaar card to apply. This is an unnecessary connection being made, and one that is very difficult for disabled people who are unable to provide their biometrics to enroll.*

Rajesh is relieved that he does not yet have to think about the Aadhaar card and its problems.

Do you think all bodies are the same? the activist asks. *How do you design these cards? What do you imagine people's bodies can do? Disabled people are consistently having difficulties getting all three—the Aadhaar card, the disability certificate, and the unique disability ID—and you need one to get another. It's like a loop. And getting each one is difficult, because the system doesn't recognize all kinds of bodies, even when it is supposedly designed for enrollment for everyone to be able to easily enroll—only some people are able to.*

You must be seeing all kinds of complaints coming in from disabled people—these are not new, or the first time.

And still, the data on people with disabilities is not good enough. Whatever efforts are being made to capture it assume that these are people without disabilities, that all people have the same body, can do the same things. How do we know how many people have tried and failed to get an Aadhaar card if we are not collecting data on these things?

To that last point, Rajesh is in agreement. The data often doesn't feel good enough.

There is no space currently to enter "multiple disabilities" within the database and to write the names of all the disabilities that a person has. It is almost as if a disabled person can have only one kind of disability at a time.

Less laughter this time, more uneasy silence.

Do you think, the last activist remarks, that bodies are only the way your database makes them out to be? Or that they can be other things too?

Later that evening, Rajesh looks at the WhatsApp messages he missed during the meeting. He sees one from his cousin's uncle, whose family knows of a teenager named Praveen in their city. As it turns out, the message says, Praveen has a little bit of a complicated situation—he has multiple sclerosis, and a detached retina. Rajesh works in the department that oversees the issuing of the unique disability ID cards, this uncle has heard—*is there anything that he could possibly do about Praveen's case? Could he ask his boss, maybe, to see if they can get a card done for Praveen from the main office where Rajesh is based?*

Rajesh thinks of his meeting from earlier in the day, of all of the technical errors that were listed. This isn't quite a technical error, he realizes, or a human one—I think the system works okay, but the categories listed for the disability ID card don't work for Praveen. They don't allow us to record the sum of his experiences, as they are, in a way that will let him get the support he needs from school.

He thinks all these things, but for now, he says nothing firm, only telling his uncle that he'll see what he can do. He suspects, however, that there is very little he can do without a national overhaul of categories, something that feels too complicated even to think about. *Not much I can do*, he reassures himself, *this is really more of a problem for doctors first—even if I did want to change categories or make them more expansive, they wouldn't approve.*

As he is preparing to write back to his uncle, he types, and types again, and deletes the words. It sounds strange, he realizes, for this to be his job, and for him to then say he can't do anything for Praveen. Before this, his uncle messages, *for now nothing needs to be done, I think we should wait—online the family checked the status of their application, and it says that the card has been issued.*

Under what disability category, though, Rajesh wonders, hoping that these have been marked as multiple disabilities, but also wondering if the disability percentage estimate is able to capture all of what Praveen needs for his school. He makes a note to check in when they have received the card, tired already at the thought that it could take many more months to rectify if the disability percentage on the card is not sufficient.

When is my card coming?

Praveen asks his father every day,
sometimes even twice a day.

*I'm not sure if I should prepare for these exams,
or if they will only let me sit for them next year now.*

He jokes as a way to cope with anxiety, but is still nervous: What if the card is not accepted, or if the school wants something else, or if his disability on the card is not mentioned correctly, or if his father has to go fight again?

*Don't worry, his father says each time,
the card will come. I am tracking it online.
Two days ago I saw it had been sent for printing.
Today it says dispatched.*

*How long do you think it will take to get to us
after it has been dispatched?*

*Within the same city?
I am not sure, but it should not take more than a week.*

*My exams are less than a month away,
Praveen presses.*

*I know, his father affirms each time,
I am always checking about where your card is.*

When the month for his exams rolls around, the card has not yet reached Praveen's house. *Dispatched*, the website affirms, but there is no other way for his father to locate it. Praveen has been preparing, somewhat half-heartedly, somewhat hopefully, until the school tells him that it will not work for him to take these exams this year.

*Maybe next year then, his father says,
angry but also attempting to placate him.*

*What if the card doesn't come to us by next year, either?
Praveen wonders.*

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