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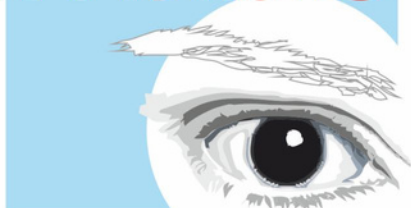
seeing the
invisible



EXPERIENCES OF SUCCESS OF THE EDUCATIONAL INCLUSION OF YOUNG PEOPLE WITH RARE DISEASES AND LOW VISION



seeing the
invisible



Coordinator entity: RedTree Making Projects
Coop.V.

Address: Jesús y María 26 - ground floor.
46008 - Valencia, Spain.

e-mail: info@redtree.es

Phone: 96 015 06 04

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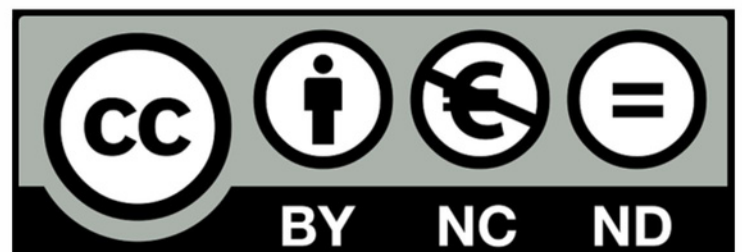
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INTRODUCTION

Low vision is a condition that involves a significant reduction in a person's visual capability that cannot be corrected with the usual means (glasses, contact lenses, surgery, drugs...) and which causes sometimes disabling difficulties to carry out some activities of daily life due to the non-adaptation of the environment.

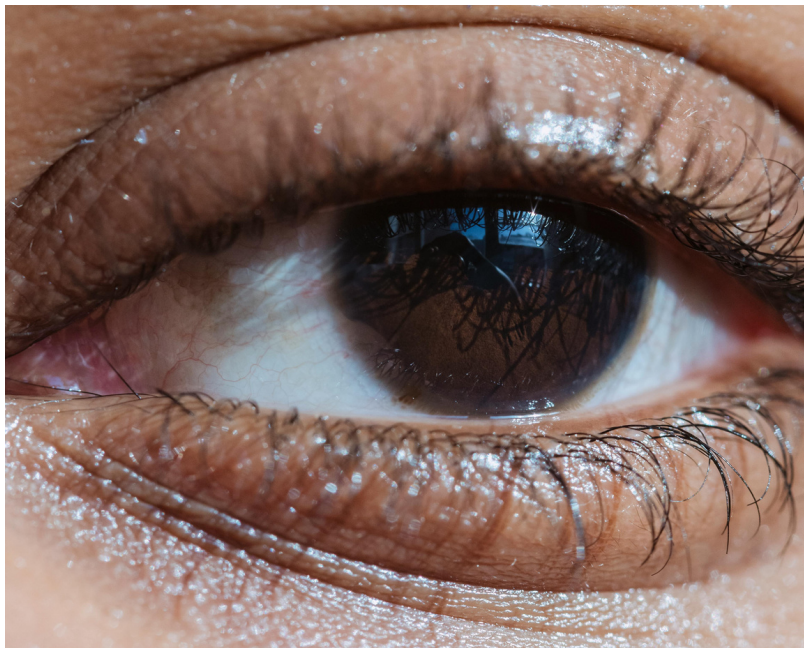
Low vision can result from a series of various diseases and genetic alterations: macular degeneration, retinitis pigmentosa, myopia magna, diabetic retinopathy, glaucoma, and in the case at hand, Albinism and Aniridia.

Albinism is a genetic disorder caused by mutations in several genes, which can affect humans and other animal species. The most visible and well-known effect of this condition is a lack of melanin, although the most characteristic effect is actually related to problems in the person's vision. It is a hereditary and recessive alteration, which means that in order for it to occur in a person it is necessary for them to have the mutation in both their genetic copies. Thus, a person carry the mutation and yet not show it physically.



Aniridia is also a genetic condition, whose name means “missing iris” and which impacts the visual system through iris hypoplasia, retinal and optic nerve problems, not only limited to the eyes, but which can also impact other organs of the body.

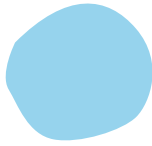
It is a very rare disease, since its prevalence is estimated at 1 in every 40.000 or 100.000 births. People with Aniridia have low visual acuity, usually below 20% (0.2), and they often develop other linked conditions, such as glaucoma, cataracts, keratopathy, photophobia, and nystagmus.



Low vision can also be traumatic in origin or even happen due to infectious diseases. Its symptoms are also varied, making vision sometimes blurred or patchy, prone to glare, night blindness, visual field limitation, tunnel vision, loss of contrast, chromatic alterations, etc. The daily life of people with low vision can be quite impacted due to the lack of environmental adaptations. The World Health Organization (WHO) considers vision as low when visual acuity is below 30% (0.3) and up to a minimum of 10% (0.1), or when the visual field is between 30° and 10° (parameters below these are considered as legal blindness).

Furthermore, each case of low vision has its own specific peculiarities: each person with low vision sees differently and has their own needs depending on their visual problem and their remaining vision, which means facing different challenges at different stages of life and as they progress through successive levels of education. Overcoming them is something that all people with low vision have in common; below we showcase several testimonial examples of young people who have successfully overcome their challenges in various stages of the educational system.





INCLUSION EXPERIENCES



Bea, 19-year-old university student (Spain)

“I’m Bea, I’m a person with Albinism, and I want to briefly explain my experience in the education system and with the various adaptations that were necessary:

The truth is that I don’t have many complaints, especially now that I’m 19 years old and in college. Nowadays in the university almost everything is very well regulated, and the adaptations are quite good. However, it also has some flaws or gaps that, for a visually impaired person, mean that specific difficulties may still arise. It is understandable that a disability department doesn’t know what to do in all cases of low vision, since visual impairment is so broad and diverse. But honestly, I don’t have many complaints.

At the educational level, I had some problems in primary and secondary school. Things aren’t as regulated at those stages as, for example, in college. The issues occurred more because the teachers showed different dispositions to adapt the materials to my specific needs than for any other reason. Teachers have a theoretical obligation to adapt the classroom or materials to the students, but they sometimes don’t, and make it a difficult or even frustrating process to follow the lesson and their explanations at the same pace as others.

But to be honest, I cannot complain too much; I've learned that it's better to do things yourself and not rely excessively on others. I've gotten used to "managing by myself" so to speak, and I know that it is a bit unfair that we -visually impaired people- have to "manage by ourselves" in regarding adaptations or to be on the same level of education at the same time as others, but I think that is better than having nothing.

The truth is that I've learned a lot to be quite independent, which is good in every way. I've learned to look for things on my own, to adapt them and also to complain a little from time to time. Even though I've learned to manage by myself, there's times when you have to complain and claim that it's not right that things aren't adapted to us."



**Carol, 16-year-old high school student
(Spain)**

“I’m Carol, I’m 16 years old and I’m a person with Albinism.

I am currently studying the 1st year of bachelor’s degree in health sciences, and for my studies I mostly use a 12-inch iPad Pro. I’ve tried other things, like the Wacom tablet and other devices as well, but the iPad is the one that has worked best for me and the one that has been most comfortable for me to work with.

I work with all the materials on the iPad, meaning that I have both the book and notebook in the same device, plus all the PDFs and files that we use during classroom lessons, which I find very useful.

The Albinism support association ALBA has helped me a lot when it comes to getting the PDFs of the books I need, because since I need to zoom them in a lot due to my visual condition, some PDFs lose quite a lot of quality when zoomed-in so much, making them very difficult to read, and this is something that ALBA has always managed to solve, providing me with high-quality PDFs so I can read them without issues and comfortably.”



**Enrique, 20-year-old university student
(Spain)**

“I’m Enrique, I’m 20 years old and I study Physics at the University of Valencia.

I have used many adaptations throughout my educational stage: I started using exams in A3 format and with enlarged font in primary school. I also had A3-enlarged textbooks and I learned how to use a telescope so that I could follow the teacher’s whiteboard.

During secondary school I started having a screen on my desk to display the digital whiteboard, since the telescope was starting to fall short, and in addition I continued having the textbooks as PDFs so I could zoom them in without issues.

Currently, in university, I’m using a device called Bemyvega^[1] to follow the teacher’s whiteboard and their lessons. This consists of a set of cameras that display three different points of view in my tablet: one camera is fixed, focused on the whiteboard, another camera focuses on and follows the teacher, and the third displays the presentations. All of them allow me to zoom-in as much as I need to.”

^[1] Bemyvega is a platform that provides accessibility tools that help people with low vision, low hearing, color blindness, or ADHD.



**Ramon, 19-year-old university student
(Spain)**

“I’m Ramón, I’m 19 years old, I have nystagmus and I currently study a degree in Philosophy at the University of Valencia.

Regarding materials or adaptations, I currently use *Bemyvega* to follow the lessons, a screen connected to a laptop that allows me to record and zoom into the part of the classroom where the whiteboard is, also allowing me to record the lessons or the whiteboard’s contents. During exams I use materials with enlarged font and sheet size (A3), and teachers also upload documents online, allowing me to handle them at my convenience and when I need them.

During elementary school my family fought for a series of adaptations, such as the use of tablets like the Wacom, and although there were some teachers who made things more difficult because they didn’t want to learn how to use that type of tool, there were others who helped me more.

Generally, although I am not a 10/10 student, I consider mine as a significant story of overcoming the obstacle of low vision and having passed the academic cycle previous to university with very acceptable grades.”



Alma, 19-year-old student (Norway)

“My name is Alma, I’m from Oslo in Norway, I was born in 2004 and I’m 19 years old.

Last spring I finished 13 years of school in Norway. I also had a job there, in which I organized events for young people in museums in Oslo; my role was to plan and organize them and transmit the art in an interesting way to young people. Some of my hobbies are to knit, to run, to be with friends, play games and watch series.

Right now I attend something called Folkehøgskule^[2] in Denmark, where I’m living since half a year ago because I have a gap year. This is a school teaches quite different subjects like theater, philosophy, psychology, and some art subjects that you can choose if you find them interesting, but you don’t get evaluated and it’s mostly or just for fun. Learning is mainly community-based here, it’s very social and fun and we always play after class. We also have different conferences in the evenings; for example, last night a Holocaust survivor was here and taught us some important things, but I mainly focus on relaxing and having fun with friends.

[2] Specialized secondary education centers that allow students to learn a wide number of lines with multiple electives to facilitate specialization and the discovery of one's own interests.

My first day of class here was what I would consider very normal. I was excited, maybe a little nervous, but mostly excited, and people responded very normally. My day-to-day life here is also very good, I feel like people want to be helpful when they deal with me; if I have trouble seeing things, I ask those around me and they are very helpful and understanding.

I think I'm good at adapting: I find solutions when I can't see things. For example, I use my phone a lot to take photos and zoom-in, or if I have the chance I zoom-in on the things I need to see. However, there are still some issues when seeing who people are from a long distance.

Regarding the adaptations for my special needs at school, I think my screen-zooming PC –I could zoom in with my fingers on the screen– was very useful, I used it a lot. It was important to me that my support mechanisms were effective, fast, and didn't slow down my work, so I used my PC a lot with the zoom and took a lot of pictures with my phone as well.

Besides academics, I had a lot of good friends, so on the social side I had a good time at school. I loved going to school. I had my own mechanisms when it came to helping me with vision: when I couldn't see, I used my phone or computer, or I just told the teachers that I couldn't see clearly and they were very understanding and helpful.

My advice to teachers is to provide the contents of their lessons as PowerPoint presentations to all students before class, so they can display it on their own computers, use the zoom-in, and it will be much easier to follow the explanations of the classes.

Also, that it is always very helpful for teachers to write in large letters on the board. But the most important thing is to have good communication between the teacher and the student when dealing with students with low vision, since the help each individual may need varies a lot, so good communication is always key.

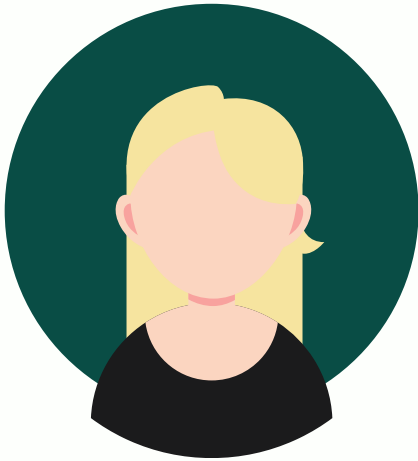
On the other hand, providing the student with low vision with enlarged-font exams is very good, because even though we have more time to finish them, we need the big letters because in this way it's easier to notice mistakes –you read with a lot of mistakes when you have low vision– so large fonts in exams is very useful, although I think taking the test on the PC would be the best. Using the computer more than physical things is very good and something I appreciated a lot. I always asked teachers to use the computer when possible, and they allowed it and was very helpful.

Another tip for teachers is to acknowledge the student by name when addressing them when they raise their hand to speak. For example, when I raised my hand I didn't have eye contact with the teacher, so I didn't know if or when I could speak, so when they addressed me like "Alma, it's your turn", that was very helpful.

My advice to other young people with low vision is to find their own support methods, because the best techniques and mechanisms vary from person to person. Also that they shouldn't let low vision get the best of them, because it can be overwhelming not to see, but instead of thinking about the things they can't see, think about everything else you're good at.

Another thing I did in class was to focus a lot on what the teacher was saying: I wrote down basically all the teacher said instead of just copying what they wrote on the board. But I think everyone should just do what works best for them and not give up. It can be easy to give up, but I would tell everyone not to give up, even if it's hard, of course.

Don't be too hard on yourself and don't be ashamed: you are good enough!"



**Sunniva 20-year-old university student
(Norway)**

My name is Sunniva, I am 20 years old, and I live in Sandefjrd, Norway. I'm currently studying a Master's degree in Psychology at the University of Troms.

My first day in class was great, I felt like any other student, I didn't feel out of place nor that my disability was something remarkable. Both my classmates and teachers responded with absolute normality, the students were happy to get to know me, there was nothing different from anyone else.

The day-to-day at the university is great, I have great classmates and great teachers, and I've had many good experiences throughout my school and college years. At this level, adaptation mechanisms work a little differently than the previous stages. The university is not obliged to provide anything, but at the beginning of your studies you can ask what tools or mechanisms they can provide, there's always something, like extra time when taking your exams.

Even with special needs you want to be in the same classroom as the other students, but there may be some adaptation problems in some classrooms, often due to technical problems and other times because the teacher doesn't agree with the adaptations you want to have, although this is getting better. For example I like having the lesson as a PowerPoint beforehand, and although they are not obligated to give it to you, they usually try to make the difference or gap with others smaller, even if it cannot be completely closed.

Regarding my school period, when they started to provide me with some adaptation measures these weren't officially in place, since the department didn't really exist. It was only when I got to university, halfway through my study years there that I received the information that they had changed the system and it has now improved considerably.

During that period I found it very positive that some teachers were indeed open to give you better accessibility even if they didn't have to, and also that I didn't continuously feel like they treated me as a person with low vision.

Throughout my academic life I would have improved some things, like making various measures more accessible to make things on equal footing to all students, making the gap not so big, and that they had given me access to those measures from the beginning. When I started all of that was a very high mountain to climb, and that caused me a lot of stress; you have to really be engaged to receive any accessibility measures, and you have to have great motivation to get through all of it.

Regarding teachers and school staff, I would ask them to be more involved in the whole process for those students, to ask what their needs are, and to do so not only at the beginning of the course, but also during it, because both teachers and students will have to progressively learn what is needed. In my case, when I started at the university, I was in a new environment that I knew nothing about, so I had new needs that also changed over time, and as such, adaptations shouldn't be rigid nor unique to the initial period. When the stages or levels of study change, the lessons are different, and accessibility measures must adapt at the same pace with them.

My advice to other young people with low vision is to never give up, to find different and new solutions on their own, especially benefiting from technology, which is now everywhere and makes things easier and better to learn than the traditional way.



Marta, 25-year-old university student and worker (Italy)

I'm Marta, I'm 25 years old, and I live in Padua, where I studied psychology at the University. I am currently starting to establish myself in the world of work, although I will not officially become a psychologist until I pass my state exam.

I work now in schools as an hourly teacher doing substitutions and also as a social worker in some cooperatives related to disability, but I am particularly interested in the field of neurodevelopment, and when I become a full psychologist, I want to continue working on evolutionary development.

In terms of my work, I have tried to fit into some contexts that I have considered inclusive. In all the contexts in which I have found myself, it was not only me who tried to adapt to the environment, but also the environment has always tried to find better solutions to guarantee the best possible quality of work.

The tools I use at work are mainly sunglasses and prescription glasses, and I also sometimes use magnifying glasses when the texts are particularly small, or the PC always as a support and help.

Regarding the school environment, since primary school I always recognized my condition of low vision and photophobia, and I was always lucky enough to have teachers interested in my inclusion within the school environment, not only from the educational and learning point of view, but also from the social point of view. Since I was a child I always had the opportunity to use devices like electronic whiteboards, sometimes enlarged textbooks, and I've been allowed record some lessons to listen to them again later from home to complement my notes, because I often missed some parts on the whiteboard.

Another important factor is that I have always used contact lenses adapted to protect my eyes against the sun, so in this sense during elementary, middle school, and high school I would sometimes use drops to lubricate my eyes during classes.

I have always thought that my schools were inclusive environments, but there were some episodes that made me realize that there's still much more that can be done regarding inclusion and adaptations. An example that I sometimes give of not feeling included, and to which I think teachers should pay attention, was when manual activities were proposed in which fine manual dexterity was required, and in any case a certain hand-eye coordination. In those cases, for example when we were asked to sew, it was really very difficult for me to see the needle go in and out and follow the thread.

Despite this, I've also experienced situations where inclusivity has been highlighted, like during sports hours at the gym, when new rules were integrated to ensure that games of volleyball and basketball were feasible for me.

One piece of advice I would give to teachers would be to remind them of the importance of always listening to their students, listening to their needs, and to remember that the condition of low vision is different for each individual. One visually impaired person doesn't necessarily see like another person also with visual impairment they might already know, the same as a person with photophobia doesn't necessarily have the same photophobia they may have studied or read about in a textbook. Children, teenagers, and adults also with low vision and photophobia know how to describe how they see and can also state what they need, you just have to give them the space and way to feel safe to open up.

It is also important to remember that the student shouldn't be constantly stigmatized and reminded of their limitations; instead they should have their resources highlighted, or when they find a limitation, remind them for example of everything they are indeed capable of doing. This is positive and useful for the child, their peers, and for the teacher themselves, so they continue to believe in the possibility of learning.

On the other hand, as for the advice I would give to a younger visually impaired person, I would tell them not to be afraid to tell their story, not to be afraid to ask for help from the people around them when they need it. Also, I would remind them to believe in themselves, to be confident in their own resources, and to try to discover them every day. Remember that these resources are there and are yours, not just your limitations.

And to students with low visions, during the educational stage, I would remind them that teachers often haven't had the opportunity to know everything about low vision and visual or other physical conditions, so you also have to be patient, have some tolerance, and explain them, as many times as necessary.

Don't get anxious if you aren't immediately understood, but remember however, that disability can also be a taboo subject for some, so have this kind of tolerance as well.

That said, remember to never accept discrimination; the same as you have to be patient to be heard, you must also have the strength to say "no" when you feel discriminated against or stigmatized because of your condition.

Lastly, I would also want to remind you of how important it is to build solid and wholesome social relationships. School is not only a space for learning, but also a place to socialize, so I would like to invite especially all younger students to integrate into social groups and understand the benefits that these groups can bring them, both from the learning point of view in the school environment and from the emotional well-being and self-esteem point of view.





Michael, 32-year-old worker (Italy)

I'm Michael, I'm 32 years old, and I live in Osimo, in the province of Ancona, Italy. I work as a tour operator in a company that organizes and creates tour packages. I deal with marketing, specifically business customer relations, so you can say I'm a marketing guy.

My main passions are traveling -obviously, which connects completely with my work-, I like walking and trekking in the mountains, and also physical effort from a sports point of view. I really like listening to music, like classical music, to attend shows, concerts, opera... and I like sports in general.

Regarding my first day of school, I unfortunately don't have a very clear memory of it, but what I can say is that especially in elementary school and high school I didn't feel any particular problems with studying. I remember that my teachers always tried to find solutions or at least to carry out a less frontal and more group-based didactics, with practical work also in terms of explaining new knowledge and concepts, and they placed great emphasis on teamwork and research.

I can say that what I was taught at school was a very humanistic learning, to face challenges, problems, and difficulties, to try to find other paths and solutions to reach the didactic and learning objectives. And I took this learning to the university and then to the workplace.

In terms of difficulties, my biggest challenge or problem during school, which was also a considerable negative experience, was in high school, when the only adaptations I used were enlarged photocopies and little else. I realized that as I progressed in my studies and having more and more of a love for studying, I felt the need to know how I could get to the same level as others, because with the means I had at my disposal I simply couldn't. So I asked the teachers for solutions to the problem to catch up with others, to find solutions that were ideal for me, and their response was that "why should we rack our brains to find a solution", since graduation was just two years away, they told me to just keep going as I was for those last two years and just get the diploma and that would be fine.

I experienced that situation very badly in the last seven or eight months before the state exams. My teachers noticed my behavior regarding studying, which was obviously not positive. I had tried to look for other solutions, but I couldn't find an answer, not even at a didactic level. So they realized this and, without asking, they found their own solution, which was for me to use a video magnifier -a tool that I didn't understand because I didn't even know it existed- and they gave me extra time to do my homework in class. The purpose was for me to write in capital letters, because they said that I could read my writing more easily. However, it was hardly legible to me, so they had done that work mainly for them, to correct my homework; it was an adaptation for their side, so to speak.

It was difficult to adapt to the new study system, at first I didn't accept it and I tried to use and do what I had before; I felt excluded by my classmates, because I seemed privileged in their eyes, even if I understood that these aids were indispensable to me, but I refused them, understandable also for my age back then, 18 years old. Finally I had to grit my teeth and try to do my best to get to the state exam in these conditions.

My advice to teachers is that they should do a lot more practical experience in their teaching versus just the theory explaining of certain concepts, since these practices make an important contribution to the final goal, which is to involve all students, including visually impaired students, even in the evaluation of inclusion and adaptation measures in the classroom so everyone can make their contribution and reach the learning goals.

Another advice is to not just display graphs, charts, or any other mathematical formula or image on the whiteboard without describing it; teachers must describe what they're doing on the board or what's being displayed on screens, and try to explain as much as they can, not only to any student with low vision in the classroom, but to everyone. This is good for all students, and visually impaired students won't be reminded again that they have special needs compared to others.

Finally, my recommendation to any visually impaired student is to face their difficulties step by step, to try to understand their limitations and notice their obstacles but not give up when they do, to tackle it one step at a time. This, in my opinion, opens many opportunities for growth and positive self-discovery.



CONCLUSIONS

Young Europeans with low vision generally have a high resilience when facing the challenges posed by the environment. This ability to face their limitations is the main driving force that leads them to successfully achieve their life goals, and the obstacles they find in their training are usually more related to a lack of training of teachers regarding the needs of adapting the environment to low vision and their use of the tools of students with this condition. These young people have a good ability to ask teachers and schools for the proper and necessary adaptations.

On the other hand, the rest of their classmates tend to be sympathetic to their personal situation and socially accept students with low vision. This doesn't mean that there may not be specific problems, but the acceptance and integration into the education system seems to be good.

Youth with low vision show a high ability to adapt to the environment through their use of the corrective tools available to them. It is usually not them who have issues in learning how to use these tools, but teachers who may have more issues when modifying their work habits to include them effectively.

Schools and the systems that structure them have these adaptive tools available, and provide them in the educational environment without many problems for any students who need them, which makes life easier for them. However, national education systems must make a greater effort to train teachers in the use and specific needs related to the tools that students will use in their classes.

The current general aim of European education systems towards inclusive education has led to a fundamental structural change from previous systems, which used a segregation of pupils that proved to be negative. Applying equity to these increasingly inclusive environments, which generally adapt and assume the principles of universal design, is the best way to overcome individual functional diversity and achieve fairer and more plural societies.





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