INTERNATIONAL DAY OF PERSONS WITH DISABILITIES

3 December 2021



INTRODUCTION

The International Day of Persons with Disabilities (IDPD) is observed annually on the 3rd of December, to promote the rights and wellbeing of persons with disabilities in all spheres of society and development, and to increase awareness for the situation of persons with disabilities in every aspect of political, social, economic and cultural life. The theme for the IDPD this year is "Leadership and participation of persons with disabilities toward an inclusive, accessible and sustainable post-COVID-19 world".

Space exploration has historically been dominated by persons without disabilities, while astronomy has been a largely visual science. To celebrate the IDPD, we interviewed several individuals driving new ideas and innovation in fostering accessibility in space. We hope these articles will encourage collective efforts to make space more inclusive and equitable for all.

The interviews have been edited for brevity and clarity.

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"Astronomy is a visual science. It was born because people observed the lights in the starry night. But we need to ensure inclusivesness. It is a Science for all and we need to transmit the knowledge in different ways."

SIGN THE STARS: ASTRONOMICAL TERMS IN SIGN LANGUAGE

An interview with Dr. Beatriz Garcia

Sign language is practised in almost every country. However, independent development of signs across diverse heritages and different cultures meant that specific signs to designate common objects or identical situations differ. Moreover, many astronomical terms have no equivalent hand sign in any sign language. This makes the deaf community particularly disadvantaged in communication.

In December 2017, the International Astronomical Union (IAU) published the first international comparative list of astronomical terms in sign language with 47 of the most commonly used astronomical terms. In April 2021, a second list was published with 86 new terms, including neutron stars, gravitational waves and the expansion of the Universe. The main goal of the project is to make astronomy more widely accessible, as a step towards removing structural barriers that persons with disabilities face. The project also aims to stimulate reflection on the differences between various languages, to help communities

develop their own signs for particular astronomical terms that they don't already have signs for, and to promote discussion in deaf communities about the wonders of astronomy.

We speak to Dr. Beatriz Garcia, coordinator of the project, on her mission to make astronomy accessible to all.

What is special about astronomy that makes it so attractive and relevant to everyone on Earth such that no one should be left behind, including persons with disabilities?

Astronomy, according to many people, is the oldest scientific activity on the planet. It is the first scientific approach to nature. There is a need to explain the lights in the sky, or the repetitive processes in the planet like day and night, or the seasons. This knowledge has enabled human beings to improve their quality of life. Hence, astronomy is more than a science, as it is part of our experience as

Dr. Beatriz Garcia is an astronomer, PhD from the National University of La Plata, specialized in stellar astrophysics, high energy astrophysics and development of detection technologies. She is deputy director of the Institute of Detection Technologies and Astro-particles (ITeDA), a member of the international collaborations at the Pierre Auger Observatory and QUBIC, an



observational cosmology project. She has been president of Commission 1, for Education and Development of Astronomy of the IAU (2015-2018), founder of the IAU Working Group of Astronomy for Equity, Inclusion and Diversity, National Outreach Coordinator in Argentina for the IAU-Office of Astronomy Outreach (OAO) (2014-2021) and currently leads several projects that develop tools for multimodal data analysis. She is a college level professor, but also teaches at high schools to show the power of the sciences to young people and to develop STEM special programs.

human beings, as we are a product of the evolution of the cosmos, and also a part of the cosmos. The link between human beings and the stars and the universe has always been there. Astronomy is a particular science as everyone is curious about the origin of the universe and the scenarios for the possible end of the universe. And it is a door to enter into other disciplines, as the initial interest in what is beyond the stars exists in everyone.

What is the aim of this project?

This project aims to make astronomy accessible for all. Considering that astronomy is largely a visual science, for everyone regardless of disability to be on board, knowledge must be transmitted in various ways. In the same sense that people without visual impairment develop a special feeling when they see a marvellous picture, we need to permit everyone to feel the same. For this, efforts should be made to transform the image into something palpable. This involves changing the approach of knowledge into a multisensorial experience. The aim should be towards transforming visual images into ways in which we can use our five senses.

How are persons with disabilities involved?

We invited persons from the deaf community to create the terms, if they have not been created yet. Then we compare the signs in different countries, so as to identify whether there are any connections, and whether it is possible to propose as a universal sign

for that term. For the moment, it seems not possible to create a universal term, but it is very interesting to identify similarities. For example, it is very interesting to see that the signs for sky and telescope and are similar across countries, so it may be possible to propose a universal sign here. But on a whole it is not an easy task.

We are always in contact with the deaf associations from all over the world to make sure that what we publish is correct. And they are more than happy to help because historically no one asked them; people tend to produce things or propose things without first consulting the target audience. But we work in the opposite direction. First we ask, then we publish only when we are sure that the deaf community agree with us. This involves iterative discussion within and with the deaf community. To choose the signs, community consensus is needed, and the process is repeated in every country. For this reason, you cannot advance fast. But overall, it's a fantastic exchange and an amazing thing. Very touching!

What makes you most excited about this project?

This project is more than just transmitting knowledge. It is also about the process of inclusion and inviting persons with disabilities to be on board. Persons with disabilities often feel that they are segregated, discriminated. However, our approach is the opposite. In our project, we invite them in the development. Our approach follows the principle of user-centered



The term "astronomy" as represented in sign language in different countries. Credit: IAU.

design and there is constant feedback from persons with disabilities. We ask them what they need and adapt to their demands instead of imposing on them what we want. In doing so, we attract more people on board to advise us and produce with us on a very solid base.

How will the project develop going forward?

We are inviting more people to be part of the expansion of the list of astronomical terms in sign language. We are trying to produce a whole set of materials available to all, especially for schools. In the development process, we continue to consult the deaf community through iterative proposals and discussions. For example, out of the eighty-eight constellations, we propose to start with the thirteen zodiac constellations. We are making a first connection between the constellation and animal and then we try and work towards a sign.

A lot has happened in the last two years especially regarding the COVID-19 pandemic. How has this project been affected by the pandemic?

The second list of signs was made almost completely during the pandemic. For us, the pandemic was not an impediment. It was possible to contact the deaf associations and other groups in different places through online platforms. On the contrary, more people could be reached.

Has the pandemic helped you to see different perspectives? Do you feel hopeful that there will be more opportunities for disability inclusion with this project?

Yes, without any doubt. By connecting via the internet, we realized that many people all over the world are interested in the project. We produced conferences and workshops using online platforms and managed to reach thousands of persons, some from very far locations and isolated communities, including those who with limited finance or limited mobility who would not have an opportunity to travel to a central place for the workshops. The pandemic showed us an opportunity.

Has anyone ever questioned or doubted the necessity or relevance of this project? How did you respond?

In general, people are very interested. The people who are not interested are those who don't know about the project. Thus more people need to be informed and awareness needs to be increased for the project. Those who are aware always have a proposal, or can suggest participants.

How can we move beyond tokenism, and what kind of paradigm shift is needed to achieve real disability inclusion?

Yes, there are many tools and developments that are superficially inclusive. We need more persons with disabilities in the development group, as a developer, not just a user. We need more interdisciplinary and inter-ability groups. This is also the approach of the user-centered design. If not, we will never reach real inclusion and we will not remove the systemic barriers.

How can persons without disabilities work closer with persons with disabilities?

Persons with disabilities tend to say everything is fine. They prefer to be in good relation with the rest of the world and avoid establishing a discussion or creating a perception of burden. Sometimes due to fear of judgement, they may hide their true feelings, especially negative feelings, so it is difficult for them to express the challenges that they face. Therefore, you must establish a good relationship with them first of all, then explore carefully their ideas and feelings. For us, we use focus groups with different formats to try to extract their honest opinions.

"Persons with disabilities need to represent the reality in different ways and we need to learn from them to enlarge our own vision of the cosmos by using all our senses and to liberate the power of the brain to approach nature."

Based on your experience, how have space science institutions adapted to include persons with disabilities over the years?

Well, we are trying. Awareness to the challenges is being raised. But it is a very hard road. Even the adaptations to access buildings for persons with limited mobility are recent things. And this is just one example. Imagine other adaptations that are required for those who are blind or deaf. Some adaptations are not good because they were implemented by persons without disabilities without the consultation of persons with disabilities. It is a long road to convince the authorities that consultations must be done.

In your opinion, what can universities, policy makers, space agencies etc. do for persons for disabilities?

First of all, they must recognize that there is a problem. Secondly, they must hear the proposals and suggestions made by persons with disabilities.

Moreover, IAU has produced a document "Springboard to Action: Recommendations for improving equity, inclusion and diversity in Astronomy" to promote inclusion of astronomers in universities etc. First, we must start with ourselves, we must change our mindsets, then we can change our near-space and the planet.

What more needs to be done?

The topic of disability inclusion must be part of the discussion in more forums, not just within the IAU or among astronomers or universities. We are sure the United Nations is the right forum to speak about that and we are ready to help. In addition, we must also address the challenges faced by women in Science, Technology, Engineering and Mathematics (STEM) to make progress in diversity and inclusion.

Finally...

I want to give my thanks to persons with disabilities because they teach me a lot about how to approach the universe. We have preconceptions about everything. But when you are ready to recognize the diversity and to hear what the other is ready to share with you, you will improve your own perception of nature and you will recognize the other as an equal. In this sense, I am very grateful to persons with disabilities for teaching me so much. Thank you.

For more information about the IAU Astronomical Terms in Sign Language project, please visit https://iau.org/news/announcements/detail/ann21024/



Credit: Beatriz Garcia.



"We may seem like resource intensive and challenging to deal with at first glance, however, note that we also have gathered and possess so much knowledge and so many experiences.

There's so much more to us than the eye can see.

Make use of all these experiences! Nurture us, and we will grow to become foundations of big things."

SIGN THE STARS: DEVELOPING THE LANGUAGE TO QUESTION, EXPLORE AND UNDERSTAND THE COSMOS

An interview with Dr. Marius Eide

From an early age, Dr. Marius Eide was amazed by the countless stars in the night sky. The breathtaking nature of what exists beyond us ignited his curiosity, as questions arose in him on who we are, whether we were alone in the universe, whether there is a God, what the concepts of time and light are, and how and when everything all began, and will end.

Dr. Eide found science appealing through astronomy, as he knew that some of the hardest questions we face are explored by astrophysicists. Inspired by the reward of knowing that he would be joining forces with some of the brightest minds to advance our common understanding of the world, he pursued a career in this field.

In this article, Dr. Eide discusses his role as the national contact for Norway in the International Astronomical Union Astronomical Terms for Sign Language project, and how his work contributes to

building an inclusive and accessible environment for scientists and for society in general.

Why are you passionate about disability inclusion in science education?

I have experienced the privilege of living in a society that strives to empower people with impairments. As a deaf student, I only had one classmate at school to study advanced mathematics with, and yet, the school gave us the chance to do so, even though the cost to pay interpreters to give two students special classes must have been enormous.

The costs were covered by the Norwegian state, as it is a right that all deaf students have. Had we gotten a no to taking classes in physics, chemistry, mathematics and biology, and instead, had been forced to follow most of our classmates who chose social sciences, I doubt the doors to astronomy would have been open to me.

Dr. Marius Berge Eide (b. 1990 in Oslo, Norway) is a theoretical astrophysicist who also is deaf and a sign language user. He has authored several peer-reviewed articles on themes such as cosmology, black holes and radiation. He was a nominee to the 2021 Rudolf-Kippenhahn-award. In 2021, the IAU released the second list of astronomical terms in sign language. Dr. Eide chaired the work with the Norwegian contributions. He has been an advisor to the IAU

Inspiring Stars exhibition and the ESA/IAU/SKAO/ESO Saras2020 accessibility symposium. He is today a teacher of deaf students, a project manager in a sign learning app company, and the founder of a space startup.



IAU Astronomical Terms in Sign Language workshop. Credit: IAU.

It would probably be more costly to a society to have impaired people incapacitated at home, perhaps living on welfare benefits and not producing any taxable income, and worse, being barred from a obtaining an education. The saying is that an impairment doesn't become a disability or a handicap before you experience barriers because of said impairment.

Please tell us about your involvement in the IAU Astronomical Terms in Sign Language Project.

I got involved in the project in 2018 through my doctoral supervisor, who put me in touch with the IAU, when the project was aiming to develop a second list of signs. At the IAU's General Assembly in Vienna in 2018, I sat down with my interpreters, and we wrote down all the words that we often used that weren't on the first list, and we released the second list in April 2021.

It is up to the national contacts of each country to choose how their contributions are developed and submitted. As the national contact for Norway, I have chosen to collaborate closely with the sign language community through an established and authoritative forum under the national language council. Over the course of a year and a half, a panel of sign

language experts gathered multiple times to develop and propose signs. I provided this panel with direction and assistance, from the early discussions, to our final filming of the content.

It has been up to this forum to decide the astronomy signs, not me. At the end of the day, it is the sign language users, where a big fraction of them is deaf, who decide if a sign will be adopted into the daily language. The governmental forum I have worked with has been clear that they only provide "suggested" signs.

I hope this project will move forward and that we will see additions of signs to our existing lists, now from countries that haven't yet done so. A good starting point would be the names of the planets.

How do you think the sign language project could help to contribute to a more inclusive and sustainable world going forward?

It is perhaps not very surprising that people with impairments experience them as disabling. However, I believe in a world where no one is disabled. Societies must change to make this a reality, and it is not solely up to the unimpaired to accommodate the impaired to remove barriers. The impaired also must

lead way by showing how this can be done.

With the IAU Sign Language Project we make sign language visible and show that it is fully capable of conveying some of humanity's most intricate and hard-to-understand phenomena with a visual brilliance that provides meaning and context where the written and spoken words don't.

Take, for example, the word "gravitation" – what is this about? In Norwegian Sign Language it is signed as two crossed palms each pulling and being pulled towards the other. Here, the sign itself makes it clear that massive bodies both pull at each other, circumventing the classical misunderstanding that only one object, like the Earth, pulls at the other, such as humans jumping on its surface!

I hope that the project can be used to debunk myths about deafness and show that deaf people are capable of just about anything.

I also hope that the project will bring sign language to a person that otherwise wouldn't have learned it and make them understand astronomy with a visual clarity where the written words and the maths only confound things. Maybe this will give us another Einstein?

What has been the greatest challenge during Covid-19 in your context in science education and scientific research. How do you overcome these challenges?

As the digital transformation of our society has significantly lowered the barrier to entry to participate in forums, we need to practice ways of being digitally inclusive. For example, participating in online meetings and speaking with the camera turned off is severely disabling for a hearing-impaired person such as me who then cannot follow the lips nor interpret the tone from the body language of the speaker. Organizers also need to enable automatic captioning on platforms for participants with visual impairments to follow presentations. Materials should also be provided in advance so that their screen readers can assist them. Regular breaks are also important for people with dyslexia or mental impairments that are

completely invisible and unknown to the others, who might have to concentrate harder to follow along.

Has the pandemic helped you to see different perspectives, and given you hope for more disability inclusion?

Absolutely. I feel a lot more connected with people. The initial discomfort with digital meetings pushed me far out of my comfort zone. I feel much more confident during digital meetings now, and surprisingly, this comfort has spilled over to also apply to physical meetings. I believe many of us have grown stronger from adapting to a new reality. I hope that we are more capable of handling unknown situations, such as when accommodating for a person with an impairment.

"The IAU Astronomical Terms in Sign Language project is so important to us because it gives us a way of documenting the language we are using. That way, we also give other aspiring astronomers the language they can use to explore, question and understand cosmos everything that has been, is, and will be, such as the stars, planets, and astrophysical phenomena such as black holes and other unpassable or unescapable horizons in time and space. These things become so much harder to understand if you don't have the proper language!"

In your opinion, what can stakeholders like universities, policy makers and UNOOSA do make further progress towards disability inclusion?

I believe there is much greater interest in addressing this theme now. Fundamentally, inclusion is about fighting inequality and injustice for those that are weakest positioned in our societies. Inclusion is also beneficial to everyone, as it is a way of thinking that acknowledges that we all are different, and all have our needs.

However, we cannot wait for the weakest to speak. As long as a deaf illiterate person without any functional language remains so, we won't notice the challenges of their life. Even the closest relatives of that person won't be speaking up, as, for everything they know, that deaf person is cognitively disabled to them, and they treat them so, barring them from education, work, self-realization, language, love and their own family.

This makes it even more important to pay attention to the experiences that the minority communities share. In Norway, we have grim stories where the deaf community warns about the dangers of closing schools for deaf in favour of integrating deaf students in ordinary schools, and yet, the government does so regardless of the restricted lives that may forge.

In essence, I would recommend UNOOSA and other stakeholders to acknowledge that minority groups can and should speak on behalf of others. This is uncomfortable, as it is much more pleasant to address the need of an individual by making that person a part of your own "pack", rather the needs of an alien, slightly different, and perhaps angry minority who pose hard and uncomfortable demands.

Has anyone ever doubted your work due to your disability? How does that affect you?

I have never really questioned my work. I understand that doing science is a process where one may learn new things and develop oneself if you are open to the pains of learning and receiving feedback. No one starts off as the best scientist alive.



Credit: Marius Eide

It is however important to not confound this with the doubt of others, that they don't overlook your potential or ability because of your impairment.

Others often place a higher judgemental bar for those with an impairment, than for someone else that speaks, acts and have needs that are like their own.

A recurring story is that you must excel and fight harder in order to be on equal foot with someone that don't have your impairment. I believe this is true, however, I also believe that this does something to you as a person that you might not want. You may become a harsher, colder and more bitter person with a resentment that puts off other people, making your successes temporary and not of the kind that you truly want and deserve.

I believe that a better way than proving to "the world" that you are better, or at least as good as "them" (who are "they", anyway?), is to work with those around you in order to make them help you reach your goals. It is as simple as a question of whether you should be making the world your enemy, or trying to find friends in it. And yes, you will have demands that no one else seemingly has. People will cherish you for them, and they will love to be on your team.

Any last words...

I follow Desmond Tutu's principles of peace; it should always start within. True inclusion can only be achieved by recognizing your own needs and quirks within yourself first. By accepting that you are not like everyone else, and that no one is like you, you have a much better starting point when you then try to understand the demands of others from you. Suddenly, you may start to see that people around you have true needs that you have been silently ignoring, that their deviations are on them to take care of.

Finally, each one of us can be an ambassador of inclusion by waking people up from the dormant state of ignorance of others' true needs. Institutions may start by considering the diversity among their staff, by asking this simple question: "Are there people here that may enlighten us? Do we listen to them?".

Read more about the IAU working group on astronomy for equity and inclusion at https://iau-oao.nao.ac.jp/iau-inclusion/



Screenshots of the term "Gravity" in British sign language. Credit: IAU/Spread the Sign



Screenshots of the term "Gravity" in French sign language. Credit: IAU/Spread the Sign



Screenshots of the term "Gravity" in Chinese sign language. Credit: IAU/Spread the Sign



"Persons with disabilities like me had been completely left out of the field for no reason. When I realized that the future was in my own hands, I decided to use my results to equalize participation in the field."

ENGAGING IN SCIENCE AND IN SOCIETY JUST AS I AM

An interview with Dr. Wanda Diaz-Merced

We need to strengthen our multimodel ways of perception as we are multi-sensory beings. This includes strengthening our auditory perceptions, in various fields including space science, where sight perception is used predominantly. Our ears, for example, are powerful tools as well. Moreover, they work 24/7. There is really no such thing as a place without audio. It doesn't matter whether the sound is ambiguous or discernible. Based on this, there are increasing efforts to make the science of astronomy a more multi-sensorial experience.

We speak to Dr. Wanda Diaz-Merced about sonification of astronomical data, a process that enables her to engage in astronomy just as she is, and the larger goal of promoting inclusion and access of persons with disabilities in astronomy.

What attracted you to a career in astronomy?

Honestly, I did not know that astronomy was a science until I got into university, even though I had always wanted to become a scientist.

When I started losing my sight at the university, I was exploring how I could achieve my dream of becoming a scientist, because I could not understand what the professor was explaining. The only thing that made sense to me during the lectures was the sounds on the chalkboard and the babbling of the lecturer.

I was inspired when I got familiarized with a project at NASA called Radio JOVE, and I heard a sunburst, detected real-time by a radio telescope. I then realised that there was hope for me in the field of science, a field that seemed to be closing up to me fast and aggressively.

From that sentiment, I wondered why audio wasn't utilized much to study data. With my mentor, I started conducting experiments with professional astronomers, and we found that when astronomers use audio, it increases their sensitivity to events in data that are blind to the human eye.

I then decided to undertake more research into this, as there was a space for this kind of exploration in space science. This was also an indication that space science by its own nature should be more diverse.

Please tell us more about the Gravitational Waves Noise Hunting project and the role of sonification in this project.

There are two projects, one is about identification, and the other, which I work on, is an exploration project, to increase our sensitivity to events in the data that by nature are blind or ambiguous to human eye.

Sonification is a process of conveying information using mainly non-speech sound. It is the auditory analogue to data visualization. It offers the possibility of introducing a way that is real-time, adaptive to the data, and enables us to explore information that otherwise may be

hindered by data expansion techniques that we usually use. When we use sonification, instead of deciding data expansion a priori, one can decide data expansion while they analyze the data.

How does sonification differ from other sensory methods of capturing data, and what are the efforts being made to integrate it into mainstream astronomy?

What sonification may provide, that is, what its possibilities are, is a more detailed analysis of data. It also facilitates a more dynamic and detailed inspection of the data sets. What I refer to as mainstream in this case, is the people who do research, and the process of data exploration to produce the science. It has been difficult to bring sonification into the mainstream because the yardstick of performance makes people inclined to pursue what is profitable or what is already possible in terms of data production. Also, most of the efforts, besides those of Dr. Katsanevas from the European Gravitational Observatory (EGO), are directed towards education and public outreach, and not exploration of data.

How does your work on sonification and the Gravitational Waves Noise Hunting project help to contribute to a more inclusive and sustainable world going forward; not just for persons with disabilities, but for society as a whole?

It is a way to open up the field so we can perform scientific research just as we are, so we can have a work field that will support and enhance the way in which we work by nature. It will also be a win-win situation, as the field will grow by enriching itself

with more perspectives and more perception styles, (with evidence) that increases sensitivities to events in data, and people like me will have an opportunity to participate similar as my peers without disabilities.

How has science education in general adapted to include persons with disabilities over the years?

There is great progress in terms of awareness towards inclusion. Some institutions have disability or functional diversity offices, and there is also a lot of assistive technology. The change, should however go beyond, to allow persons with disabilities to work just as they are, and institutions should foster a metric of productivity that is humanistic.

What can policy makers, the UN and UNOOSA do to promote inclusivity for persons with disabilities?

What is important are the frameworks and the institutional mindsets to foster and support disability inclusion. One of the things UNOOSA is in a position of addressing, is the gap between what countries report that they have achieved in terms of the presence of persons with disabilities, and the rank of the presence of those groups in space sciences.

In terms of the UN in general, they can establish a high-profile award to recognize the state nations that achieve an honest progress, and engage in addressing these issues. This would elicit a chain reaction, with formality. Also, it would send a strong message to the scientific community if the UN establishes a high-profile award, similar to the L'Oréal-UNESCO For Women in Science International Awards, for scientists with disabilities. While it is

Dr. Wanda Diaz-Merced is an astronomer and the leading proponent of sonification, a method of turning astronomical data sets into audible sound. When she lost her sight in her early 20s, her dreams of studying stars in a predominantly visually oriented field suffered a major setback, until she realized that she could audibly detect patterns in stellar radio data through sonification. She received a Bachelor's in Physics from the University of Puerto Rico, and undertook astrophysical research at NASA Spaceflight Center, before completing a Ph.D. in Computer Science at the University of Glasgow. She is currently based at the European Gravitational Wave Observatory.





Dr. Wanda Diaz-Merced presenting at Ted Conference in February 2016.

important to recognize women scientists, the expertise of scientists with disabilities also needs to be recognized, to demonstrate to the scientific community that we can also perform excellently in science. I am very passionate about this, because it helps promote the trust that we are capable of doing the work if institutions are willing to recognize us as experts.

A lot has happened in the last two years especially regarding the pandemic. Do you feel hopeful that there will be more opportunities for disability inclusion with this project, and in science education in general?

The pandemic has been devastating and has affected the lives of many people. It has also forced people to imagine different ways of working as it has exposed the vulnerabilities faced by everyone. People have had to be productive from home. However, even before the pandemic some persons with disabilities needed to work from home but were likely denied the chance. If we try to generate some value from the experiences learned, we may achieve in generating a new metric of productivity, or a new economic model that will benefit everyone. I hope that the change of consciousness that is required, for everyone to be included, is not forgotten.

Do you ever doubt yourself or your work sometimes? How do you overcome this?

If you would have asked me that before I did my perception experiments, when I thought that one had to be a robot in order to become a scientist or an astronomer, I would have said yes. But after I did my experiments, I do not doubt myself. Now my position is different. I am searching for allies, and I aim to generate value with those who are making an honest effort to do data analysis. Now, I mainly try to see how I can contribute and offer advice to others.

How can we move beyond tokenism, and what kind of paradigm shift is needed to achieve real disability inclusion, rather than superficial inclusion?

We need to change the perception that persons with disabilities are only beneficiaries. For example, I am not just an expert in accessibility, but an expert in other fields. I believe that the Space for Persons with Disabilities project is a creation that will create a movement that will foster the space science community to trust that we will be welcomed in the sciences and produce just as we are, and that we will be safe to produce that knowledge.



Credit: PRI.

What further developments can we expect from this project, and how do you see its role in the disability movement?

The goal is to be in a place where as soon as I arrive, the basics of what I need to perform are available, and where persons with disabilities do not have to disclose them, or ask for accommodations in order to at least experience a certain degree of inclusion.

In terms of sonification, I would like to focus on opening the field for those who would like to make further contributions. It is our hope to find more people employing, or considering to use sonification in their data analysis, and teaching students to use sonification or audio sound for data analysis techniques. At least for now, we are at the beginning stages of these efforts, but we would have to wait for around seven to ten years to see what will happen. What I am conveying is that here is the hope. Right now, we are at the stage with the future in our hands. It is a non-stop step by step process, but I am hopeful that we will achieve this.

How can persons with disabilities lead or participate in activities going forward?

They can get in touch with the team at the European Gravitational Observatory to either participate in some data recognition experiences, or to get involved with me in the work of analyzing data, figuring out

perception techniques and perception experiments, designing trainings, and doing experiments on training. The people who are involved in the pedagogical aspects can also get involved and no one needs to worry, as we will do the work just as we are.

Finally...

I would like to encourage everyone, including persons with disabilities to never give up. It only requires will and determination to continue until you feel victorious. To win is to never give up. Trust yourself.

Find out more about the Gravitational Wave Noise Hunting project at

https://www.reinforceeu.eu/demonstrators/gravitational-wave-noise-hunting

"Science is for everyone. It has to be available to everyone, because we are all natural explorers."



"IN SPACE
EXPLORATION,
THERE ARE A LOT
OF INHERENT
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PEOPLE WITH
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VOELKER

MAKING OUTER SPACE ACCESSIBLE TO ADVANCE ACCESSIBILITY ON EARTH

An interview with Anna Voelker and Dr. Mona Minkara

On 17th October 2021,
AstroAccess, a project that aims to promote disability inclusion in space exploration, embarked on a historic parabolic flight with a crew of twelve persons with disabilities from various fields, including scientists, veterans, students, athletes and artists. This weightless flight was operated by the Zero Gravity Corporation (Zero-G).

AstroAccess aims to increase accessibility and inclusion of persons with disabilities in space access, by demonstrating how space vessels can be made more accessible through universal design.

This project was a part of the wider SciAccess Initiative, a nonprofit that promotes disability inclusion and equity in STEM, and conducted through the fiscal sponsor Yuri's Night, a nonprofit that uses the excitement and inspiration of space

as a catalyst for educating and developing the next generation of explorers.

We speak to Dr. Mona Minkara, one of the participants of the flight, and Anna Voelker, the Executive Director of the SciAccess Initiative and Co-Founder of AstroAccess who share their insights on the planning and findings from the flight, as well as the wider goal to increase access for persons with disabilities not only in outer space, but on earth as well.

Why are you passionate about disability inclusion in science?

Mona: I deeply believe that humanity cannot truly find solutions to problems until we include people of diverse backgrounds, to come up with diverse solutions to the problems that we encounter. Only a few people with disabilities work in science, but it is because there are few opportunities in terms of access in the field.



Dr. Mona Minkara floating in zero gravity. Credit: AstroAccess/Zero G Corporation

Anna: Persons with disabilities constitute 15% of the world's population. Excluding this population from STEM, as has been done historically, is not only unjust, it is harming our science and impending the process of discovery, something that everyone has the right to be a part of. SciAccess was created in order to help break down these barriers to STEM research and education.

Tell us more about the AstroAccess project.

Anna: For a long time, I wanted to start a new project that focused on addressing accessibility barriers specific to space exploration. The opportunity to launch such an initiative presented itself last year when I had the pleasure of meeting George Whitesides, my AstroAccess co-founder. George shares this passion for inclusion and equity in space and it has been an absolute honor working with him to transform our passion into action. Together with our rapidly growing team of amazing organizers and volunteers, we created Mission: AstroAccess in order to advance access to space for all.

Our goal is to investigate and advance the accessible design of future space systems and spacecrafts, promoting the concept of universal design. We believe that enhancing access also means enhancing mission safety for everyone by allowing astronauts to utilize multiple senses, which may prove necessary in emergency situations (for e.g., if the lights go out).

In order to begin investigating these concepts, we selected twelve ambassadors through a national open application and had the opportunity to work with Dr. Minkara and our other incredible ambassadors for our very first microgravity mission. Not only do we want to do more zero gravity flights and collect further data, and do further demonstrations on accessible universal design, but we also want for that to pave the way for inclusive space exploration, and space design. The goal of making space accessible also has a ripple effect for inspiring inclusive and intentional design here on earth.

Mona: I decided to get involved in this project because Dr. Sheri Wells-Jensen, a Mission: AstroAccess leadership team member and an academic expert on disability and space, encouraged me to apply. I was excited at the prospect of being part of a project that will help make science and space for all more accessible.

What were you trying to test during the zero-g flight?

Anna: There were a multitude of things we were investigating and demonstrating. We had three core research groups. Dr. Minkara, and three other ambassadors were in our Blind Demonstrations Team and were investigating numerous concepts, including the use of audio and tactile cues for orientation in microgravity.

Mona Minkara is a blind Assistant
Professor of Bioengineering at
Northeastern University. Born and
raised in the United States, she lost
her sight having been diagnosed
with macular degeneration and
cone-rod dystrophy at seven years
old. Still having ambitions in
science, she pursued a degree in



Chemistry and Middle Eastern Studies at Wellesley College, and a graduate degree and Ph.D. in Chemistry from the University of Florida. She also received the National Academies of Science Ford Foundation Fellowship as a postdoc. In 2019, Mona was one of three winners of the Holman Prize, an award given to individuals who want to push limits and change perceptions about blindness around the world.

Anna Voelker (they/them) is the founder and Executive Director of the SciAccess, an international nonprofit dedicated to advancing disability inclusion in STEM.

Through SciAccess, they lead numerous science inclusion initiatives, including an annual



conference launched by their receipt of The Ohio State University (OSU) President's Prize in 2018. Along with George Whitesides, Anna serves as the Co-Founder of Mission: AstroAccess, a new SciAccess project that aims to pave the way for disabled space explorers. They were named a 2018 Brooke Owens Fellow, 2021 Future Space Leader, and previously worked at NASA Kennedy, NASA Goddard, the Space Telescope Science Institute, OSU Department of Astronomy, and the Aerospace Corporation.

We had two ambassadors who are deaf and they investigated various forms of non-verbal communication, including lighting systems and haptic bracelets that vibrated at select times.

There was also a crew of six people were doing mobility demonstrations, proving that future astronauts with mobility disabilities can safely navigate their space and travel independently to and from designated areas.

Overall, we found that very minimal accommodations were needed. As an initiative, we have only begun the work on demonstrations such as these and we are excited to continue investigating the best ways in which accessibility aboard space vehicles can be maximized.

Mona: In our group specifically, Sina Bahram was testing a braille notetaker to see whether in zero gravity, or in 1.8g, we would still be able to use a braille display. Dr. Jensen was in charge of demonstrating whether she could use a slate and stylus.

I was in charge of testing out three devices. We had

1) a "space cane", a tiny telescoping kind of cane that
is manual, 2) a haptic device that vibrates when it is
closer to a beacon, to help find other persons in the
flight, and 3) an ultrasonic device that sends off
waves and it vibrates when there is an obstruction in
front of you. We tested these to demonstrate their
uses to aid in orientation.

"We need to include all sorts of diverse backgrounds and all sorts of diverse people in order to come up with diverse solutions, and that's what science is all about. It is all about discovering, learning and problem solving, and we need everybody on board. How could we not include people?" - Dr. Mona Minkara



Centra Mazyck, who is an incomplete paraplegic, aboard AstroAccess Flight One. Credit: AstroAccess/Zero G Corporation

How was your experience during the flight?

Mona: I was excited even months before the project. I was really intrigued to see how oriented I would be in a zero-gravity environment, and the sensation was indeed phenomenal. Firstly, we experienced Martian gravity, and then lunar gravity, where at some point your body floats off the surface of the ground.

How do you think the AstroAccess project, and the inclusion of persons with disabilities in general in space exploration or space science research, could help to contribute to a more inclusive and sustainable world going forward, not just for persons with disabilities, but for society as a whole?

Anna: When we talk about the future of society it is critical for us to think of universal design – designing for all. I believe that this is a mindset and perspective shift that has global implications beyond just space. We aim to use AstroAcccess as an opportunity to challenge people around the world to think about access. With AstroAccess, there is an opportunity to have people confront the accessibility (or lack thereof) of their own environments, communities, universities and workplaces. We want to challenge people to think about what changes need to be made and then go out and be the catalysts for that change.



AstroAccess crew of disability ambassadors. From left to right, back row, Mary Cooper, Cheri Wells-Jensen, Eric Shear, Apurva Varia, Sina Bahram, Zuby Onwuta, Mona Minkara, Viktoria Modesta; and front row, Sawyer Rosenstein, Dana Bolles, Mr. Ingram and Ms. Mazyck.Credit: AstroAccess/Zero G Corporation

We have a mission phrase that if we can make space accessible, we can make any space accessible. If we can demonstrate that outer space is accessible, this has tangible effects on the perception of what is and is not possible, and that is the power of a project like this – to create widespread change, both here on earth and beyond it.

Mona: We are indeed opening people's minds to making space accessible, whatever space that may be, and on top of that, showing them that there is a value in that. My sister, Sara Minkara, says that inclusion for all is value for all. We are working together to progress humanity to solve the challenges we face. Since we were all part of the process together, we could demonstrate that everyone can play a role in inclusion, and it is for everyone.

Has science education in general adapted to include persons with disabilities?

Mona: I definitely think that in terms of blindness, we still have a long way to go. For example, a lot of the publications and journal articles online are not readable. This is something we can easily implement by making people who submit applications include alttext so that a blind person can use their screen reader. This is not just beneficial for a blind reader,

but also for any writer, or the person who is publishing, to think about what they are trying to convey, for example, in their figures. There is an archive of knowledge that I personally do not have access to. There needs to be a change, into a world where I am one of many blind scientists who are following their passion and contributing to their fields. We still have ways to go in terms of inclusion but were starting the efforts and should continue to build on that.

What can policy makers, the UN and UNOOSA do to promote inclusivity for persons with disabilities?

Mona: Speaking from the lens of a blind person, the UN can work on making sure that their websites are accessible, their materials are provided in braille for example general, there should be increased consultations and engagements with persons to inquire what is needed for access so that persons with disabilities are part of changemaking processes.

Anna: More broadly, it is important for policy makers to promote policies that ensure that basic needs of persons with disabilities are met. For example, in terms of healthcare, certain states in the United

States have income limits for persons with disabilities, after which point they will lose coverage of essential healthcare services. Policy makers need to eradicate these systemic barriers in order to advance disability justice.

A lot has happened in the last two years especially regarding the pandemic. Do you feel hopeful that there will be more opportunities for disability inclusion going forward?

Anna: In the pre-pandemic period, there were calls from persons with disabilities to have more virtual conference and educational opportunities, and they were often denied this, as organizers and institutions stated that it was too difficult to implement. But then suddenly in the wake of COVID, this is all became possible as soon as everyone else needed it too. The takeaway is that we can and should be maintaining virtual professional and educational opportunities, and I would hope this is maintained even after the pandemic. I am also interested in learning more about hybrid models and their potential in promoting accessibility in STEM conference organization.

Mona: The pandemic has opened up the opportunity to continuously consider accessibility in hybrid formats. Additionally, I think a dialogue with persons with disabilities is needed to consult on whether the various online platforms that are being used are accessible. What is phenomenal, from my teaching experience, has also been the sense of collaboration with my students in this regard. It has shown me that nothing is too unreachable if we all learn to communicate in order to overcome barriers.

Do you ever doubt yourself or has your work ever been questioned? How do you overcome this? What is your advice to others?

Mona: I definitely doubt myself. I think imposter syndrome is a common issue in academia. I deal with it by reminding myself that at the end of the day, I am doing what I love. If I have doubts, I will sit down and learn, and ask. Of course, there have been naysayers and doubters, but at the end of the day I know my potential. My advice is for people to follow their passion. If you truly love what you do, and it brings joy to you, slowly but surely you will make a contribution.

Anna: I have definitely encountered people who assume that access to space for people with disabilities is impossible simply because it has never been done before. As a team we are working to change these perspectives, and to convince people that inclusion is not only possible, it is essential, and not just for its own sake but for the sake of science, safety, and the future of exploration.

I think that finding mentors and people who support what you do is essential. I am incredibly grateful for my mentor Dr. John Beacom from the Ohio State University, who has made all of SciAccess possible through his unwavering support. I think a great mentor like Dr. Beacom teaches people to be bold and as Dr. Minkara says, to do what you love.

How can we move beyond tokenism, and what kind of paradigm shift is needed to achieve real disability inclusion?

Anna: Creating opportunities for people with disabilities to be in charge and to be leaders is critical. When it comes to accessibility advancement, making sure that persons with disabilities are part of the process and the progress and beyond that, but have the opportunities to lead the change is important to make this shift.

Mona: To foster inclusion, it important is to work together, and for persons without disabilities not to have the perception of serving or taking care of persons with disabilities. Persons with disabilities are cannot be regarded as a pitiable group. Even though I am blind, we can work together, and it is important that I am seen as more than just my blindness.

"Just because one does not encounter a barrier, does not mean that it is non-existent. It means that one has the privilege of not noticing it." - Anna Voelker



Azubuike "Zuby" Onwuta aboard the Zero G flight. Credit: AstroAccess/Zero G Corporation

What further developments can we expect from this project?

Anna: There is so much happening in terms of space exploration especially in the private sector, and commercial space. There are new space stations being built, and new satellite and lunar missions being planned. Now this is the time we need to have conversations about access, and to take action, while we are still in these planning stages.

For me, AstroAccess is the springboard to implement changes for this generation of space design. It is so critical to have conversations on universal design. That is how AstroAccess is making changes in this process. We are making it known that disability inclusion in space is not a theoretical thing of the future; it needs to be addressed now, and our team is here to help make that happen.

Is there anything that you or anyone that you know who have done something that is particularly impactful and useful for disability inclusion that we can learn from?

Mona: I love to share about how my postdoc advisor J. Ilja Siepmann reached out to me, and encouraged me by telling me that there is an advantage to how I approach science. Because I don't approach science

as sighted people do, I might see patterns that other people miss, and this perspective I got from him enables me to make a contribution and become a much better scientist.

How can persons with disabilities lead or participate in activities going forward?

Anna: I would encourage people to check out our website astroaccess.org and connect and contact us there! To connection with SciAccess more broadly, they can check out sciaccess.org. In addition to the annual SciAccess Conference, we have a professional working group that meets regularly to discuss access and inclusion in STEM, as well as mentorship opportunities for high school students. Through AstroAccess we also work with Disabled for Accessibility in Space (DAIS), which is a space science peer networking group for people who identify as disabled, neourodivergent, and chronically ill.

Mona: Growing up, I wish I had a blind scientist I could reach out to, and now I value being available for and being there for people who reach out to me. I try to get back to those who reach out to me, from all over the world, and people can reach out to me through my website, monaminkara.com.

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THE UNITED NATIONS OFFICE FOR OUTER SPACE AFFAIRS
SPACE APPLICATIONS SECTION
SPACE FOR PERSONS WITH DISABILITIES PROJECT

DECEMBER 2021