operating a moving vehicle of some sort, etc.).

With both types of devices, instructional time centers on better understanding and adjusting to optical limitations.

As your child or student becomes more proficient with basic distance viewing, critical object or condition awareness and basic distance low vision aid skills on foot, similar types of skills can be introduced and reinforced in the car under what is commonly referred to as “commentary drive” or “passenger-in-car” types of conditions. This will be the main topic of an article that will appear in the Summer Issue of *Albinism InSight*.

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**My Story as a DMV Edge Case: How to Battle Bureaucracy and Win**

By Hannah Birch, ProPublica

*When I showed up with paperwork for my low-vision condition, the DMV was totally baffled. Here’s how I walked them through an edge case and how you can use the strategies yourself.*

“I don’t know what this is,” she said, sliding the form back to me. “I’m not a doctor.”

Thank you, I thought. I realize that. You work at the Department of Motor Vehicles.

I was at a New York DMV office and the form — an MV–80L — is what people with low vision need to submit in order to get a driver’s license. You take the form to your eye doctor, who evaluates whether you’re safe to drive. If the answer is “yes”, the doctor fills out the form, you mail it to the Medical Review Unit in Albany, and then you go get your license.

I have an eye condition called oculocutaneous albinism, which affected how my eyes developed. My retinas — they’re at the back of your eye, helping you see detail — were late to the party. Think of having underdeveloped retinas like using a camera phone from the early aughts: You can see general shapes pretty well, but there just aren’t enough pixels to see small details, like text that’s far away.

Albinism includes other issues that affect things like depth perception and light sensitivity. Basically, I trip and squint a lot. My mom tells me it’s cute. And I’m guaranteed to fail that eye test at the DMV every time.

But even though I can’t read those tiny little letters on the sheet of paper they hold up, doctors in three states now have concluded my vision is good enough for me to safely drive. The doctors fill out paperwork for me and then I steel myself to make it through a situation that feels designed to make me fail: walking DMV employees through an edge case.

The Americans with Disabilities Act outlaws discrimination against, you know, people with
disabilities. But government workers can still make it difficult for you to get what you’re qualified for under the law.

That’s where the woman refusing my form at the DMV comes in, and where I can offer advice about your fundamental rights.

**Know As Much As You Can in Advance**
Understand as much of the process from start to finish as you can so you’re able to tell if someone is bluffing or, more likely, uninformed. A New York DMV spokesperson told me that employees are trained on how to handle documents for people with disabilities. When I asked her why no one seemed to recognize my paperwork, she told me my MV–80L isn’t something an employee would encounter often since it’s intended for another office, the Medical Review Unit. Ideally, the employee would still be able to help me out. But that wasn’t the case for me.

Even though I’ve gone through this process in two other places before, every state handles low-vision drivers differently. So whenever I get a license in a new state, I have to learn a new system. That’s the next step.

**Figure Out As Much As You Can Quickly**
If the system is new to you, observation of what’s right in front of you might not be that helpful. The MV–80L, for instance, is currently missing information about how the approval process works. After receiving your paperwork, the Medical Review Unit sends a letter back to you for you to take to the DMV. I know this now, but I didn’t when I started this process. So I crossed my fingers and mailed the form, having no idea what was going to happen.

(The DMV spokesperson later told me they’re adding language to the form that walks people through the process.)

In the absence of knowing the next steps, a phone call did the trick for me. After a DMV employee told me my form wasn’t for the DMV, I asked her to call the Medical Review Unit for clarification on what to do. She refused. So I called them myself.

Luckily I was connected with someone who explained to me how the process is supposed to work. Anyone who’s an expert in the system you’re battling is an obvious power-up in these situations. Look for them wherever you can, and bear in mind that they might not be part of the organization you’re dealing with.

**Use Keywords**
This is important. While my Medical Review Unit guy was talking to me on the phone, I was taking notes. I latched onto keywords he let slip — the names of computer systems the DMV would use to look up my records, the date they received my paperwork, and the letter codes of the restrictions they would place on my license.

After I got off the phone, I used these keywords in conversations with DMV workers who otherwise wouldn’t have known what I was talking about. I slipped in terms they were familiar with, as if I regularly used them, too. It worked. They stopped arguing and did as I asked. Take away the ambiguity and people lose their ability to hedge with an “I don’t know.”

**Speak Directly and Stand Your Ground**
At one point, the DMV employee I was talking to called over her supervisor. “Why are you refusing to take the eye test?” the supervisor asked me, hands on her hips, like I was being argumentative. (Having an MV–80L precluded me from taking the test at the DMV. I knew
“Because I have a low-vision condition and someone with a medical degree is better qualified to evaluate my case than you are,” I replied, without sass but also without smiling or apologizing.

I talked with design expert Derek Featherstone — he founded a design company specializing in accessibility — about the balance between being open to dialogue and being defensive. “There’s this sliding scale and you’re always somewhere in between, and there’s an appropriate mix for each situation. And I think that changes depending on the situation and how people are reacting.”

**Bottom line:** Don’t get pushed around. As much as you can, know what you are and aren’t obligated to do in a given situation. Be open to talking something through, but don’t get bullied into unnecessary hassles.

**Follow Up With the People Who Helped You Out**

After some tactful maneuvering, I was eventually able to walk out the door with a driver’s license in hand. Then I immediately called the guy in the Medical Review Unit office and gave him my heartfelt thanks. He responded with warmth and good grace.

That became the conversation I remembered at the end of it all. I added it to my collection of “wait ‘til you hear what happened to me at the DMV” stories. And it affirmed for me how, for all the times dumb systems thwart smart people, sometimes smart people can win.

If you or someone you know has low vision and wants to know more about getting a driver’s license in New York, or if you’re interested in talking more about accessibility and design, email me at hannah.birch@propublica.org.

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**Let’s Take a Walk**

By Judi Duffey & Deborah Kitchin

“Do you know where we are going?”, Hannah asked her mother. “Yes,” said her mom taking her hand, “I have been there before. I will show you.”

Walking down the educational document road is new for some of us. There is new verbiage to be learned, new technologies to be discovered, and new ways of navigating obstacles on the path. Some of us have been on the road for a while but a bend in the road has taken us in a new direction and we now need navigational help again. The National Organization for Albinism and Hypopigmentation (NOAH) can be a great resource for you as you journey down the educational document road with your children.

A well thought out educational document with appropriate goals and accommodations can give your child the help they need to progress academically. Create Albinism Resource for Education (CARE) is a program that aims to provide parents with resource information that will aid them in formulating their child’s IEPs, IFSPs and 504s. The Individualized Education Program (IEP) is a written statement of an educational program designed to meet a child’s individual needs and is typically reviewed annually. Children under the age of three can have an Individual Family Service Plan (IFSP), which is a plan for special