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The Sky I Don’t See

Heather Grizzle · October 8, 2026

Waxaan ahay Deaf-Indho, waan wadaa gaariga, waxaana door bidaa iimaylka. Qaybta RP, barta Deaf-Indho, iyo AuDHD ayaa sharaxaya sababta aysan midkoodna isku khilaafsanayn.

Waxyaabaha ku jira

1. Saqafka
2. Waxa sector RP ay dhab ahaan qaadato
3. Sababta aan u dhahayo DeafBlind
4. Sababta aan si fiican ugu kaxeeyo
5. Sababta aan ugu jecelahay iimaylka, iyo sababta aanay ahayn qaybta DeafBlind
6. Sababta ay sii ahaato mid aan la arkin
7. Waxa aan weydiisanayo
8. Tixraacyada

Waxaan ahay Dhega-adag (Deaf), waxaan ku hadlaa ASL, oo nooc dhif ah oo retinitis pigmentosa ah ayaa tirtiray qaybta sare ee goobta aragga. Waxaan isku magacaabaa DeafBlind. Waxaan sidoo kale la indho-indhaystaa dadka, akhrin karaa wejiyada, iskaga wadaa gawaarida shirarka, waxaana jecelahay email-ka. Tan waa sababta ay xaqiiqooyinkan midna aanay isku khilaafin.

SI KOOBAN

- Sector RP waxay qaadday wax kasta oo ku dhacaya qiyaastii heerka isha. Aragga bartamaha sida qeybta furka ah ee ~20/30 ah ayaa ku wanaagsan, bartamaha iyo meesha hoose ee goobtuna way cad yihiin.
- DeafBlind describes a spectrum. What defines it is that two losses remove each other's backup, not how little a person can see.
- Minnesota's license test measures the horizontal field only. My loss sits in the one direction it never checks, and the road rarely needs.
- Doorbidkeyga email-ka wuxuu ka imanayaa inaan AuDHD ahay, mana aha indhahayga ama dhegahayga sababtood.

Saqafka

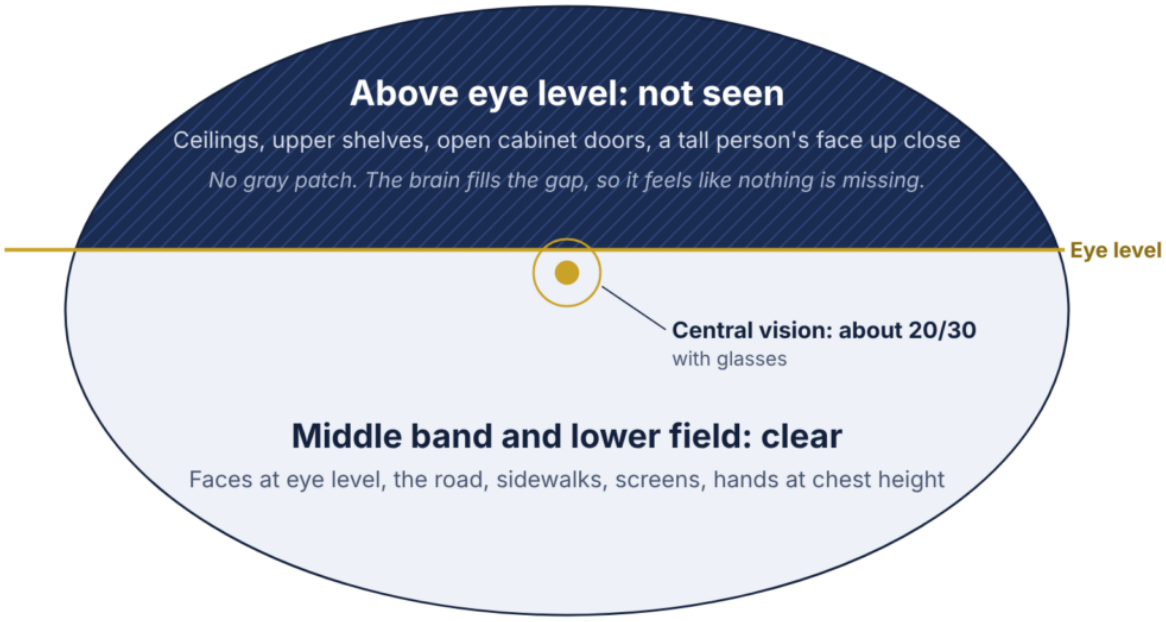
Albaabka armaajada ayaa mar walba i gaadha. Qof jikada ku jira ayaa ka tagay furan, waan ka jeesanayaa saxanka, geeska albaabkana wuxuu helayaa foodahayga ka hor inta aanan garanayn inuu jiro. Taasi ma aha dabacsanaan la'aan, mana aha isku indhaha yaraan. Albaabku wuxuu ahaa oo kaliya meel ka sarreysa khadka ay adduunkaygu ku dhammaado. Laamo hoos u xidhan oo jid lugeyn ah ku yaal, geeska daboolka sanduuqa gaariga oo kor taagan, calaamad dukaan ka soo laalaaday saqafka, gacan iga tilmaamaysa oo ka sarreysa garabka: dhammaantood waxay ku nool yihiin qayb cirka ah oo aanan arkayn. Waxaan adduunka ku socday oo qaybta sare laga gooyay inta badan noloshayda, geesta dadka igu dhow kuwa aanay marnaba dareemin.

Taasi waa waxa qariibka ah ee naafonimadayda. Waxaan ahay Dhega-adag, waxaan ku hadlaa ASL, waxaanan qabaa nooc retinitis pigmentosa ah oo qaybta sare ee goobta aragga qaatay. Waxaan isku magacaabaa DeafBlind. Markaan taas sheego, dadku way ii eegaan sidii ay u eegi lahaayeen qof dhawaan kuu sheegay inuu pilot yahay isagoo safka DMV joogo. Waan la indho-indhaystaa dadka. Waan akhriyaa wejiyadooda. Isla iskaga wadaa gawaarida shirarka. Email-ka waxaan ugu jawaabaa si ka dhakhso badan intooda badan dadka maqalka leh ee aan aqaan. Wax kasta oo ku saabsan sida aan qolka ugu socdo ma sheegayo 'indho la'aan', sidaa darteed ereyga wuxuu u dhacayaa sidii buun-buuninta, ama ka sii xun, sidii sheegasho faa'iido aan u doonayo. Qormadani waa isku daygayga ah inaan sharraxo waxa dhab ahaan socda,

maxaa yeelay kalahaanta u dhexeysa waxa dadku arkaan iyo waxa aan nool nahay waa mid ballaaran oo aan ku daalay inaan ku dhaco.

Waxa sector RP ay dhab ahaan qaadato

Retinitis pigmentosa is a family of inherited conditions in which the light-sensing cells of the retina slowly die off. Most people who have heard of it picture the classic version: the field closes in from the edges until a person is looking through a straw. Mine is a rarer variant called sector RP, in which the damage stays confined to one or two quadrants of the retina instead of spreading around the whole ring. In most people with sector RP, and in me, the damaged quadrants are in the lower half of the retina. Because the eye's lens flips the image, damage at the bottom of the retina erases the top of the visual field. Clinical reviews describe exactly this pattern: degeneration along the inferior retina, matching defects in the superior field, and slow progression over years [1].



Illustration, not a clinical visual field test

Goobta aragga ee kayga, qiyaastii. Wax kasta oo ka sarreeya heerka isha way maqan yihiin; bartamaha iyo goobta hoose way shaqeeyaan.

Si waafi ah, tani waa waxa aan haysto. Aragga bartamaha, qaybta af-fiican ee lagu akhriyo oo lagu aqoonsado wejiyada, waa qiyaastii 20/30 marka la gaadho muraayadaha, taasoo ka wanaagsan dad badan oo aan marnaba is tixgelin lahayn naafo. Xadka bartamaha goobtayda iyo badhka hoose way cad yihiin. Waxa maqan waa wax kasta oo ka sarreeya qiyaastii heerka isha. Haddii aan si toos ah u eego hore, ma jiro saqaf, ma jiro dusha albaabka, ma jiro basta sare, mana jirto weji qof dheer oo ag taagan. Ma jirto sidoo kale bar madow oo meesha ay waxyaalahaasi ku yaalaan ka muuqata. Maskaxdu kuma tusayso godka; wuu simaa, sidaa darteed qaybta maqan ma dareento inay maqan tahay. Waxay u dareentaa wax aan jirin. Taasi waa sababta albaabka armaajadu uu u yahay mid yaab leh mar kasta. Ma dareemayo bar indho la′aan ah oo aan hareereyn karo. Waxaan dareemayaa adduun u eg mid dhammaystiran, kaasoo si kastaba ha ahaatee leh waxyaalo aanan arkayn ilaa ay igu dhufanayaan.

Sababta aan u dhahayo DeafBlind

Waxaan rabaa inaan halkan ku saxiixo, maxaa yeelay saxnaanta ayaa ah dood dhammaystiran. Qeexitaanka ugu adag ee sharciyan ee indho-la′aanta-dhegaha ee Maraykanka, oo ku qoran Helen Keller National Center Act, wuxuu ku dhisan yahay tirooyin: af-fiicnaanta bartamaha ee 20/200 ama ka hooseeya, ama goob aan 20 digrii ka ballaaran, ama luminta sii socota ee u sii jeedka middood [2]. Tirooyinkaygu ma dhowa inay heli karaan heerkaas, mana dhigan karo wax kale. Haddii DeafBlind ay macnaheedu tahay oo kaliya dadka buuxiya xadka u-qalmida federaalka, ereygan ma aanan isticmaali lahayn.

> Qof maqal leh oo leh lumis goob oo fudud wuxuu lumiyaa dusha albaabka. Anigu waxaan lumiyaa dusha afkaygu.
>
> Heather M. Grizzle

But that is not what the word means to the people who live it. DeafBlind is a spectrum, and the large majority of people on it have some usable vision, some usable hearing, or both. The DeafBlind community has long made a point that the numbers miss: deafblindness is not deafness plus blindness. It is what happens when the two losses remove each other′s backup. A hearing person with my exact eyes would hear the cabinet door creak open. A Deaf person with perfect eyes would see it. I get neither

channel for that slice of the world. Every piece of information that reaches me comes through vision, and part of my vision is missing.

Yaa qabta waxa dhaca ka sarreeya heerka isha

Daqiiqad	Qof maqal leh oo haysta indhahayga	Qof Dhega-adag ah oo haysta aragti dhan	Aniga
Albaabka armaajadu wuxuu kaga furmaa korkayga	Wuu maqlaa qarkiisa	Wuu arkaa	Midna
Qof ayaa wici ama uga taagan daloolka salliga	Way maqlaan	Way arkaan ruxmashada	Midna
Gacmo ayaa ka sarreeya heerka isha sheekaysi sare ah	Mid khuseyn maayo	Wuxuu arkaa calaamad kasta	Wuxuu lumiyaa qayb ka mid ah jumladda

Il: Waayo-aragnimada qoraaga

Qaybta luuqadu waxay ka dhigtaa mid cad. ASL waa luuqad muuqaal ah, goobteedana saamaxday waxay ka bilaabmaan dusha madaxa ilaa dhexda. Liis dheer oo calaamadood ah ayaa laga sameeyaa foodda iyo caafimaadka dhabanka. Marka qof dheer oo ag taagan uu igu calaamadeeyo, qaybta sare ee goobtiisa sheekaysigu waxay ku dhici kartaa qaybta aanan haysan ee goobtayda, waxaanan dib u dhisayaa ereyada iyadoo la raacayo macnaha hareeraha iyo badhka hoose ee qaab-gacanta. Marka koox ay calaamaynayso qolka dhexdiisa, waxaan lumiyaa gacmaha kor u kacaya.

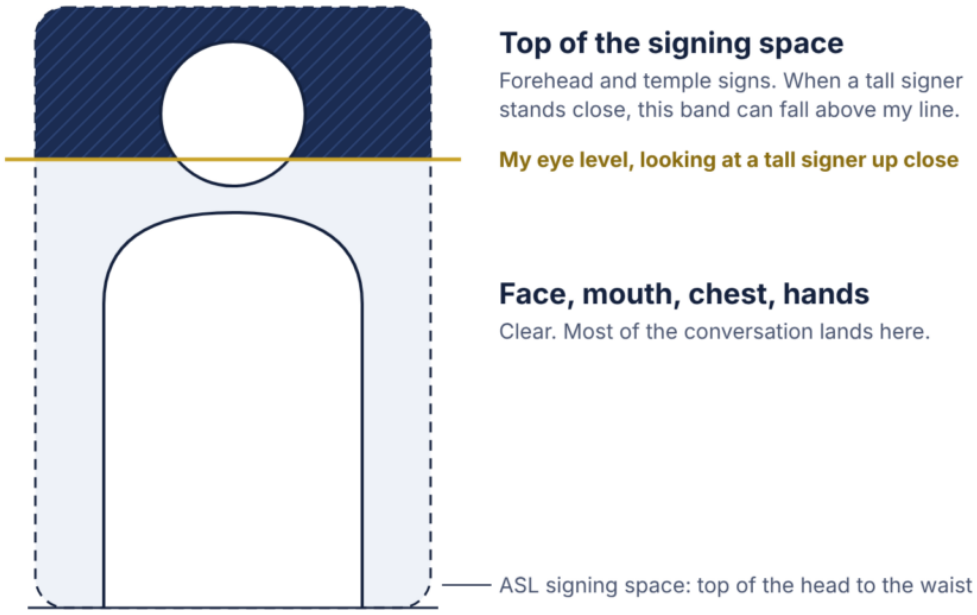


Illustration. How much is lost depends on the signer's height and distance.

Goobta calaamadaynta ASL waxay ka bilaabantaa dusha madaxa ilaa dhexda. Haddii calaamade dheer uu ag taagan yahay, xadka sare wuxuu ka dhici karaa aragtayda.

Qof maqal leh oo leh lumis goob oo fudud wuxuu lumiyaa dusha albaabka. Anigu waxaan lumiyaa dusha afkaygu. Taasi waa sababta aan u dhahayo DeafBlind. Ma aha sheegasho ku saabsan intaan arki karin. Waa sharraxaad daacad ah oo ku saabsan waxa dhaca marka kaliya dareenka ay adduunkaygu ku socdo uu leeyahay qayb laga gooyay.

Sababta aan si fiican ugu kaxeeyo

The question I get most, sometimes asked out loud and more often asked with a look, is how a DeafBlind woman has a driver's license. The answer is that driving happens almost entirely in the part of the world I can see. The road, the lane lines, the car ahead, the pedestrian stepping off a curb, the mirrors, the dashboard: all of it sits in the horizontal band and the lower field, which are clear for me. Minnesota's licensing rule reflects this. To hold an unrestricted license, a driver needs 20/40 acuity and a field of at least 105 degrees measured across the horizontal diameter [3]. There is no vertical field standard at all.

TIROOYINKA MUHIIMKA AH EE WADADA

20/30
Fiicnaanta dhexe ee aan ku haysto muraayadaha indhaha

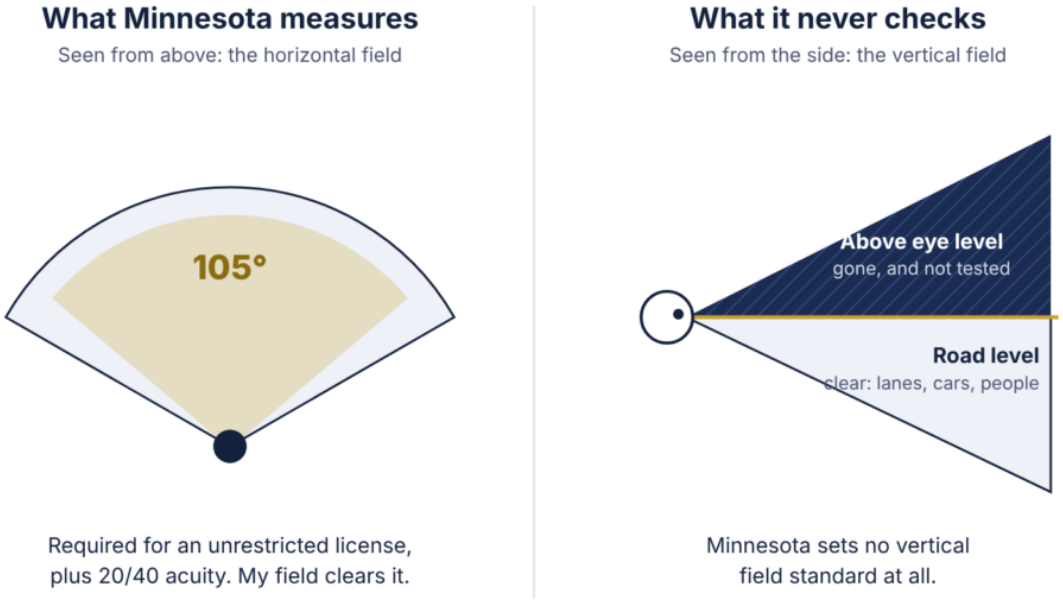
20/40
Heerka Minnesota ee shatiga aan xayirnayn

105°
Berrinka dhinaca ee dawladu u baahan tahay

0
Heerarka berrinka dhaadheer ee xeerka ku jira

Il: Minn. R. 7410.2400; imtixaamaadkayga indhaha

Waxaan buuxiyaa heerka dawladu dhab ahaan isticmaasho, oo waxaa iga haray meel fara badan, sababtoo ah lumintayda waxay ku taal jihada kaliya ee imtixaanku aanu cabbirin oo waddadu si dhif ah u weydiiso.



Minnesota waxay imtixaamtaa sida aad u ballaaran u aragto, ee ma aha sida aad u sarreysa. Lumintayda waxay ku taal jihada xeerku aanu waligiis hubin.

The overhead parts of driving are the parts I have learned to handle on purpose. A traffic light or an overhead highway sign sits near the horizon when it is far away, which is exactly when I need to read it, so I read early. As I pull close to a stop line I lift my chin rather than trusting that the signal is still where I last saw it. None of that is heroic adaptation. It is the same kind of habit every driver builds around their own car's blind spots. The irony is that driving is one of the places where my disability matters least, and it is the single fact most likely to convince people I do not have one.

Sababta aan ugu jecelahay iimaylka, iyo sababta aanay ahayn qaybta DeafBlind

Dadka og in aan ahay DeafBlind oo og in aan jeclahay iimaylka ayaa inta badan isku xidha labadan arrimood. Waxay samaysaa sheeko habboon: waxay aragtaa si liidata, waxbana ma maqasho, sidaa darteed waa caddahay inay qoraan. Sheekadu waa khalad, waxaanan doorbidayaa inaan saxo halkii aan u daayo inay sii jirto, maxaa yeelay waa caddaalad-darro labada arrimood ee la isku khaldo. Waan ku saxeexi karaa calaamadaha calaamadaynta wicitaanka muuqaalka ah. Waan akhriyi karaa wajiga shaashadda telefoonka muuqaalka ah; qofku wuxuu dhexdhexaad ku yahay hortayda,

heerka indhaha, oo waxaa ku taal gaar ahaan qaybta xaglahayga ee shaqeysa. Doorbidaadayda iimaylka waxay in yar la xidhiidhaa indhahayga ama dhegahayga. Waxay ka timaadaa AuDHD-nimadayda, autistic iyo ADHD labadaba.

Live conversation asks for many things at once. I have to take in the language, track the other person′s face and intent, hold my own thoughts in working memory while they keep moving, decide what matters, and answer in real time without the pause that would let me answer well. For my brain, that is not one task; it is five tasks running in parallel, and the cost shows up later as exhaustion and as answers I wish I had given differently. Writing removes the clock. I can read the whole message, let it settle, think it through properly, and send something precise. Many of my best hours of work arrive in deep, focused stretches, and asynchronous exchange lets me meet people inside those stretches instead of being pulled out of them by a call that lands at the wrong moment. Email is not me avoiding people. It is the setting in which I show up as my most competent and most generous self.

> **LABA XAALAD, LABA SHARAXAAD**
>
> If I let people believe email is a DeafBlind accommodation, someone eventually watches me sign fluently on a video call and concludes I was exaggerating all along. Each condition deserves its own true explanation, and each is easier to believe when it is not being asked to carry the other′s weight.

Sababta ay sii ahaato mid aan la arkin

Saddexdayda xaalad oo dhan asal ahaan waa kuwo aan la arkin, waxayna isqariyaan. Dhegoolnimadu ma muuqato ilaa aan bilaabo calaamadaynta. Luminta aragtidayda gabi ahaanba ma muuqato, sababtoo ah qaybaha dadku eegaan, sida la isku socod-eeg, akhrinta, mareynta jidka, waa qaybaha shaqeeya. Autism-ka iyo ADHD-ga waxay inta badan u muuqdaan doorbidaad u eg dabeecad: caadada iimaylka, toosnimada, baahida in la fahmo qorshaha ka hor inta aan la fulin. Marka la isku daro, dadka badankood waxay i arkaan sidii naag Deaf ah oo kartida leh, oo leh aragtiyo adag iyo xidhiidh yaab leh oo albaabada khaanadaha ah. Fahamkaasi si buuxda khalad ma aha. Waxay uun ka maqan tahay lakabka sharraxaya sababta aan u sameeyo waxaan sameeyo.

Inta badan annaga

> waxaan ku socnaa, wadnaa gaadhi, shaqeynaa, oo iimaylka ka jawaabnaa, iyadoo qayb ka mid ah adduunkeenna aamusnaan ku maqan tahay.
>
> Heather M. Grizzle

Qiimaha in si khaldan loo fahmo ma aha mid aad u weyn, taasoo qayb ka ah sababta ay ugu adag tahay in laga hadlo. Qofna ma bixiyo hoyaal naafo oo aysan arki karin, markaas waxaan ama weydiiyaa oo khatar ku jiraa inaan u muuqdo sidii aan weynaynayo wax, ama aan weydiin oo aamusnaan ku qaato qiimaha. Si joogto ah ayaan u eegaa, madaxaygana waan u leexiyaa si aan u hubiyo meesha korkayga ah, oo dhawaaqaas hoose ee digtoonaanta wuxuu noqdaa mid daal badan leh dhammaadka maalinta. Waxaan ka maqnaadaa gacan-salaamid qof ka soo jeeda qolka kale oo waxaan u muuqdaa qof qabow. Jaalaha wax ila la hadla isagoo ku taagan tallaabo ka sarreysa, waan weydaa badh waxa ay sheegeen, oo waa inaan dooranaa inaan mar kale weydiiyo ama aan qiyaaso. Nabrarka wejigayga waxaa loo arkaa khalad la′aan. Mid kasta oo kuwan ayaa yar. Dhammaantood waxay ka samaystaan dareenka nolosha naafonimo oo aan u eg sawirka ay dadku xambaarsan yihiin.

Dadkuna waxay xambaarsan yihiin sawir. Haddii aad sheegto DeafBlind, maskaxda badankood toos ayay ula tagtaa Helen Keller: aamusnaan dhan, mugdi dhan, gacan gacan ku taal. Qaar ka mid ah dadka DeafBlind ah ayaa u dhow nolosha noocaas ah, noloshoodana waa inlagu fahmaa shuruudahooda gaarka ah. Inta badan annaga sidaas ma aha, oo sawir keliya ayaa ka cidhiidhisa dhammaan kuwa kale ee heerka ku jira, oo ay ku jiraan dad badan oo naga mid ah oo ku socda, wadnaa gaadhi, shaqeynaa, oo iimaylka ka jawaabnaa, iyadoo qayb ka mid ah adduunkeenna aamusnaan ku maqan tahay.

Waxa aan weydiisanayo

Ma weydiisanayo in qof uu arko waxa aan arko. Taasi ma suurtagelna, aniguba si buuxda uma arko, sababtoo ah maskaxdaydu way daboolaa farqiga. Waxaan weydiisanayaa wax ka fudud: marka qofku kuu sheego sida jidhkiisu u shaqeeyo, u qaado sharraxaadda inay tahay macluumaad halkii ay noqon lahayd sheegasho la baadhayo marka loo eego sida ay u muuqdaan. Haddii aan idhaahdo DeafBlind, waxaan kuu sheegayaa in sare ee adduunku aanu ii hubna oo aanan haysan dhawaaq

aan ku kalsoonaan karo. Haddii aan idhaahdo waxaan jeclahay iimaylka, waxaan kuu sheegayaa sida maskaxdaydu ugu shaqeyso si fiican. Labaduba ma ahan codsi naxariis ah, labaduba kuma beeni karo xaqiiqadda ah inaan ku wadi karo xafiiskaaga.

HADDII AAD ILA SHAQEYSO AMA AAD ILA SAXEEXDO

☐ Gacmahaaga iyo wejigaaga ku hay heerka indhahayga, hana u qaadan si shakhsiyeed haddii aan ka maqnaado wax ka dhacay sare.

☐ U soo gal aragtidayda halkii aad kor uga salaami lahayd.

☐ Ii qor marka aad rabto fikirkayga ugu fiican, oo waqti i sii si aan u jawaabo.

Haddii aad kulanto qof naafonimadiisu aanay la mid ahayn sawirka ku jira maskaxdaada, ka fekeer in sawirku uu yahay waxa dhammaystirnaanta ka maqan. Kaygu dhab ahaan sidaas buu ahaa, ka hor inta aanan baran sida loo xisaabiyo qaybta cirka aan arkin.

Tixraacyada

1. Coussa, R. G., Basali, D., Maeda, A., DeBenedictis, M., & Traboulsi, E. I. (2019). Sector retinitis pigmentosa: Report of ten cases and a review of the literature. Molecular Vision, 25, 869–889. https://pmc.ncbi.nlm.nih.gov/articles/PMC6937219/
2. Helen Keller National Center Act, 29 U.S.C. § 1905(2) (definition of "individual who is deaf-blind"). https://www.law.cornell.edu/uscode/text/29/1905
3. Minnesota Rules, part 7410.2400, Vision. https://www.law.cornell.edu/regulations/minnesota/Minn-R-7410-2400

TIPS

Know something about a sign language AI system that the public should know? Send it to tips@novaracg.com. Every tip is read by me and kept confidential. If you work in the UK, writing to us is not by itself a protected disclosure under the Public Interest Disclosure Act 1998, so before you share employer information, check your options with Protect (protect-advice.org.uk), the free whistleblowing advice line.

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Sida loo tixraaco

Grizzle, H. M. (2026, October 8). The Sky I Don't See. Novara Consulting Group. https://www.novaracg.com/so/2026/10/08/the-sky-i-dont-see/