

How (and when) to talk about disability?

A guide for
cultural
communication
professionals
and journalists



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Preface

Acesso Cultura | Access Culture is an association of cultural professionals and cultural organisations that promotes access – physical, social and intellectual – to cultural participation. We are interested in all forms of participation: at formal and non-formal cultural spaces, as a member of the audience, as an amateur or professional artist, or a cultural professional, in general. We wish to contribute towards building a curious and inclusive society, in which anyone can dream, have opportunities to participate and be the best they can.

Considering our mission, issues related to disability have occupied a prominent place. As an association of people with and without disabilities, collaborating with consultants and trainers with and without disabilities, we have sought to raise awareness in the cultural sector regarding these issues, we have invested considerably in professional training and we have sought to support the work of our colleagues in the field.

We are very much aware that, at different times - **precisely due to lack of knowledge and contact with certain realities** - the cultural sector has helped to perpetuate stereotypes in relation to Deaf and disabled people, revealing **ableist** mentalities and attitudes. The same happens with another sector linked to communication, that of the media. At various moments - when pieces of news with sensationalist titles, ableist references and incorrect terms reach the public - we have tried to get in touch with the people responsible for their authorship.



Ableism is the word that defines discrimination, oppression and abuse against people with disabilities, considering them inferior to people without disabilities. In other words, it is discrimination based on capacity (physical, intellectual, psychological). Ableism is based on a set of beliefs, processes and social practices, which produce a body standard (physical and intellectual) without disability, seen as superior, perfect/ideal and essentially human. People who do not fit this pattern are, in a way, dehumanised and excluded. This perspective is highly oppressive, because it focuses on a person's condition, blaming their disability for the problems people experience, instead of focusing the problem on oppression and social barriers.

There are, however, two issues to consider here:

- These contacts are nothing more than specific, individual actions, which do not change the system and which often go unanswered;
- This news and these approaches are the product of both journalists and newsrooms, as well as the communication teams of cultural organisations themselves.

In June, several cultural professionals (from the areas of artistic direction, programming, communication) and journalists received an email from dancer and choreographer Diana Niepce. In that email, Diana (who is also a member of Acesso Cultura) shared her displeasure at the “great lack of sensitivity in the ways you communicate my work, thus weakening it” and reaffirmed that “The work and the author with disabilities cannot, in any way, be presented in an ableist way, creating a context of overcoming, paternalism, condescension.”

This was the push we needed in order to get in touch with journalist Dora Alexandre (author of “Disability in the media: guide of good practices for journalists”, 2012), as well as several Deaf and disabled artists and activists, and invite them to create a guide aimed at cultural communication professionals and journalists.

Why this guide?

- Because we are very much aware of the constant discomfort and inconvenience experienced and felt by colleagues, cultural professionals, who do not feel represented and end up feeling offended by the way their work and life stories are presented to society and the public;
- Because each person - and especially, in this case, communication professionals - has a responsibility to contribute towards the creation of a society where everyone can have the right to dream and be the best they can, without “labels”;
- Because, Portugal has got specific legislation and has signed very relevant conventions on this matter. However, as we all know, people's attitudes do not change by decree;
- Because it is urgent to break the ableist paradigm in the Portuguese society.

The focus of this publication is the area of culture, which is our area of work. We know, however, that what is presented here also refers to other areas, and we hope that it may also be useful to other professionals.

Rita Pires dos Santos
President

“The minister is really autistic”

“The café where people with cognitive problems work has already opened in Portugal”

“The coalition is sitting in a wheelchair”

“A ballerina with one leg”

“An exotic body”

“The Joyeux team has currently got nine people struggling with these difficulties.”

“...where people with intellectual and developmental disabilities (IDD) such as Down Syndrom or autism spectrum disorders are employed.”

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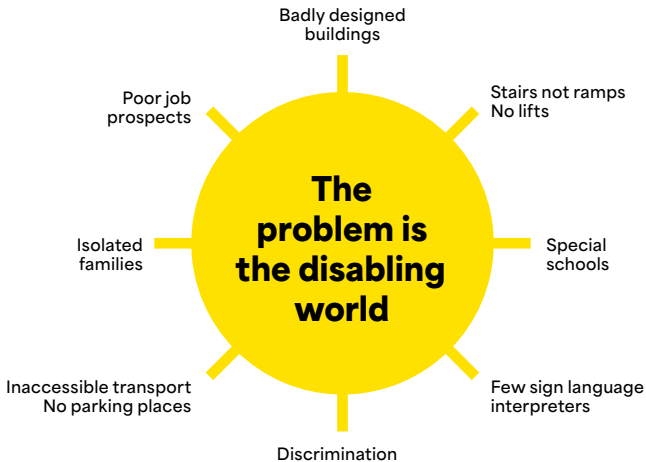
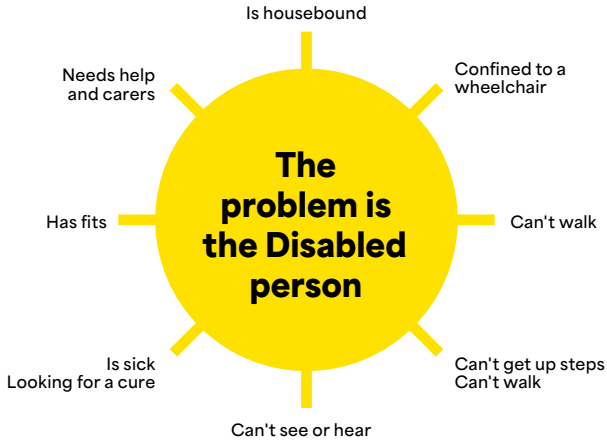
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**Framework:
each person's
responsibility
in building an
inclusive society**

From the medical model to the social model of disability



For a long time, our mindset regarding disability has been shaped by the so-called “**medical model of disability**”. This is a way of looking at a person with a disability based on their medical diagnosis. It shows us that the main problem for society are people with disabilities, whose condition disables them and reduces their quality of life. The aim is to cure or mitigate the effects of this condition, through medical interventions and various “special” services - aimed at “special” people.

In the 1960s - more than 60 years ago - several disabled people in the United Kingdom joined the Social Disability Movement and proposed another way of looking at people with disabilities, called the “**social model of disability**”. This model shows us that the main problem is society itself, a society that excludes, as it does not present equitable or diverse solutions. A society that does not take human diversity into account, but rather a “norm” referring to a “majority”. It, thus, builds an exclusionary world: it places barriers in public and private spaces, in people's personal and professional lives, in our life in common, in society. Disability exists, but people are disabled by lack of accessibility and equitable opportunities.

The political positioning proposed by the social model of disability places the issue in very different terms and within the broader scope of human rights. We highlight three specific articles from the Universal Declaration of Human Rights:

- **Art. 1:** All human beings are born free and equal in dignity and rights.
- **Art. 6:** Everyone has the right to recognition everywhere as a person before the law.
- **Art.27:** Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

The fact that everyone has the right to be and to participate forms the responsibility of all members of society, not only as individuals, but also as professionals from different areas, to create conditions of access so that any person can be whatever they want, wherever they want; freely, with respect and dignity.

The power of words: language and mentality

Words are powerful. First, because they create images in our heads, they influence the way we perceive the world. Then, because they can make someone feel good or bad, cause feelings of comfort or discomfort, serenity or irritation, enthusiasm or outrage, etc. Our mentality is reflected in the language we use; and the language we use reflects our mentality.

The medical model of disability is still deeply influencing society's mentality and language. These oscillate between two extremes: on the one hand, pity ("poor" people) and, on the other, admiration (people who "overcome" themselves), with nothing in between. In general, society looks at Deaf and disabled people as individuals with "problems", with "limitations", without capacities. Disability is a burden people carry around and society expects very little from those people.

For that reason, when some disabled people become more visible, they are present in the public space, society expresses its surprise and admiration with words such as "overcoming", "despite [the disability]", "inspiration". Disabled people become "heroes".

We live between these two extremes, pity and admiration, perpetuating ableist mentalities and attitudes.

“I am not your inspiration, thank you very much”, declared the late Australian activist Stella Young. **“I don’t want to be a hero, can I have access?”**, asked Greek activist Georgia Kaltsi.

Deaf and disabled people are, above anything else, people: they can be artists and cultural managers, they can also be teachers, hairdressers, scientists, clerks. They don’t live their lives “despite” their bodies, condition or impairments and they have the right to have opportunities in life, be respected and treated with dignity. The social model of disability states that any impairment, problem or limitation is not the natural result of a person’s physical or mental condition; it is the result of society’s actions, of all people who build a world without taking into account human diversity, creating barriers to those who do not fit in “the norm”, the established “standard”. If Deaf and disabled people are confined, isolated and need to fight against a number of adverse conditions in order to have a place in society, this is the responsibility of society itself, which keeps excluding and is incapable to imagine a greater world, able to embrace diversity.

The role of communication professionals

This is the context in which communication professionals are invited to act. We refer to journalists, press officers, communication directors in cultural organisations. We also refer to people in other posts, who also communicate – for example, cultural mediators, artistic directors and cultural programmers. All these people work with words, build narratives, aim at influencing human thinking and behaviour, wish to contribute to the construction of a better society.

That said, the question to ask is the following: How to tell stories related to Deaf and disabled people? How are they presented to society? What kind of mentalities and behaviours these representations mould?

Deaf and disabled people, like all people, wish to be treated with respect, knowledge and sensitivity. They wish to feel represented. Communication professionals (or rather, professionals who communicate) owe them this respect, they must listen and learn before speaking about their lives, personal and professional. The mention of disability may make sense (or not) and references must be made with rigour, without overstatements, without dramas, no patronising, pity or sensationalism.

One must admit that communication professionals do not always have the know how or feel at ease in handling these issues. This is precisely the reason why we made this guide. Considering the essence of working in communication, there is a need for greater conscience and more and better knowledge, so that we don't contribute to the perpetuation, and even reinforcement, of stereotypes. Professionals in this field must contribute towards a more informed society, more conscious of its responsibilities, more inclusive and equitable.

The role of people with disabilities

It might seem that we are talking about “us” and “them”. It is not our intention to cause this misunderstanding. Building an inclusive and equitable society involves people both with and without disabilities. Deaf and disabled people can tell their stories, directly or through intermediaries; they can also be communication professionals. And, just like every other person, they have distinct, very personal ways of identifying, looking at themselves and projecting their image.

There are people who feel victims, people who feel vulnerable and focus on social support and benefits. There are people who wish to denounce barriers and injustices, deny the role of victim and demand the right to live their lives fully, be and do whatever they wish. There are different ways of looking at disability and they also influence the way other people look at disabled people. The responsibility of building an image lies also with Deaf and disabled people.

What is their choice? What world do they wish to build?
A world based on medical diagnoses or a world which respects human diversity and the human rights of all people?
Are they poor people, heroes or, simply, people?

Six myths regarding disability and three clarifications

Myth 1:

Deaf and disabled people are not active in society

Every case is a case, but inactivity is not the rule, in any way. Apart from some very severe cases of impairment and/or social isolation, Deaf and disabled people can and do give their contribution to society. Even more so when they act in spaces built to be accessible and inclusive, which take into consideration their specific needs.

Myth 2:

Deaf and disabled people always need assistance

Not always. The more accessible and inclusive an environment is, the more autonomous people are, more free to live alone or in company, according to their wishes. In this context, the profession of personal assistant has also come to contribute towards this autonomy and freedom, whenever necessary. Just like the wheelchair, crutches or prosthetics are elements that support autonomy and freedom to those who need them.

Myth 3:

Accessibility is the absence of architectural barriers

Also, but not only. Accessibility is a much broader concept, which adapts to every person's specific needs. It can be physical, sensory, intellectual, social, communicational.

Myth 4:

Access is important only for disabled people

It is not. Accessibility concerns everyone, without exception. It is important for disabled people, for the people around them and those who accompany them, for those who push a baby stroller, a travel trolley or carry out loading and unloading activities, without forgetting anyone who has - or will have in the future - an impairment, even if temporary, whether physical, sensory or intellectual. Overall, at one time or another in life, accessibility is vital for the entire population. Nowadays, it is also known that when accessibility conditions and services exist, they are used by many other people, because they facilitate many tasks and experiences.

Myth 5:

Deaf and disabled people have few financial resources

This idea is often conveyed by dramatic cases presented in the media. Many Deaf and disabled people have active professional lives and, consequently, financial resources. However, it is true that in, virtually, all countries, Deaf and disabled people are more likely to be unemployed or have a low income - something directly associated to lack of access to education, professionalisation and, later on, to the workplace itself. This is yet another result of a society that excludes. It is also important to note that no person is completely autonomous. We are all interdependent, as we function daily, using and providing resources. Interdependence enables a deeper and more meaningful relationship between people.

Myth 6:

Dealing with disability is depressing

If we only focus on extreme cases and consider that people's misfortunes are the result of their condition (and not the responsibility of society as a whole), it can be painful, yes. However, disability is not limited to dramatic cases. Most Deaf and disabled people do not live in bitterness, pitying themselves. Although they deal with increased challenges in their daily lives, fighting against a society that excludes them, disabled people try to live their lives in the best way possible, like everyone else.

Furthemore, three clarifications:

#1:

Deaf people have a hearing impairment

Throughout this guide, we use the expression “Deaf and disabled people”. Writing the word “Deaf” with a capital D is a convention adopted by Deaf people in several countries. It serves to identify people whose mother tongue is the sign language of their country and who consider themselves to be part of a linguistic minority, having their own culture. Deaf people do not consider that they have a disability. People who identify as having a hearing impairment are deaf people who do not speak sign language, who use hearing aids, or who have cochlear implants. They may also be people who have lost or are losing their hearing due to their age, genetic issues or accidents.

#2:

People with cerebral palsy have intellectual disabilities

Rarely, but the designation - cerebral palsy - can lead to this misinterpretation. In reality, the area of the brain that coordinates certain parts of the body (movements, speech...) is affected and, therefore, people with cerebral palsy may have difficulty articulating movements and words. However, it is a physical and not an intellectual disability.

#3:

All disabilities are visible

There are many people whose disability is not visible. This is the case of people on the autism spectrum, people with low vision, chronic pain, among others. These are conditions that, in many cases, significantly affect a person's day-to-day life. As a society, once again, we know very little about invisible disabilities and we do not have adequate preparation to create spaces and relationships where these issues can be talked about and cared for. Many people with an invisible disability choose not to disclose it, in order to avoid stigma and discrimination, and this can lead to social isolation, making them feel unsupported and misunderstood.

“...the project includes deaf people, blind people, people with cerebral palsy, cognitive impairments and Down Syndrom, as well as people without limitations.”

“Quadriplegic dancer presents book.”

“Filming begins of the first Portuguese series starring an actress with Down Syndrom”

“A proof of overcoming in concert”

“[name of the person] is 46 years old and has lived in a wheelchair for seven years.”

“The limitations of these dancers have not prevented them from getting to countries like Germany or France, in dance festivals as important as Festival d’Automne à Paris. Nor does it stop them from working directly with renowned Portuguese choreographers...”

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Strategies for cultural communication professionals and journalists

In the specific context of the cultural sector, we are faced with two concrete needs:

- Talk about disability in an informed way, without drama, paternalism, overstatements and commiseration, respecting the way each person wants to be portrayed.
- Know how to distinguish between situations in which it is relevant to mention a disability or not, and how to do so. For example, there are artists with disabilities who prefer the focus to be on their work and not on their disability; there are cases, however, in which it may make sense to mention the disability.

This must be a common effort, made by cultural communication professionals and journalists alike, but also by Deaf and disabled people themselves.

Preparing and collecting information

In the context of the cultural sector, information is needed for the preparation of promotional materials (websites, social networks, press releases) or for an interview.

Before the first contact

- Try to find out in advance a little bit about the specific needs of the person you are going to talk to and how that person identifies.
- Choose a form of communication that best responds to these needs: if you are going to contact a Deaf person, it will have to be via SMS, WhatsApp or email; if it is a visually impaired person, it can be by phone, SMS, WhatsApp or email.
- If you are going to speak with a Deaf person, it will be necessary to have interpretation in sign language. The responsibility for having an interpreter and the associated costs do not lie with the person, they must be handled by yourself/the organisation you work for. The person you are going to interview will be able to recommend someone, but there are also several associations, such as Access Culture, that can provide contact details.
- If you are going to talk to someone who uses a hearing aid or has a cochlear implant, choose a quieter place, without much noise and visual distractions.

- If the meeting or interview is with someone with reduced mobility, choose an accessible location and, preferably, with an adapted bathroom.

During the conversation

- When you meet the person, greet them in the same way you usually greet other people. If you normally shake hands, offer the same greeting even if the person has limited use of their hands or uses prosthetics. The person will show you which greeting is most appropriate.
- Always ask the person if they need help, don't just give it. A good rule of thumb is to respect the person's autonomy. If your help is needed, the person will give you this indication.
- If you are talking to a person of short stature (for example, people with dwarfism) or a wheelchair user, sit down to be at their level. Otherwise, you will cause them the discomfort of constantly looking up.
- If you are with a Deaf person, it is not worth talking loud. You should also look at the person and not the interpreter. Some D/deaf people (sign language speakers and non-sign language speakers) are oralists (they can speak). It may not always be completely easy to understand. If you don't understand, ask to repeat.

- If you are talking to an adult with an intellectual disability, do not treat them as if they were a child. Pay attention to your tone of voice, the words you use and don't address in ways you don't normally use with other adults whom you are not acquainted with.
- If a person needs more time to express themselves (for example, a person who stutters or has cerebral palsy), let them finish their sentence, don't try to complete it, allow more time than usual.
- In the case of people with cerebral palsy, they often find it difficult to articulate their speech. Keep focused and, if you don't understand, ask to repeat. The person knows whether they speak clearly or not and will be accompanied by someone who can help with communication, if necessary. As a general rule, always remember that the disability of people with cerebral palsy is physical and not intellectual.
- If you are going to speak to a person with visual impairment (blind or low vision), identify and describe yourself (physical appearance - for example, height, hair, eyes - and clothing).
- A blind person may be accompanied by a guide dog. As tempting as it may be, avoid petting the animal, as it is in work mode and should not be distracted or fed.

- If a visually impaired person needs your help to move around, offer your arm as a guide, lightly touching theirs, so they know where you are. The person will take your arm so that you can guide them. While walking together, always stay slightly ahead and warn them if any barriers appear. However, you don't need to describe the path, count steps, etc. Be careful not to put the person in danger. To help them sit down, point out the location of the seat and make a guiding noise with the chair, so they understand where they are and can approach and sit down independently.
- Throughout the conversation, listen to the person, that is, practice active listening. Try to understand how the person wants to be portrayed and how relevant their disability might be to the interview, report or other content you are preparing.
- Most disabled people probably do not mind answering questions related to their disability. However, don't ask questions just out of curiosity. Determine, together with the person, whether talking about the disability is relevant to the information you are preparing and how it should be addressed.

Overall, you should always treat the person naturally, with respect, avoiding condescending attitudes or language. Find out and prepare for this in advance. And never forget that you are interacting with an adult, so treat them as such. Obviously, you must address them directly and not their assistants or interpreters, as if they were their “representatives”.

If an embarrassing situation occurs, a good dose of politeness, sincerity and humour never fail!

How to write or talk about Deaf and disabled people

Perhaps the biggest challenge is defining whether or not disability is relevant to the piece you are preparing. The focus of your work must be the person themselves and/or their work. Only afterwards, and if considered relevant, should disability be mentioned. Some examples:

- If the subject is new work by a Deaf or disabled artist, it may not make any sense to mention or explore that aspect. It could result in mere sensationalism.
- If it is an autobiographical work or if the person also sees themselves as an activist for the rights of Deaf and disabled people, it could make sense. The person themselves can help you understand and make this decision.
- In the case of theatre or dance companies that work with artists with and without disabilities, or TV series starring or including disabled actors, it may make sense to mention disability, as these are still the first steps in the inclusion of these artists in the professional world. However, as already mentioned, disabled artists do not occupy these places “despite” their bodies or their condition, but because conditions of access and inclusive workspaces are being created.

- If the focus of the work is to make known the story of a Deaf or disabled person, it is natural to make reference to this fact. However, this reference must be made with respect and knowledge, without patronising and without talking about “heroism” and “overcoming”. Furthermore, a person is not limited to their disability. There will certainly be other facets to be explored.

Another aspect to keep in mind is that a Deaf or disabled person is not necessarily a sick or frail person. Respect the way the person presents themselves, how they talk about themselves. Avoid dramas, but also avoid expressing admiration just because the person does something in their life. Portray people as they really are.

As cultural communication professionals and journalists, you also have another relevant task: to contribute to the construction of an individual and collective mentality in society in relation to disability and make everyone aware of their responsibilities when accessibility conditions do not exist. In that regard:

- When your piece refers to a specific cultural space, include information about the accessibility conditions - physical, sensory, communicational. It will be useful both to raise awareness in society in general and to inform Deaf and disabled people.
- Be also aware and make reference to the lack of accessibility conditions, both for the public and the staff or artists. Access is a common cause, not just for Deaf and disabled people. We must be demanding.

- Interview Deaf and disabled people as experts in their field of knowledge. Don't look for them just to talk about disability.
-

Terminology: choose your words carefully

As we have already highlighted, words have enormous power and, if they are not chosen well, they can create inappropriate images or even hurt someone. In addition, the correct use of words is essential so that our audience finds in them a true correspondence with the reality we are portraying. And also, so that disabled people feel portrayed. If you have questions regarding the terms to use, simply ask.

Below, we share a list of terms that can be used today and others that should no longer be used. We emphasise “today” because, naturally, the language related to disability evolves, following the transformation of society and mentalities. It is necessary to be aware of these developments, at the same time as we must be aware that there will hardly be a consensus on language, even among disabled people. It is therefore advisable to listen actively and sensitively, in order to choose the words and expressions used by the person we are addressing.

Use	Do not use
Person with a disability Disabled person Person with impairments Person with functional diversity Neurodivergent person Person with specific needs	Cripple Crip* Handicapped Abnormal Person suffering from a disability Person with problems/limitations Person with special needs
Person with a physical disability Person with reduced mobility Wheelchair user	A person confined/trapped in a wheelchair A person limited to a wheelchair The wheelchair (when referring to the person using it)
Person with a visual disability Blind person Person with low vision	
Deaf person (a person for whom sign language is their mother tongue) deaf person Person with a hearing impairment	Deaf-mute
Person with an intellectual disability Learning disabled person	Mentally handicapped Retarded
Person with Down Syndrom	Mongoloid
Person of short stature Little person Person with dwarfism	Dwarf

* More recently, disabled activists have appropriated this once derogatory term and use it to identify themselves.

Summarising

- Look for information and training on these issues if you want to write and speak about them.
- Practice active listening.
- Look for specialised, knowledgeable and diverse sources. The lived experience of a person with a disability is not enough for them to be able to speak for an entire community. And no community thinks homogeneously.
- Deaf and disabled people may be the subject of your piece, but they are also the readers.
- Deaf and disabled people must also be part of the teams (in cultural organisations and the media). Support these professionals, help create access conditions, safe and inclusive workspaces.

ANNEXES



Legislation and other information

Universal Declaration of Human Rights

Convention on the Rights of Persons with Disabilities

Your country's constitution and laws against discrimination, promoting physical and digital access.

Articles and interviews

Jess Thom, I don't suppress my ticks - it's definitely Beckett without biscuits

Mia Mingus, Access intimacy: the missing link

Mickaella Dantas, My parents gave me the freedom to choose what happens to my body

Videos

Al.Di.Qua Artists (Alternative Disability Quality Artists), Manifesto

Unexpected Bodies in Unexpected Places

Europe Beyond Access introduces Diana Niepce (Portugal)

Europe Beyond Access presents "Learning disabled leaders in Theatre and Dance"

Stella Young, I am not your inspiration, thank you very much

Sue Austin, Deep sea diving in a wheelchair

Guides for journalists

Centre for Disability Rights, Disability Writing and Journalism Guidelines

National Center on Disability and Journalism Resources on reporting

Open Mind, Writing disabled voices

*“[name of person]:
the paraplegic
who completed
one of the
most difficult
marathons in the
world.”*

*“A motorbike
accident sent him
to a wheelchair.”*

*“... She had a
surgery at the
age of 13 that
permanently
blinded her.
From then on,
her life definitely
changed, but this
didn't stop her
from anything.
She became a
dancer and built
her own family.”*

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