

The View from the Passenger's Seat

How can the driver's license dilemma affect a child with albinism?

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I used to daydream about how cool it would be to keep lipstick in the glove compartment

of my car. To me, this image summed up everything that a driver's license

encapsulated – maturity, independence, a social life, freedom.

When I was a child, I was often told, “Maybe you’ll be able to drive, maybe you won’t.” Like many with albinism, my visual acuities were on the borderline of my state’s bioptic driving laws. Nobody could tell me for sure if a driver’s license was in my future, but that didn’t matter. I had put my hopes on “Maybe you will.” I wouldn’t even call it “hope.” I was going to get my license. I was going to be a success story. I had even picked out what I would wear for my driver’s license photo.

I went through driver’s ed in my high school, got my permit to drive with bioptics when I was 16 and endured many months of behind-the-wheel training. I tried and I tried. It wasn’t until I was 18, and realized that several months had passed since I had driven, that it truly sunk in that it wasn’t going to happen - at least, not then.

I don’t know the statistics for how many people with albinism are able to drive. Of course it varies from state to state. Some adults with albinism obtain a license using bioptic lenses in states that allow them. Others may meet the vision requirements for restricted or unrestricted licenses in their state without bioptics.

It’s no secret that driving is a hot topic in the albinism community. After they were told that their child was visually impaired, many parents say one of the first fears was, “What if he’s never able to drive!” For a person with albinism, the question of driving involves an almost laughable degree of maybes. Ask a low vision optometrist if your child with albinism will be able to drive as an adult and you may hear, “Maybe... that depends.” Perhaps that’s one of the reasons that it hurts so badly when one finally has to admit that driving is not in her future. There may have been hope

for that possibility.

For many who have gone through childhood with few barriers and restrictions, being told, “You will not be able to drive,” may be the first time they’re faced with something they positively cannot do. You can play soccer even if your face makes more contact with the ball than your feet. You can participate in activities, class projects, family vacations, but when a teen is denied that fundamental rite of passage to earn a driver’s license, that hurts like nothing else. When I came to the realization that I wouldn’t drive, it felt like a failure.

I’d like to offer some advice to parents who are preparing their children with albinism for the driving dilemma. Whether your child will be able to drive or not, there are some steps families can take to help prepare for the future.

Don’t sugar-coat it.

All the corny pick-me-up phrases such as, “Look on the bright side,” don’t matter to a teen who’s contemplating a revival of the lost art of hitchhiking just to hold on to some semblance of a social life.

And guess what? Not being able to drive sucks when you’re 16. Constantly reminding your child of all the contrived reasons why driving isn’t fun, such as insurance and gas prices, is meaningless. Your child will see right through it. Approaching the issue with

honesty – even when the truth can be painful and ambiguous – is the respectful thing to do.

Now that I’ve gone several years as a non-driving adult, I can concede that there are some advantages, but that is not to say that being a non-driver is always a walk in the park, even though sometimes it literally is. I never have to be the designated driver on a night out with friends (perhaps the best perk of all). I don’t have to pay for car insurance or endure the headaches of parking. I smirk when



newscasters prattle about rising gas prices. I can take a 90-minute nap during my commute to work. But sometimes, I still feel like it would be nice to drive, to be a success story.

If it has become apparent that your child will not be able to drive in your state, give her a chance to grieve. Even if this verdict wasn't entirely a shock to your family, this could still be quite a loss. For most teens, proudly holding up that new driver's license photo and taking that first solo trip to the grocery store is a rite of passage. Be respectful of that, and don't try to overshadow the loss.

Make public transportation a reality.

Not everybody takes the bus to work, but for those who do, public transportation is a reality. It's important for kids with low vision to explore public transit early and to see that it's possible.

I grew up in a small town where the term "public transportation" was a novelty. You didn't walk or ride a bike (unless you were 12), you drove. I wasted many hours in my parents' home gazing out the window, waiting for a friend to pick me up. There were no alternatives.

Occasionally, my family would take the train to Chicago, which was an amazingly positive experience for me. Seeing normal, happy adults taking the train downtown and hopping on a bus provided me with a positive image of public transportation. This was also probably the reason that I made a beeline to Chicago and its wealth of transportation options the moment the high school diploma hit the palm of my hand. Especially for families in rural areas, giving your children opportunities to see and hear and even smell public transportation early helps to show them that it could be a viable and enjoyable option as an adult. It helps to take some of the emphasis off driving as an all-or-nothing thing and show them that the decision

isn't necessarily, "Drive or my life is over."

Similarly, when you go on vacation, take local public transportation, even if it's difficult. Work with your child to plot routes to important sites. If you're going to Washington, D.C., let your child see a map of the area and point out landmarks like your hotel, the White House, the Smithsonian and monuments. Show him how your family will get from point A to point B using public transit. And then do it!



Give your child choices.

Make options available to your child at home so that she isn't stuck relying on one person to get somewhere. This is easier said than done, but the sense of independence and self-esteem that choice brings is invaluable. If possible, show your child that he could ride a bike, walk or take public transit to certain places if appropriate. If mom or dad isn't available for a lift, help your child identify other friends or family members who could help.

To avoid feeling like a "charity case," you might encourage your child to give friends gas money or offer to wash a family member's car in exchange for rides. I still occasionally find myself feeling sheepish asking someone for a ride, but if I have something to offer in exchange, be it gas money, navigation skills or a cup of coffee, I feel a little better about it.

The point is to have options. In my situation as a teenager, it felt like without driving, I had no options, which is a pretty hopeless state. I would have liked choices, even if it was just a choice between two chauffeurs, so the situation felt less limiting.

Conquer your own fears.

Perhaps most importantly, get over your own fears of low vision driving. You're not fooling anyone. If your words tell your child he can achieve anything with perseverance and the right attitude, including a driver's license, but your actions say otherwise, you're doing your

child a disservice. If your child decides that she would like to pursue every option to drive, your support could make all the difference. Besides, people with low vision have proven themselves to be capable drivers.

If you're uneasy about the prospect of your visually impaired teen behind the wheel, start small. While little compares to Matt Bailey's and Brian Evans's *How We See* presentation from past NOAH conferences, it might help if you engage your child in some visual activities. For example, when in the car, ask your child to read the speed limit signs when they become visible, or point out pedestrians crossing a street or no passing zones. You might be surprised.

If your child uses a monocular, give him a chance to test these skills by spotting signs or landmarks in the distance. It might take a little getting used to focusing on moving objects with the telescope, but these skills come in

handy if bioptic driving becomes a possibility.

Find role models.

NOAH events are loaded with success stories of adults with albinism who earned a license and have driven for years without a blemish on their record. You and your child can talk to someone who truly understands what it's like to navigate the driver's license dilemma first-hand.

And don't forget the non-drivers. Especially if your child is feeling saddened that a license may not be in the cards, it might help to hear reassurance from someone who can truly empathize and offer comforting words. It can be overwhelming for both teens and parents to take on the driving dilemma alone. Take advantage of the resources NOAH and its members have to offer.

Did you know?

NOAH offers fun Orientation and Mobility training for teens at the National Conferences!