



How can portraits and podcasts change perceptions of disability?

Dr Pamela Block, Dr Nádia Meinerz and Bruna Teixeira

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How can portraits and podcasts change perceptions of disability?

Disability is often portrayed as something undesirable, something that prevents people from living a happy, healthy and fulfilling life. Creating and championing positive depictions of disability can help to change this misguided narrative. **Dr Pamela Block** from **Western University** in Canada, **Dr Nádia Meinerz** from the **Federal University of Alagoas** in Brazil and **Bruna Teixeira** from the Brazilian feminist art collective **Ateliê Ambrosina** are exploring disability and identity through portraits, podcasts and visual activism.



Dr Pamela Block

Professor, Department of Anthropology,
Western University, Canada

Field of research

Disability anthropology: cultural perceptions of disability, disability culture and activism



Dr Nádia Meinerz

Associate Professor, Institute of Social Sciences,
Federal University of Alagoas, Brazil

Fields of research

Health, gender, sexuality and disability studies



Bruna Teixeira

Founding Director of Ateliê Ambrosina

Fields of research

Visual arts, queer bodies, disabled bodies

Website

retratosdeficas.com

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Talk like a ...

disability anthropologist

Ableism — discrimination, prejudice or social bias against people with disabilities, based on the belief that disabled lives are less valuable or desirable

Albinism — a rare genetic condition characterised by a lack of melanin pigment in the skin, hair and eyes, often resulting in vision impairments and sensitivity to sunlight

Creative participatory research — a collaborative approach to research that actively involves participants to co-create knowledge and represent lived experiences, often using artistic or expressive methods

Visual activism — the use of visual media such as photography, film or art to challenge injustice, raise awareness and promote social or political change

Research project

Exploring disability and identity through portraits, podcasts and visual activism

Funders

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From the gigantic oil paintings of kings and queens to the glamorous photographs of modern-day celebrities, portraits have always been a symbol of power, status and wealth. Through exposure to these depictions, we build

an image of what a happy, healthy, successful person should look like.

In contrast, people with disabilities are often depicted in the context of sadness or suffering. Charities show us images of disabled people and ask us to help,

support or pity them, while healthcare and medical advertising shows us the problems caused by disability and how they can be fixed or 'cured'.

"Disability is usually portrayed as something undesirable; as the opposite of health, beauty, professional success, parenthood and happiness," says Dr Nádia Meinerz from the Federal University of Alagoas. "Creating positive depictions of disability is important for changing the way we feel about and look at disabled people." She collaborated with Dr Pamela Block from Western University and Bruna Teixeira from the feminist art collective Ateliê Ambrosina on a creative participatory research project called Retratos Defiças, or Defiant Portraits in English.

This project empowered disabled people to co-create self-portraits using visual media and podcasts. "The goal of Retratos Defiças was to create a space for disabled people to represent themselves the way they want to be represented, to be seen as they want to be seen," explains Pamela. "These are strong, creative, resourceful, funny and interesting people, and it was such a pleasure to work with them in bringing their portraits to life."

Portraits and podcasts

During Retratos Defiças, 22 co-creative duos created **11 pieces of visual art** and **11 podcast episodes**. "In each duo, one or both of the co-creative partners were disabled," explains Pamela. "In some cases, they had previous experience of making art, but for others it was an entirely new experience."

"Before starting the project, I did extensive research into the potential of using visual art for disability activism during my master's in anthropology," says Bruna. "I discovered vibrant contemporary artworks made by disabled women, which showed the value of self-portraits as a way for people to be the protagonists of their own images."

The idea of using podcasts as 'sound portraits' was partly inspired by the Disability Visibility Project, founded by Alice Wong, a disabled activist. "This project includes a podcast channel where disabled people tell their stories, and listening to that kind of autobiographical narrative allowed us to think about portraits from another point of view," says Nádia.

Co-creation and participatory research

Throughout the project, Bruna and her team of disabled artists at Ateliê Ambrosina were on hand to support the co-creative duos through their creative process as well



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as ensure disability access. "We are a 'hands on' organisation, and we helped bring this project to life," says Bruna. "Making a creative participatory research project work in the 'real world' requires a different approach to projects that take place in the academic community within the walls of a university. We needed another language, another way of doing things and communicating that allowed us and our participants to improvise and be spontaneous." Artists from Ateliê Ambrosina, Lart Malta and Olga Aureliano, who have lived experience with visual disability and deafness, took the lead in ensuring that the process of co-creation and the portraits themselves were accessible by creating audio-description and transcripts.

As this was a creative participatory research project, the co-creative duos were not just participants but also collaborators with the researchers, influencing the aims and methods of the project and adapting and improving Pamela and Nádia's original vision. "Originally, we had planned that disabled people would be paired with researchers, but our participants pushed back and told us that was too limiting," explains Pamela. "In the end, we let them choose who their partners would be."

This co-creation required co-operation and equal ownership, and for the members of each duo to reflect on their own positions. "The disabled person needed to break out of a cycle of seeing themselves as a patient of a diagnosis by taking ownership of their story and their creation," explains Nádia. "The able-bodied partner had to face the issue of ableism and connect with their disabled partner in a positive way. In the same way that gender issues involve both men and women and race issues need to

be faced by white people, disability needs to be thought of as something that affects everyone, not just those who are labelled as disabled."

Sharing the portraits

The portraits and podcasts were exhibited in an online digital art gallery. They were made accessible to blind and low-vision people through audio descriptions and to deaf people by the transcription of each podcast episode. All this content is available in both Portuguese and English. The team hosted in-person art shows in Brazil and Canada, where the artists were able to attend remotely and answer questions. The team also hosted four online discussions around themes such as sexuality, Indigeneity and accessibility. "We chose one work of visual art and one podcast for each of these discussions and assembled groups of Brazilian and Canadian scholars, artists and activists to reflect and create works in relation to these pieces," says Pamela. The team also published **a journal issue** showcasing artwork and presentations from the online discussions.

"This project encompassed a very important period in Brazilian history," continues Pamela. "During the Covid-19 crisis and the Bolsonaro presidency, all of the major structures of governance fell apart. Health, education, sanitation, and even the postal system weren't working, yet somehow, in the midst of all this chaos, this beautiful project was happening, allowing people to connect with each other and proclaim: 'I exist. I matter. I am not alone.'"

About *disability anthropology*

Disability anthropology examines how disability is perceived and represented in different cultures, how disability affects people's lives, and the interrelation between disability and identity. It is a subdiscipline of sociocultural anthropology which investigates human societies and cultures, focusing on how people live, think, interact and make meaning in their everyday lives.

The topics that sociocultural anthropologists study reflect the variety and diversity of individual humans and their communities. "When I started doing anthropology, there wasn't anything called disability anthropology – there was only medical anthropology, which I had never done," says Pamela. "I was a sociocultural anthropologist doing disability research and there wasn't really a place for me in the field at that time, but things have changed now."

Disability anthropologists use many research methods including participant observation, focus groups and interviews, ethnography, and creative participatory research. "In participatory research, the whole process – determining what's going to be asked, how it's going to be asked and what to do with the information – is all decided together with the community," says Pamela. "Sometimes, researchers have a hard time giving up that control, but I think it is the most ethical way of doing research." The creative aspect of participatory research means that the research outputs are not just academic papers that are published in scientific journals. "This kind of research involves something other than just writing words on a page, so the artwork and podcasts were all part of the results of our project," continues Pamela.

In addition to collaborating with groups, communities and other participants, anthropologists will often collaborate with experts from other fields including social and political sciences, linguistics, history, medicine, and media studies. This interdisciplinary way of working allows anthropology to explore human issues from multiple perspectives. "Anthropology can learn a lot from visual arts and digital technologies, especially in improving research tools and expanding the possibilities for social impact," says Nádia.

Pathway from school to *disability anthropology*

Study humanities and social sciences at school. History, psychology and geography can help you prepare for cultural anthropology and archaeology. Language and literature can provide a basis for linguistic anthropology, and health and biology can prepare you for medical or physical anthropology. Learning other languages may also prove to be useful in anthropological fieldwork.

Most universities offer courses in anthropology, and you can specialise as you progress through your studies. "Whatever interests you – from video games to insects – there is probably an anthropologist somewhere who has studied it," says Pamela. "So, search for anthropology projects or books about topics that interest you."

Look for opportunities to take part in research, fieldwork or community engagement, especially internships or opportunities which allow you to immerse yourself in unfamiliar cultures or experiences.



Meet Pamela

I was always interested in why there are power differences in society among different groups of people, and I followed that interest to study things like racial inequality, gender inequality and eventually disability inequality.

It's hard to choose just one thing I love about my job. I enjoy the research, but what I really enjoy is the opportunity to teach people something that's going to change their lives for the better, to help them figure out what they want to do with their lives. I like seeing that light bulb come on.

My persistence has enabled me to lead a successful career. In this life, there are always going to be people telling you that you don't belong or that you're not good enough. It can take some time and creativity to figure out how and where you fit within your chosen field. Find the people who uplift you and support you. It is also important to be flexible and open to moving to where the jobs are.

I have a sister who is autistic, and my mother was a special educational needs teacher. Over the years, I have been a disability activist, a researcher and a personal assistant to disabled people while I was at university. I had a mentor, the historian Lawrence Goodwyn, who once said, "Social knowledge is experiential," meaning that we are the most passionate about things that come from our own personal experience. For me, living life with a disabled sister and having some disability

issues of my own (ADHD and anxiety) has been that spark.

To unwind, I enjoy spending time outdoors, walking or kayaking. I am part of an activist drumming group which I enjoy. I have a dog who I love spending time with, and I'm lucky to have children and a husband who are all excellent cooks, so I love to eat whatever they make (and I do the dishes!)

Pamela's top tips

Find a good mentor and keep learning as you go. Don't be afraid to make mistakes and don't be afraid to apologise for them. Have some humility and understand that even when you are advanced enough to become a teacher like me, you are still a learner, and you always will be.



Meet Nádia

My parents are descendants of German immigrants who settled in southern Brazil in the early 20th century. They were part of what we call 'whitening policies'. I was already aware of this racist legacy when I studied anthropology in Rio Grande do Sul, but migrating to Alagoas changed my perspective. It was here, while training other anthropologists, that I realized how limited my knowledge was, especially since my references were Eurocentric.

I like being able to contribute to building safe spaces in which women, Black, Indigenous and disabled people can access formal education and build a research career of their own. The most important thing is to use my white, able-bodied and cisgender privilege to discuss how racism, ableism and transphobia are interconnected with gender inequality.

Research in gender inequality, sexuality and disability is a huge opportunity to observe structural changes in culture and society. The social anthropology programme at the Federal University of Alagoas works with local organizations to support and encourage students to produce multimedia projects that increase the awareness of these changes.

One of the things that relaxes me the most is walking. I walk a lot on the sandy beach in Maceió, soaking my feet in the sea water and watching the waves move. I like walking in the forest, hiking and discovering new landscapes. I only consider myself to have truly visited a new city when I have walked around it on foot.

Nádia's top tip

Pay attention to how people around you react to difficult topics, especially when they avoid or resist them, and think about why they might react the way they do. It's not always easy to speak up, but even small actions or questions can make a difference.

Explore careers in disability anthropology

"Anthropologists work in many different fields," says Pamela. "All over the world, medical anthropologists collaborate with clinicians in research and teaching as well as in community health. Anthropologists work for nonprofit organisations, museums, government agencies and universities."

Explore the websites of the Canadian Anthropology Society (cas-sca.ca), the Associação Brasileira de Antropologia (portal.abant.org.br) or the American

Anthropological Association (americananthro.org) to read about the latest research. You could even become a student member and attend events and conferences.

Discover more about the latest stories and findings from anthropology researchers all over the world by reading online magazines and journals such as *Sapiens* (sapiens.org), *Somatosphere* (somatosphere.net) or *Vibrant* (Virtual Brazilian Anthropology) (vibrant.org.br).

My self © Julia Arume and Mirely Cervieri

Ateliê Ambrosina

Ateliê Ambrosina is a feminist art collective and activist group founded by Bruna in Alagoas, Brazil. “In 2017, I was searching for a feminist group that I could collaborate with,” says Bruna. “However, I realised that the main feminist movements in the city were linked to political parties led by men, which did not convince me. So, I gathered old and new friends and we founded Ateliê Ambrosina in 2018. We carry out activism, research projects, interventions and events led by LGBT women, white women, Black women, fat women, women with disabilities, and women of different social classes, education levels and ages.”

Team members at Ateliê Ambrosina are ‘artists’, meaning they use art for activism. “We use all kinds of art, including visual arts, audiovisual creations, music, theatre and podcasts,” explains Bruna. “Anthropology has taught me to be a better activist through listening to others more attentively and with more patience.”

Ateliê Ambrosina runs a community homeschool, called Casa Ambrosina, in Maceió, Bruna’s hometown. “Casa Ambrosina supports the shelter and emancipation of girls and young women aged 12 to 21 in a state of social vulnerability,” says Bruna. “We

offer weekly courses in subjects such as photography, digital arts, theatre, percussion and futsal (a version of 5-a-side football).” Team members at Casa Ambrosina also offer support and guidance around combating poverty, child pregnancy and sexual abuse in adolescence, and they work to improve their students’ options and access to freedom later in their lives.

You can learn more about Ateliê Ambrosina’s bold, beautiful and groundbreaking projects by visiting its website: ateliembrosina.com.br



Meet Bruna

As an independent activist, it has been amazing to work with academic activist women like Pamela and Nádia. We learned so much from each other! The secret to success in projects like these is ensuring that the relationships are honest, straightforward, direct and spontaneous. The desire to learn how to communicate with lots of different people, whether they are academics or residents in remote, isolated villages, has helped me massively.

There comes a time in projects when you need to stop theorising and start doing. I think one of my best traits is knowing exactly when that time comes and how to make it happen. I am also committed to publicly displaying the results of the projects I am involved in, because I believe that activist

initiatives should be shared with as many people as possible. So, I think the courage to receive feedback is extremely important, both to improve in the future and to encourage the continuity of our ideas.

I have a master’s degree in anthropology from the Federal University of Alagoas and am currently studying a PhD in visual arts at the University of Brasília. My research is now focused on my own bodily experience as a queer, plural-bodied person, without boundaries between the genders of lesbian woman and transmasculine person. What motivates my research is knowing that our queer points of view are still underrepresented within the visual arts in Brazil. Expanding the enjoyment of visual arts, from a queer point of view, excites me. My artistic practice oscillates between activist urgency and long-term investigative processes. You can see more of my work on my website: brucateixeira.com.br

As an artist and researcher, I had the privilege of meeting Nádia, an advisor who was passionate about the anthropology of disability, gender studies and sexuality. She

really helped change my way of thinking about the world, and that is priceless.

I’m an independent artist, so the line between relaxing and working is a bit blurred! But when I’m not having fun working, I enjoy going to the beach and to art galleries, hiking, playing pool, eating well, meeting friends, laughing and having good conversations.

Bruna’s top tips

1. Look for people who can guide you, but make sure that they approach your relationship as an exchange based on mutual respect and admiration.
2. Don’t give up on your project. When you’ve found something that you completely fall in love with, never stop believing in it!
3. In terms of visual arts: practice, experiment, do.



Filús

Pamela has collaborated with Bruna and Ateliê Ambrosina on another creative participatory research project called Filús, in which they co-created a documentary film with, for and about the people living in this community. “The community of Filús is descended from a type of community in Brazil called a Quilombo, formed by enslaved people who escaped into the forests and mountains,” says Pamela. Located in a remote area in northeastern Brazil, it can be hard for the people of Filús to access education, employment, healthcare and clean water, although recent developments include a small schoolhouse for younger children, a medical office and some access to the internet.

“In Filús, there is a larger concentration of people with albinism than almost anywhere else in the world,” says Pamela. “In much of the world, albinism is seen as a disability, but I don’t think that’s how people in Filús look at it. They certainly see it as a disadvantage,

as it impacts your vision and makes your skin vulnerable to cancer, but other than that, they don’t see it as something strange or scary or negative. It’s just part of who they are.”

“Unfortunately, previous research projects in Filús have been primarily biomedical and extractive,” continues Pamela. “Scientists came in to collect information and medical samples but, according to community members, gave very little back, despite the fact that they were receiving huge grants worth hundreds of thousands of dollars to conduct the research. None of this money ever trickled back into the community.”

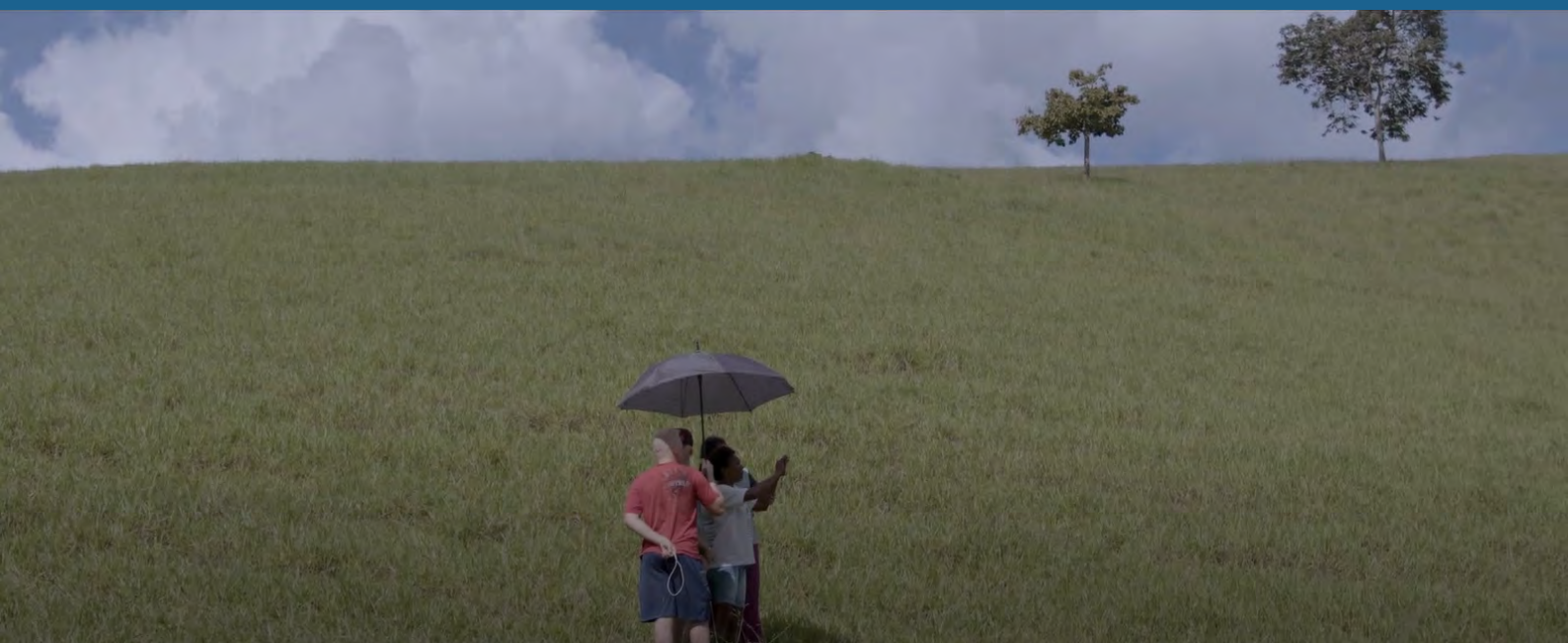
Pamela and Bruna wanted their research project to be different. “We wanted the community to be in control, and we wanted to share the resources that we received for the project,” explains Pamela. As the community shared stories of their lives, the team from Ateliê Ambrosina shared their film-making expertise. Everything from the interviews and script writing to the final edits was done co-creatively. “It was very

important that control of the project be with the community and that they approved anything that was done,” says Pamela. “The Ateliê Ambrosina team has a great deal of experience doing this kind of participatory research and they were great at building a relationship of trust and mutual respect.”

As well as sharing their technical expertise and training community members, the team from Ateliê Ambrosina paid participants and hired local people to work on the project with them. “However, the creative economy does not revolve only around the fair distribution of resources,” says Bruna. “It also involves acknowledging co-authorship, so the entire local team is also credited with the research and production of the film.”

“The story is best told in the film itself and by the people who live in Filús,” says Pamela. You can watch the Filús documentary on YouTube:

<https://www.youtube.com/watch?v=rIcdnkV-e2k&t=496s>



Talking points

Knowledge & Comprehension

1. What were the aims of the Retratos Defiças project, and how were they achieved?
2. What is creative participatory research, and how does it differ from traditional research methods?
3. Why is it important for disabled people to co-create portraits of themselves, rather than having an artist produce a portrait of them?

Application

4. What areas of anthropology interest you most, and why? What steps could you take now towards a career in anthropology? What relevant skills do you already have?

Analysis

5. How and why is co-creative participatory research valuable in sociocultural anthropology? Why is it important that anthropological research is not one-sided?
6. Pamela, Nádia and Bruna wanted to make the Retratos Defiças project accessible to all. To what extent do you think they achieved this aim? Why is accessibility important?
7. Working in disability anthropology involves collaborating with colleagues from other areas including social and political science, medicine, visual arts, and technology. What do you think are the benefits of collaboration? What might be challenging about this type of collaboration?

Evaluation

8. Ableism is not always as prominent in public awareness as other prejudices such as racism or sexism. Why do you think this is, and what impact do you think it has?
9. In what ways has learning about Pamela, Nádia and Bruna's work challenged your own views of disability?

Creativity

10. The Retratos Defiças and Filús projects used visual arts, sound portraits and documentary to co-creatively represent disability and lived experiences in a new way, and to challenge ableist attitudes. What other ideas do you have about ways to collaborate with disabled people to start conversations and get people thinking about ableism?

Disability anthropology

with Dr Pamela Block, Dr Nádia Meinerz and Bruna Teixeira

Activities

1. Personal portraits

In small groups, access the Retratos Defiças website (retratosdeficcas.com) and browse through the portraits. Choose one piece of art and one podcast episode and discuss how disability is represented, and what story or message the creators were trying to tell.

Now, create your own visual or sound portrait. For a visual portrait you could use painting, drawing, collage or photography, and for a sound portrait you could use spoken word, music or other sound recordings. Use your portrait to portray or reflect upon the aspects of your identity that you would like to highlight. Consider:

- What is the story I am trying to tell?
- How is this unique to my personal experience?
- How can I use different visual or sound media to help me express my identity.

Share your portrait with the rest of your group. Has your portrait helped them understand you and your identity? Have you learnt new things about your group members through their portraits?

Reflect on your experience of producing the portrait. What did you like about the experience? What challenges did you experience, and how did you overcome them? Is there anything you would do differently next time?



Under dust and numbered hours © Ana Cândido and Caroline Gouveia

2. Representations of your school

Imagine that you are a disability anthropologist coming into your school or college to learn about the culture and experiences of disabled people. Create a storyboard for a documentary exploring this topic. Consider the following:

- What is the story you are trying to tell? How will you use audio and video to help you tell this story?
- How could you ensure that the voices of different groups within your school are represented, for example, students from different year groups, teaching staff and administrative staff?
- How could you communicate the everyday experiences of people within the school or college in a way that could be understood by people around the world?
- How are disabled people visible or not visible in your school? Is the school building accessible to disabled people?
- Are there disabled people in your networks of family and friends? Ask them about whether they feel included or excluded from school activities? Are public events in the school accessible to disabled people (for example, art shows, lectures, films, public meetings and even elections are sometimes based in schools)?
- How could the school be made a more welcoming place for disabled people?

Once you have created your storyboard, consider making your documentary a reality. Think about:

- What equipment and skills would you need?
- How would you ensure that you had consent from the people featured in your film?
- How could you make sure the script and the footage are produced collaboratively?
- Where are the disabled people on your documentary team? What are they doing?
- How could you make the documentary accessible to all?

More resources

- Browse the website of the Disability Visibility Project where you can read blog posts, view portraits and listen to the podcast:
disabilityvisibilityproject.com
- Watch this YouTube video about Retratos Defiças which shares the aims of the project, images of the visual portraits and clips from the sound portraits:
youtube.com/watch?v=J2XovB4L9Bg
- Explore the artwork of Frida Kahlo from Mexico, Riva Lehrer and Sunaura Taylor from the USA, Mary Katayama from Japan, Yulia Taits from Russia and Sonia Soberats from Venezuela, who inspired Pamela, Nádia and Bruna when they were exploring ideas for the Retratos Defiças project.
- Read these two articles about different areas of anthropology on the Futurum Careers website:
futurumcareers.com/what-if-we-could-step-in-the-shoes-of-migrants-and-inhabitants-on-the-island-of-lampedusa and futurumcareers.com/what-lessons-can-we-learn-from-past-pandemics



Art is healing © Helane Alencar and Silza Freire

Photo montage

Right: Pamela, Nádia and Bruna with two artists from Ateliê Ambrosina, Olga and Malta.

Bottom left: The Retratos Defiças project took place during the COVID-19 pandemic, so many of the discussions took place online.

Bottom right: A picture from the team’s first meeting with the community in Filús. “This is from before trust was established, and you can see it in people’s faces,” says Pamela. “They had no idea who we were and what we wanted at this point. We had to build trust throughout the process.”



“

The secret to success in projects like these is ensuring that the relationships are honest, straightforward, direct and spontaneous. The desire to learn how to communicate with lots of different people, whether they are academics or residents in remote, isolated villages, has helped me massively. - Bruna

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Visit the gallery on the Retratos Defiças, website to find full descriptions of each piece of art along with quotes from the co-creators about their experiences: retratosdeficass.com/galeria



Being in itself © Adrianna Reis and João Carlos



Under dust and numbered hours © Ana Candido and Caroline Gouveia

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