

IMAGINING COMMON SPACES



Empower Parents is an educational and community mediation programme. A pioneer in Spain, its aim is to transform museum and cultural institutions into more human and accessible spaces. It was founded in 2013 thanks to the collaboration between Queens Museum in New York, Fundación ICO and hablarenarte in Madrid after winning the Museums Connect: Building Global Communities prize granted by the US Department of State's Bureau of Educational and Cultural Affairs and administered by the American Alliance of Museums.

In 2015 the programme was included in the *Museos + Sociales* national plan launched by Spain's Ministry of Education, Culture and Sport to enable museum institutions to adapt to the current social realities.

Empower Parents was recognised as one of the three most innovative and inclusive projects in European cultural industries at the 2017 edition of the NICE (Network for Innovations in Culture and Creativity in Europe) Awards. Organised by the European Centre for Creative Economy (ECCE), the awards promote inclusion through social innovation.

The year 2020 has ushered in a new phase that has seen the programme families take the reins and create the *Empower Parents* Association with the aim of continuing the initiatives begun at Museo ICO and bringing new cultural and museum institutions on board.

Museo ICO towards a common space

This book is a testament to the *Empower Parents* programme and an invitation to reflect on its achievements. The fact that our museum was chosen to develop this programme represented a milestone for Fundación ICO and we have never lost sight of its enormous significance. This publication is part of the fair return to the families, organisations, colleagues and other cultural institutions with whom we have shared this decisive experience.

In June 2013, when the American Alliance of Museums invited us to launch the programme in partnership with hablarenarte and Queens Museum, we embraced the chance to introduce a new activity related to inclusive access to leisure and culture at our museum, building on a commitment we had adopted several years earlier: to add a whole new dimension to the “complementary activities” for our exhibitions.

For a small museum gaining its footing in the field of architectural exhibitions through sheer hard work and determination, the challenge involved the additional effort of making the arrangements in record time, creating the necessary procedures from scratch, setting up the appropriate spaces and developing an administrative framework sensitive to the needs. However, the award granted to carry out this intensive engagement with the *Empower Parents* families and with autism and its barriers materialised into an opportunity.

The families that assumed this commitment from the outset, the hablarenarte experts and management, the technical team (two people) directly responsible for the programming and the Fundación ICO board of trustees gradually managed to develop an operating framework for a constantly evolving programme. Organising the logistics to synchronise the interaction between the participants in New York and Madrid through virtual communication, the adventure of the meetings in the two cities, the sessions at the museum and the arduous subsequent tasks of transferring the lessons to other institutions have all been worthwhile, in spite of countless hurdles along the way.

There is one major conclusion which we feel it is important to highlight in this introduction. The members of the participating families in the programme were powerful before *Empower Parents* came into existence, and the impetus for the programme was the transformation of that power into a new one that appropriated and demanded an equal place for cognitively diverse people in public spaces by challenging the sadly notorious resistance of institutions—in this case, cultural and leisure ones—to become community institutions. Museo ICO continues to exert pressure in this area, but after six years of involvement and exposure to the dynamics of openness, it has left

behind the opportunity phase that was launched with the arrival of *Empower Parents* and is now in a position to rethink its public and service strategy.

Just as a solid group of families in the programme has evolved and cohered around the mission of the *Empower Parents* Association—the most eloquent indicator of the objectives achieved—so too Museo ICO has modified its relationship with audiences. The first part of this publication, Context, describes the transition of the participants from a “non-audience into a VIP audience”, while the testimonies explain how this new status has impacted the leisure of families, enabling parents and siblings with and without ASD to visit the museum together. The significance of *Empower Parents* is twofold: the capacity for action which this audience has gained; and the normalisation and naturalisation of diversity in the museum galleries. It is in this sense that Fundación ICO intends to frame the future of the museum community.

On reaching the sixth edition in 2019 and exploring the most appropriate way forward, we examined the effectiveness of pursuing a programme that has consolidated a service for a growing group of families without taking the opportunity to rethink the museum’s community model or extend the programme practices to other institutions.

This book aims to provide inspiration through the enormous possibilities to “imagine common spaces” offered by the process and results of the *Empower Parents* programme. We are also keen to publicise the development of the process and the tools used in each phase with a view to providing a starting point for adaptations and replications of the experience, not only at museums but at any other spaces that want to add a new perspective to their services for audiences.

On a final note, we would like to extend a generic but heartfelt thank you to all the individuals and teams who have made this adventure possible by bringing their dedication, good cheer and knowledge to an experiment in social and cultural construction. Lastly and very particularly, we must express our appreciation and admiration for the adults and children at the heart of *Empower Parents*, for the intelligence, curiosity, friendship and hope they have shown throughout the programme. We will strive to meet the needs of families affected by autism and continue shaping a museum that accommodates cognitive diversity by educating ourselves and our audiences to become part of a community united by art and by joining forces with other institutions devoted to this same mission.

Imagining common spaces

What if museums invited the community into a common space by accommodating different forms of heterogeneity? What if they became spaces occupied by all and in which minorities contributed to a new collective narrative? What if we dreamed that these people could one day take their place in cultural institutions, appropriating dehumanised spaces to transform them into common spaces, so that instead of being places of reference they became places of belonging? And what if we dared to believe for just one moment that this were possible, focusing our actions on publicising the processes that support, protect and humanise?

It is seven years since we launched *Empower Parents* at Museo ICO and, with considerable apprehension, formed the community on the basis of six families that travelled from different cities in Spain every Saturday to take part in an experimental programme.

During this time, both we as the educators and the families as the participants have defined a working practice that has enabled us to consolidate an accessible programme of educational activities and a stable, long-lasting community with families of children with ASD. We have also managed to turn Museo ICO into a place of belonging for all of them.

Every Saturday, the educators and families have worked to try and humanise processes and transform the museum into a common space in which to come together and talk, dance, look after each other... and also enjoy art and culture.

After several years engaged in this practice, we continue to expand the community and embrace the doubts, successes, failures and lessons. And now the time has come to write about the context in which the programme emerged, the working practices we have developed, the lessons we have learned, the bonds we have created, and the way in which we look after each other.

There is still a lot to do and a lot to dream about before we reach the ideal situation, but no one can prevent us from imagining common spaces and working to achieve them.

This book is a compilation of the experiences of these last few years, presented in the form of texts, conversations and images. Organised into three chapters, it situates and describes the programme, reproduces the conversations with some of the agents, artists and families involved, and shares the practices undertaken.

In short, the book is an excuse to reflect on what we have lived and achieved, put it all in order, raise awareness, communicate and transcend the walls of the museum. Because that is what it is all about. That is the essence of *Empower Parents*.

And, of course, it is also a way of thanking those who have joined us on this marvellous adventure. Thus far.

Laura Donis, head of the *Empower Parents* programme

Challenges of the terminology

1. The Independent Living and Diversity Forum is a community that was created to reflect on the status of people with functional diversity. In 2015 it collaborated in the organisation of the European Independent Living Congress.

The texts you are going to read are largely centred around the emotions and the bonds and relationships between people who belong to the same community but have different abilities and needs as regards support and/or attention. There is nothing particularly illuminating in this approach per se, but we believe it is important to mention it at the beginning of the publication to highlight the importance we attach to the use of the appropriate terminology in referring to people with diversity and different abilities.

“Functional diversity” is the concept we use to refer to this group throughout because it is the most inclusive and positive term. However, there is one exception in Chapter 2 related to the conversations we held with the various agents, creators and families who took part in the programme. In this chapter, we decided to maintain the concepts that each of the people interviewed use naturally because they reflect their own relationship with diversity. Accordingly, some of the conversations mention “intellectual and developmental disability”, whereas others refer to “different abilities”.

This is an ongoing debate between people with functional diversity themselves, their families and the different organisations that promote their social inclusion.

The concept of functional diversity first appeared at the Independent Living Forum in 2005¹ as a replacement for the concept of disability, which discriminates a broad group of people. However, not every one agrees. For example, the Spanish Committee of Representatives of People with Disabilities (CERMI) and federations like Plena Inclusión still prefer to use the word “disability”, arguing that “functional diversity” generates a degree of legal uncertainty because it does not specifically identify the needs and protection measures required for this collective.

Some of the *Empower Parents* families and social organisations in the sector also use “disability” in defence of the rights claimed by the group. However, for this publication we made the decision to focus on abilities as the premise for bringing about change and social transformation.

In relation to autism, a variety of concepts have evolved over time: person with autism, autism, and autism spectrum disorder or ASD are positive terms that respect the autism community. We therefore use them interchangeably in this publication.

Contents

Nuances	17
Context	19
Contexts that exclude	20
The culture of autism	26
The JFK-MAD connection	28
The museum: a space for experimentation	32
Conversations	63
Conversing	64
Agents	66
Artists	88
Families	99
Practice	145
Action!	148
Explore, learn, make visible	149

Nuances

We began this publication in January 2020, a few months after the sixth edition of *Empower Parents* at Museo ICO had ended. The idea was to offer a summary of the work and activities carried out during the past six years, but when we sat down to write about this broad, complex and highly nuanced process we immediately found ourselves wondering where and how to begin.

We were clear that we didn't want to produce a technical document or formal assessment, and that the focus should not be quantitative but allow us to discuss intangible and emotional aspects. It has not been an easy task, particularly when it is common practice to measure your work and the projects you carry out against numerical or financial criteria, or at best according to social impact indicators which in reality are still a subtle form of control, especially in the case of projects concerning processes, relationships and emotions rather than results.

Entitled *Context, Conversations* and *Practice*, the chapters that follow describe the *Empower Parents* experience with its successes and its failures.

Chapter 1 ends with a series of reflections on these first six years of the programme and highlights future challenges. We also take the liberty of mentioning other things that we would have liked to do but have thus far been unable to implement.

In *Conversations*, we include eleven interviews with different agents, artists and families who have participated in the programme over these years and they tell us about their experiences in first person.

Chapter 3 describes the activities that have been carried out as part of the programme at Museo ICO for families of children with ASD. We adopt a practical approach to this section of the publication aimed at answering the questions we grappled with ourselves when we embarked on this adventure. Or at least we hope we go some way to answering them.

Let's begin!

Context

2. Hereinafter, Queens Museum.

3. Grant and award programme to strengthen the ties between museums in the United States and other countries through innovative partnerships. The awards are granted by the American Alliance of Museums and funded by the US Department of State's Bureau for Educational and Cultural Affairs.

The *Empower Parents* programme was launched in 2013 as a partnership between Queens Museum of Art² in New York City and Fundación ICO and *hablarenarte* in Madrid thanks to a grant from the Museums Connect: Building Global Communities programme³ of the American Alliance of Museums, part of the US Department of State's Bureau of Educational and Cultural Affairs.

The award gave us a marvellous opportunity to implement the *Empower Parents* programme in Madrid with the dual aims of organising a series of accessible activities for families affected by autism and building a community that would transform the concept of the museum from a hostile place for the majority of the families to a more open, accessible and inclusive space.

There were no experiences of this nature in Spain so it was an ideal time to carry it out. The award covered the costs of an exchange programme for the professionals and families, so we were able to travel to New York on two occasions to witness other contexts and working methodologies first hand, expand our knowledge about living with autism and establish contact with new accessibility and community mediation experiences in museums and cultural institutions on the other side of the Atlantic.

At the same time as undertaking the exchange programme with Queens Museum, we needed to find out more about families affected by ASD in Spain and their relationship with cultural institutions. As our starting point, we contacted the main confederations, federations and associations that work with this collective and established a framework of cooperation that has continued to this day. Having completed this initial context analysis phase, we launched an experimental programme of activities at Museo ICO which enabled



AWARD



REPORT



NETWORKS



EXCHANGE PROGRAMME



PUBLIC PRESENTATION



WORKSHOP



PROGRAMME OF ACTIVITIES

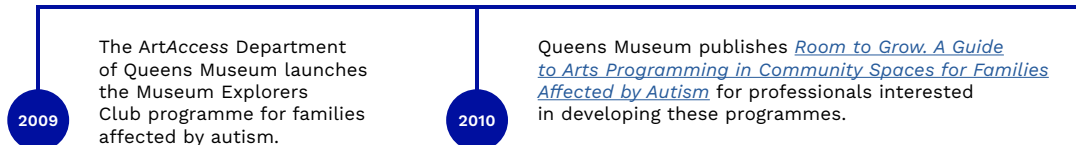


REPLICATION PROGRAMMES



MEETING

Timeline



us to start defining our own working methodology adapted to the ASD community and the needs of the families.

In 2014, the funding from the American Alliance of Museums came to an end and we embarked on a new phase with Fundación ICO that enabled us to establish a stable and long-lasting working relationship and continue the mediation programme.

Since the outset to the present day, we have prioritised networking with cultural institutions, art centres, community spaces and social organisations active in the field of accessibility and inclusive culture. More than one hundred families and seven museums and art centres have taken part in the programme,⁴ and more than twenty exhibitions have been adapted, in each case generating accessible resources and materials which the *Empower Parents* families have used in more than one hundred sessions and workshops.

In view of the absence in other parts of Spain of accessible educational and cultural experiences for people with ASD, every Saturday families from Asturias, Andalusia, Castile-León, Castile-La Mancha and Murcia travelled to Museo ICO. Cultural institutions continue to pay too little attention to these needs, which makes it all the more necessary to develop and publicise initiatives of this type.

Contexts that exclude

People with functional diversity have seen their basic rights and freedoms ignored for decades, conditioning their personal development and excluding them from different social contexts. In 2020, the advances in inclusion and accessibility are undeniable and yet this collective remains invisible and still encounters major limitations in terms of its access and use of spaces, processes and services that are often designed without taking their needs and interests into account.

This makes people with ASD doubly invisible, forcing them to cope every day with a society that neither understands them nor treats them as equals. They suffer discrimination and stigmatisation, and the support they receive is inadequate. It's for this reason that social organisations like Confederación Autismo España⁵ and its member federations insist on the need

4. Queens Museum in New York City, Museo Thyssen-Bornemisza, Museo de la Ciencia in Valladolid, Museo del Traje. CIPE, Espacio Fundación Telefónica, Medialab-Prado and La Fábrica de la Luz Museo de la Energía in Ponferrada.

5. According to the conclusions of the workshop organised by Autismo España under the title *Situación y necesidades de las personas con trastorno del espectro del autismo (TEA) en España: Resultados y tendencias sociodemográficas en 2019*. AUTISMO ESPAÑA (2019). <http://www.autismo.org.es/actualidad/articulo/se-confirma-el-aumento-de-personas-con-autismo-identificadas-en-espana> [retrieved: 10/03/2020]

6. AUTISMO ESPAÑA (2020). <http://www.autismo.org.es/sobre-los-TEA/trastorno-del-espectro-del-autismo> [retrieved: 10/03/2020]

7. *Anuario de estadísticas culturales 2019*. Ministerio de Cultura y Deporte. <https://www.culturaydeporte.gob.es/dam/jcr:3bdcb17c-050c-4807-b4f4-61e3714cbc15/anuario-de-estadisticas-culturales-2019.pdf> [retrieved: 10/03/2020]

to implement public policies that respect the needs of the ASD population and their families.

We don't know the exact number of people with ASD in Spain because there are no specific censuses or population surveys. According to the results of autism prevalence studies carried out by Spanish and European federations and confederations, the rate is 1 per 100 births (Autism-Europe aisbl 2015) compared with 1 per 68 births in the United States,⁶ but in spite of the increase in diagnosed cases in recent years, society at large still knows very little about ASD.

This exclusion also affects culture: people with ASD usually find it very difficult to access and enjoy culture, even though it's a universal right. Guaranteeing their access and participation is the obligation of all public institutions, and yet we still get bogged down in theoretical and conceptual debates that don't produce any practical results, in spite of long-standing demands from social organisations and families affected by autism.

People who don't live with this reality may well believe that access to culture is the same for everyone. Nothing could be further from the truth: in Spain we continue to cling to a cultural model designed for the few. This is evident from the results of the 2019 cultural statistics yearbook,⁷ which shows that the people who access cultural institutions most frequently have a higher level of skills and education and are not representative of the majority of the Spanish population. Although managed with public funds, these institutions are failing to guarantee universal access and participation, and they should take a hard look at themselves and admit that they are still catering to an elite minority that doesn't represent society today.

In recent years there has been much talk about paradigm shifts in culture, i.e. the social, educational and emotional changes that cultural institutions need to adopt. But while it's true that museums and cultural institutions are hosting meetings, often fraught with disagreement, that are having a major impact on the cultural sector, it all ends there, in closed groups going round and round in circles about different concepts. In practice, we still haven't assumed a genuine commitment to change course and open our doors to the community, to invite the minorities that have historically been excluded to come in to our institutions and

Phase 1 2013 2014 Experimental programme

June:
AWARD Museums Connect. Building Global Communities, granted by the American Alliance of Museums under the auspices of the US Department of State's Bureau for Educational and Cultural Affairs.

2013



October:
EXCHANGE PROGRAMME
First Queens Museum-Museo ICO trip.
PUBLIC PRESENTATION Embassy of the United States of America in Madrid.

2013



October 2013 / June 2014:
The PROGRAMME OF ACTIVITIES for families affected by autism is launched at Museo ICO.

2013
2014

November:
EXCHANGE PROGRAMME
Second Museo ICO-Queens Museum trip.

2013



occupy them, to dance and sing in them, to embrace every possible narrative to create a new one from different perspectives. This shouldn't be the product of long, drawn-out debates but an ethical attitude to return a common good to the population.

If we reflect honestly about our experiences in museums and art centres, most of us will no doubt remember situations in which we felt challenged by the institution's discourse. And the reason is that these discourses are often complex, and yes, elitist, especially in contemporary art museums and centres. They are narratives for a sector of the population which unfortunately the majority doesn't identify with.

If we couple this unnecessarily complicated gaze with highly complex content, inextricable designs and multiple barriers at the physical, cognitive and sensory level, we find cultural institutions and art centres that exclude part of the population, severely compromising access to culture for people with functional diversity.

If we state here that culture remains exclusive and discriminatory, it's not because that is the conclusion of a specific survey. Rather, it's the opinion of a mediator whose work involves promoting proximity and who interacts every day with visitors, audiences and people, especially people who encounter serious problems when it comes to accessing and enjoying art and culture. There are also ongoing debates about what it means to "open up" institutions, create access and remove barriers. Some are of the opinion that initiatives to promote social inclusion and participation are condescending, and while we are busy discussing all of these things the doors remain closed to people with functional diversity. We should at least admit that it might be a good thing to invite them to take part in these debates, to talk to us.

During the course of these last six years of the programme, conversation has been our primary tool: we've talked with cultural agents, professionals in the social sector and, above all, with the ASD population and their families. We've discussed all of these aspects about the context with them, and this publication includes some of the conversations held. They are families who talk about the exclusion and rejection they have experienced because of having a child with autism, and they explain their reasons for demanding access to cultural institutions.

“People with functional diversity have seen their basic rights and freedoms ignored for decades, conditioning their personal development and excluding them from different social contexts.”

“[...] to invite the minorities that have historically been excluded to come in to our institutions and occupy them, to dance and sing in them.”

We believed it was important to let them voice the needs of the collective, just as they did with us when we embarked on this adventure and they opened our eyes to the reality of autism.



Group of families and professionals from the Queens Museum and Museo ICO in Queens, New York (page 23)

p. 25. Programme for families affected by autism at Museo ICO

2014

January:
Empower Parents featured on the *Tengo once años* programme on RTVE 2.

2014

May:
EXCHANGE PROGRAMME Third Museo ICO-Queens Museum trip.
EXCHANGE PROGRAMME Fourth Queens Museum-Museo ICO trip.

2014

May:
PUBLIC PRESENTATION 2nd International Congress on Education and Accessibility. *Museums and Heritage. "En y con todos los sentidos: hacia la integración social en igualdad"*. University of Zaragoza. Gómez, A. and Molina, Á. publish *Empower Parents. Fomento de redes interculturales entre familias con niños con autismo*.
REPLICATION PROGRAMME Session at Museo Thyssen-Bornemisza.

“If there’s anything that defines a parent’s relationship with their child’s autism, it’s the feeling of being alone in the face of an intangible challenge. Other disorders are clearer, easier to handle.

We also often get the feeling that no one really knows what we’re going through. I imagine it’s something most parents feel when their child has a problem, even if it’s not related to a disorder, or a disability, or an exceptional circumstance. But it’s certainly what we feel, and it’s very upsetting. Being in contact with the *Empower Parents* community made that feeling disappear. At least for a little while. And that’s very important.”

Feliciano and his son have been involved in the programme since 2017



The culture of autism

In the years that the *Empower Parents* programme has been running, we have met families facing different types of challenges related to ASD and their children.

Some of them started the programme when their children were much younger and now they are grappling with the challenge of finding alternatives for a new stage as those children approach adulthood. Some mothers decided to leave the programme after taking part in two or three sessions because they were still in denial about their child's recent diagnosis and attending a session forced them to face up to it. In other cases, the parents were so motivated that once a month they travelled 650 kilometres and back from their home in Cádiz to Museo ICO in Madrid.

All of the families have been different but they have had one crucial aspect in common: the way they have structured everyday life since their child was diagnosed with autism. Some mothers carry a notebook so that, if need be, they can draw pictograms to help their child understand that they must stop an inappropriate behaviour; some fathers always carry a rubber teether to soothe their child if necessary. For some families a mobile phone becomes a useful tool for showing their child a visual agenda ahead of a visit to the museum or the doctor, etc.

Homes tend to be organised in a very similar fashion, with clearly demarcated areas, safety devices on windows, and routines and sequences of images in prominent places around the house to explain in three easy steps how to wash your hands, hang up your coat, and so on.

That's the culture shared by families of children with ASD, united by autism and the impact it has had on their lives.

The spectrum of autism disorders is very wide, ranging from children with a specific need for support to improve their communication and social skills to others who are nonverbal and have an intellectual disability.

Empower Parents began in 2013 with a group of six families and in each edition we enlarged the community by adding new families⁸ to the programme. This also meant internalising new lessons learned and challenges related to autism, education, community mediation and accessibility.

8. A total of 109 families took part in the programme between the launch in 2013 at Museo ICO and the completion of the activities in 2019.

9. Whenever we refer to the *Empower Parents* team in this publication, we mean the team comprising the programme educators and the participating families.

10. Mary Temple Grandin is a renowned autism spokesperson as one of the first people diagnosed with ASD who has shared her personal experience publicly. She is also a leading expert on animal behaviour and is a member of the American Academy of Arts and Sciences.

Something that the *Empower Parents*⁹ team was very clear about from the outset was that the programme should be open to everyone who wanted to take part, and every year we therefore worked with heterogeneous groups of children with varying ages and levels of autism. This presented a significant challenge for designing the programme of accessible activities, obliging the educational team to engage in a continuous learning process and establish solid alliances with social organisations and, above all, with the families. As the real ASD experts, the families constantly provided us with information and pointers on how to intervene in each situation, and they also helped us to design the methodology and materials.

In spite of this heterogeneity, we had to find common criteria for all the families to be able to design an educational programme and adapted, accessible activities that would ensure that every child could take part autonomously. In general, it is possible to define a series of characteristics that enable professionals and families to create the necessary support structures that encourage development, learning and inclusion as well as strengthening the areas most compromised in people with ASD: social interaction, communication and imagination.

As Mary Temple Grandin¹⁰ has pointed out, people with autism are magnificent visual thinkers, their learning is sensory-based and they pay more attention to detail. They tend to be hypersensitive to light, smell, touch, etc., and they are usually not very flexible, which means that it's vital to give them advance information about the activities they are going to do to avoid anxiety and frustration. They tend to find it difficult to generalise learning—in other words, applying what they have learned in one context to another context—and it's very important to improve their social skills. The *Empower Parents* programme therefore always encouraged the participation of siblings, cousins, friends, neighbours, etc., with a view to creating an inclusive learning environment, avoiding segregation and the design of activities that exclude people with ASD and placing a particular emphasis on social interaction and creating bonds and relationships as a strategy for promoting and facilitating communication between equals.

The learning in the museum space transcended the cultural dimension. The children created new relationships, gained new interests and learned social skills. In some cases the things they learned were therapy-based, but they learned them without labels and in a museum.

“People with autism are magnificent visual thinkers, their learning is sensory-based and they pay more attention to detail.”

Phase 2
2014
2017
Dynamic balance

September 2014 / June 2015:

Second edition of the [PROGRAMME OF ACTIVITIES](#) for families affected by autism at Museo ICO.

2014



January 2015: [NETWORKS Museos + Sociales](#) National Plan. Ministry of Education, Culture and Sport.
February 2015: [REPLICATION PROGRAMME](#) Session at Museo de la Ciencia, Valladolid.

2015



When the families entered Museo ICO they abandoned their usual roles and became educators and session leaders. They designed contents and activities, supported other children and relaxed, enabling their children to relax as well. And together, strolling through the museum galleries, they were able to explore, occupy and interact with the space and the other visitors who, like them, were enjoying some of the eighteen temporary exhibitions we have organised in these past years.

Session after session, this gentle stroll enabled us to identify areas of discomfort and excesses in a museum that previously had no knowledge of the reality of autism but, unawares, has gradually transformed, slowly expanding its walls to become a space of gathering, social interaction and learning, over and above its contents and exhibitions.

The JFK-MAD connection¹¹

“Queens Museum in New York wants to work with us and teach us their methodology for children with autism.” That was what set the ball rolling for this frenetic adventure back in the summer of 2012.

For a small museum like Museo ICO, with limited educational and accessibility resources, the fact that an institution like Queens Museum wanted us, along with *hablarenarte*, to undertake a joint accessibility and educational project, was like a fantastic dream that we were reluctant to wake from. The project was in perfect harmony with the foundational aims of Fundación ICO and very relevant to the educational activities we had been organising at the museum for nearly ten years. It also fit in perfectly with a pilot accessibility programme for people with special needs that we had implemented two years earlier as part of a series of educational actions that *hablarenarte* was running at the museum. So once we had overcome our insecurities and made sure that we had the necessary support and initial funding, we set to work defining the project so that we could apply for a grant and ensure we had all the financial resources we would need to embark on a major international project including in-person training and a cultural exchange. If we were turned down for the grant, we

11. The complete text was published in the conference proceedings for *II Congreso Internacional de Educación y Accesibilidad. Museos y Patrimonio. En y con todos los sentidos: hacia la integración social en igualdad* (Huesca, 2014) (Gómez, Alicia and Molina, Álvaro: [“Empower Parents. Fomento de redes interculturales entre familias con niños con autismo”](#), in Almudena Domínguez Arranz, Juan García Sandoval and Pedro Lavado Paradinas (eds.), *II Congreso Internacional de Educación y Accesibilidad en Museos y Patrimonio: En y con todos los sentidos, hacia la integración social en igualdad*, Zaragoza, Universidad de Zaragoza, 2014, vol. 2, pp. 487-500).

“When the families entered Museo ICO they abandoned their usual roles and became educators and session leaders.”

would carry out a more modest version with our own resources and would undertake the training with Queens Museum team remotely.

Our efforts during this preliminary phase were rewarded magnificently with a grant from Museums Connect: Building Global Communities, a programme developed by the US Department of State’s Bureau for Educational and Cultural Affairs and administered by the American Alliance of Museums, whose mission is to build communities through cultural exchanges and support for certain foreign policy objectives, such as the empowerment of young people, environmental sustainability and raising awareness about rights for people with disabilities.

In June 2013 we received the excellent news that we had been awarded a grant of 70,000 dollars to carry out a far-reaching international partnership programme focused on the following aspects:

- The cultural exchange between the participating families and educators, consisting of trips in each direction to the reference countries to carry out an immersion in the museum-family-autism spectrum disorder (ASD) context.
- The reinforcement of the values of community and cooperation by altering the notion of the museum, hitherto unknown for the majority of the participating families, to turn it into an open, accessible and inclusive space.
- The programming, design and implementation of the model developed by the *ArtAccess* Department at Queens Museum through its Museum Explorers Club programme, based on a series of sessions that would be held monthly at both museums simultaneously.
- The delivery of accessibility training and preliminary preparation for the families, educators and members of the museum staff through action strategies and tools.
- The design, programming and development of a bilingual website to share the project, publicise the activities and methodology, and

April 2015:

WORKSHOP Collective action at Campo de Cebada, Madrid. (Artist: E1000)
MEETING “Expanded Conversation”, Campo de Cebada, Madrid.
REPLICATION PROGRAMME Session at Museo del Traje. CIPE.

2015



May 2015: REPLICATION PROGRAMME Session at Espacio Fundación Telefónica, Madrid.
June 2015: MEETING “Expanded Conversation”, Medialab-Prado.

2015



invite the participation of other families, educators and agents involved in similar circumstances.

- The creation of a model that could be replicated in other museums and cultural institutions interested in exploring new channels of experimentation and cooperation in Spain.

Having established these ambitious objectives and secured the necessary institutional and financial support, we set about creating an international network which, for the Spanish side, began with selecting the participating families.

The team in the United States was in a stronger position in this respect because there was already a homogeneous, united group of people who were habitual users of the museum and had been taking part in an ongoing programme for more than four years. In our case, we managed to identify the “pilot” families in record time thanks to the inestimable assistance of Confederación Autismo España, which sent out our call for participants to all its member associations and collectives. The generosity, dedication and attitude of the families who responded was undoubtedly one of the most moving moments of the project.

Selecting the six participating families was a very complex process but we were pleased with the end result because of the geographical diversity—Madrid, Murcia, Valladolid and Cádiz—and the variety of family models and ASD cases. Most of the parents selected also played an active role in their local associations, so if we wanted to replicate the model in other places in the future we would have the advantage of having ambassadors already immersed in the project who could transfer to their home cities what they had learned and experienced during that first year.

At the same time, Queens Museum was organising the working methodology with the educators and the first of the exchange trips: New York-Madrid. Three educators from the museum and three mothers representing the American families came to Madrid. We introduced them to most of the Spanish families involved in the project and, thanks to the collaboration of Museo del Prado, Museo Reina Sofia, Museo Thyssen-Bornemisza, La

“Session after session, this gentle stroll enabled us to identify areas of discomfort and excesses in a museum that previously had no knowledge of the reality of autism...”

Casa Encendida and Debajo del Sombrero, we were able to show them a broad picture of the cultural activities that are organised in Madrid for people with ASD. The trip provided us with an initial insight into these parallel realities, and although it didn’t answer all our questions it gave us enough information to be able to organise the first session with the *hablarenarte* education and mediation team in October of that same year.

That first session gave us the opportunity to introduce ourselves and get to know the children, parents and educators, and crucially to make initial contact with a space which the participating boys and girls had never previously experienced and about which they had only obtained a general idea from the agenda we had established to organise the day. It has to be said that the session didn’t live up to our expectations: some of the children had to leave the workshop room because the experience was completely new to them and they found it too stressful; others ran around the museum galleries causing some visitors to complain; the parents seemed to doubt that we knew what we were doing and they felt out of place during the activity... In short, we discovered that there needed to be a strict structure in place for all the parties involved. At subsequent sessions therefore, when the participants were more familiar with the space, instead of children racing around the galleries we had parents playing different roles and therefore more involved, such as telling their children how to behave in a museum, and we defined a working routine in the workshop space based on the methodology used at Queens Museum but adapted to the nature of Museo ICO.

The Madrid-New York trip took place after the second session and there is no doubt that for the Spanish delegation, comprising two educators from *hablarenarte*, a representative of Museo ICO and three mothers, it was a huge revelation. We were able to see in situ the powerful idea of community that Queens Museum worked with and the natural way in which visitors actively participated in the museum to the extent of making it their own, where they behave as active users of the spaces and services rather than as mere guests. We attended meetings where they told us about the arduous journey they had undertaken in the previous four years, the gratitude that was constantly expressed to the museum’s *ArtAccess* Department, several failures, examples of families that

September 2015 / June 2016:

Third edition of the **PROGRAMME OF ACTIVITIES** for families affected by autism at Museo ICO.

2015



October, 2015:

PUBLIC PRESENTATION *Encuentro de Gestores en Red*. University of Valladolid.
PUBLIC PRESENTATION / *Jornadas “Hablamos de Autismo”*, organised by the University of Castile-La Mancha and Autismo Talavera.

2015



had dropped out of the programme, first-hand testimonies about children who had had to leave but came back as soon as they could, and the progress they had observed in those who had been able to continue throughout. When we returned to Madrid, with the lived experience still fresh in our minds, the Spanish mothers who had visited Queens Museum were clear that it was their turn and that they would lead the first sessions. And that's how we started fulfilling the primary aim of our project: empowering parents by giving them the necessary resources to promote new cooperation initiatives and build communities that would use the museum as a space for inclusion and social interaction.

After sharing experiences and the lessons learned, *Empower Parents* was launched in Madrid, highlighting the need to start at the beginning. It was important to discover the New York experience, but it was crucial to contextualise the project by getting to know and establishing connections with the social and educational organisations that worked with the ASD population and could help us to understand their needs and demands. This allowed us to discover the narrative of the communities of families and adapt the project to the reality of Museo ICO.

Alicia Gómez and Álvaro Molina



The museum: a space for experimentation

Empower Parents is the product of a six-year experiment carried out by a very broad community that began at Queens Museum in New York City and spread to Museo ICO in Madrid. I suppose it could be defined in many ways, but for us it's the result of a collaborative process between the mediation team and the team of families in which every person contributed their doubts, lessons learned, successes and mistakes.

The exchange programme with Queens Museum showed us the reality of a more open and socially-oriented museum that conditioned our work to the extent of becoming our primary aim. We knew the difficulties, but it seemed a necessary challenge, at least to start thinking about what type of institution Museo ICO was and what it would need to change to become an accessible space.

12. Museo Thyssen-Bornemisza, Museo de la Ciencia in Valladolid, Museo de la Energía in Ponferrada, Museo del Traje. CIPE, Espacio Fundación Telefónica and Medialab-Prado in Madrid.

13. Museum Explorers Club was created in 2009 by the ArtAccess Department at Queens Museum thanks to a three-year grant. The programme received the New York Mayor's Award in honour of the eighteenth anniversary of the Americans with Disabilities Act (ADA) and two national awards for excellence from the VSA arts organisation. Its main proposals and contents →

We had many doubts when we launched the programme, and in fact we viewed the first edition as a pilot experience in which we would define a methodology adapted to the context and continuously refine and extend the objectives in subsequent editions. For example, while in the first edition the objectives would be focused on developing a programme of activities for families affected by ASD, in the second edition we would aim to discover the potential of the museum as a space for learning and building a community based on a hybrid programme that transcended the boundaries of education and in which every action would be constructed around hospitality and caring.

The result is a stable and long-lasting community of families united around autism and culture, which today, seven years later, functions autonomously; and a programme of accessible activities based on a methodology that can be adapted to any museum institution thanks to a trial-and-error process conducted these past years at Museo ICO and the participating cultural institutions.¹²

The programme evolved over the years according to the following structure:

- Phase 1: Experimental programme. 2013-2014
- Phase 2: Dynamic balance. 2014-2018
- Phase 3: Rethinking. 2018-2020

Phase 1: Experimental programme 2013-2014

Starting at the beginning: contextualisation

The opportunity to work with Queens Museum gave us the chance to discover the methodology for its Museums Explorers Club programme¹³ as well as new experiences and new ways of working. But above all it revealed enormous differences between the two teams and institutions and the need to contextualise the programme objectives (initially very ambitious) and get to know the reality of the local ASD population and their families in order to explore their relationship with museums and cultural institutions.

First meeting in Madrid between Queens Museum professionals and families and their Museo ICO counterparts (Images 1 and 2) Presentation of *Empower Parents* at the Embassy of the United States in Madrid (Image 3) Work session at Queens Museum as part of the exchange programme (Image 4)

November 2015:

PUBLIC PRESENTATION Camp Meeting 80 programme. Trans Europe Halles. Bakelit Art Center, Budapest.

2015



February 2016:

MEETING "Expanded Conversation", Medialab-Prado. REPORT *Empower Parents* featured in the *La aventura del Saber* programme on RTVE 2.

2016



The project at Queens Museum had enabled the ArtAccess Department to define a programme of activities with a bespoke intervention methodology. The team comprised two art therapists specialised in intervention methodologies with people with ASD and four years' experience with the same group of families. Everyone involved in the programme viewed the museum as a community space, while the museum made a point of reaching out to the Queens neighbourhood by including the residents' realities, demands and interests in its annual programming.

This image of an open institution in constant dialogue with its immediate context presented us with a major challenge: how to fulfil the programme expectations in Madrid at a small museum with modest resources and a limited impact on Madrid society and with an external team of professionals linked to an independent organisation?

It was therefore crucial to conceptualise the programme according to the characteristics of our context. We needed to understand the relationship between families affected by autism and cultural institutions, and to supplement this outward gaze we needed to start thinking about the institution where the programme would be carried out: How flexible and permeable would Museo ICO be? What degree of involvement could we expect from Fundación ICO for a transformative process outside the programme remit?

This automatically prompted reflection about what the museum was and what it would have to become to accommodate a stable and long-lasting community of families united around autism, education and culture.

The first steps

We began by meeting with different organisations and associations that worked with the ASD population from a social and educational perspective. These initial meetings enabled us to establish collaborative networks that still function as such to this day. Securing the collaboration of Asociación Pauta was particularly important because its educational work with families and the community has made it a key reference in Madrid, and we held

→ have been shared with the Museum Access Consortium in New York and the Museum Educators Roundtable, as well as with numerous international social networks for educators.



Preparation and delivery of a session at Queens Museum

numerous meetings and conversations with Ángeles, the director of its educational establishment at the time, to discuss a suitable working methodology. These organisations and associations put us in touch with several families, and we have to say that their support during those early days was invaluable and helped us to define a practice adapted to the context and the needs of the families.

Using participatory methodologies, we embarked on a broad fact-finding mission that lasted throughout the first edition of the programme and consisted of the following actions:

- Understand the context and reality of the ASD population and their families.
- Explore the relationship between families affected by ASD and cultural institutions, assessing their possibilities of access and participation.
- Assess the difficulties that families have to overcome to make visits to museums and exhibitions a regular cultural practice.
- Together with the professionals and families, identify the learning needs of children with ASD to provide the necessary support and ensure the design of an accessible and inclusive programme of activities.

We needed to know what initiatives other cultural institutions and regions were undertaking with the collective so that we could identify synergies and create future partnerships, explore methodologies and assess the lessons that we could include in the programme. To do this, we held interviews and meetings with the professionals in the education and cultural action departments at Museo Nacional del Prado, Museo Nacional Centro de Arte Reina Sofía and Museo Thyssen-Bornemisza. We also carried out personal interviews and surveys with social and cultural agents, and we held semi-structured interviews with families affected by autism to learn about the collective's reality.

April 2016:

REPLICATION PROGRAMME Session at Medialab-Prado, Madrid.
PUBLIC PRESENTATION // Jornadas sobre autismo; Normativa, Intervención y el Arte como recurso. Regional Government of Madrid.

2016



May 2016:

PUBLIC PRESENTATION Staff exchange programme. Trans Europe Halles. Lublin, Poland.
MEETING "Expanded Conversation" Medialab-Prado.

2016



September 2016 / June 2017:

Fourth edition of the PROGRAMME OF ACTIVITIES for families affected by autism at Museo ICO.

2016
2017

Based on this preliminary analysis, we discovered that in general many of the families interviewed had had negative experiences at museums and cultural institutions, while others had developed the notion that museums didn't accommodate families like theirs. In both cases, they neither visited museums nor took part in cultural activities due to the difficulty of access and the shortage of accessibility resources and formats for carrying out family activities.

For their part, the cultural institutions offered a very limited range of accessible activities. Although they pursued a discourse in favour of accessibility, their doors remained closed to most of the population with functional diversity.

A lot of the families affected by autism said that they felt overwhelmed and had high levels of anxiety and stress. Something they all shared was the vast amount of time they dedicated to therapies in the broadest sense: behavioural, speech, music, horse, etc. This reaffirmed our desire to remove the label "therapeutic" from all the programme actions, establishing a core difference with the programme at Queens Museum.

Having a multidisciplinary team was crucial for conceptualising and reflecting on the numerous questions that arose as we proceeded with the programme. Where was the boundary between education and therapy in this type of initiative? How could we develop an accessible programme of activities that would appeal to children with ASD as well as those with a typical development? What support did we need to ensure the participation and enjoyment of all the children, regardless of the level of autism? How could we build a community around the idea of our programme? What strategy did we need to adopt to avoid the typically condescending nature of inclusive programmes?

The families: from non-audience to VIP audience

It's true to say that the first edition of *Empower Parents* was an experiment based on trial and error: with each action, we learned something new. The lines of work revolved around empowering the group of parents and activating the programme of activities for families of children with ASD between the ages of five and twelve.

“It was therefore crucial to conceptualise the programme according to the characteristics of our context.”

“This automatically prompted reflection about what the museum was and what it would have to become.”

14. Families from Cádiz, Madrid, Murcia and Valladolid took part in the first edition of *Empower Parents* (2013–2014).

15. In the second and subsequent editions the duration of each session/workshop was reduced to ninety minutes.

The first step was to create a stable team of six families who would be willing to commit themselves to the nine-month programme, attend all the meetings, gatherings and workshops at Museo ICO, and take part in the exchange with Queens Museum. From day one, we were very clear that we didn't want to create a group of families who "consumed" a programme of activities. Our aim was quite different: the families would have to learn the programme methodology and collaborate in all the actions, including designing the activities and the web contents. So in June 2013, with the support of Confederación Autismo España and the Pauta and Aleph associations, we launched the first call for participants.

This collaboration enabled us to reach the vast number of confederal social action organisations that provide services for families affected by autism nationwide. We were astonished when we started receiving applications from families living in distant places like Cádiz, Murcia, León and Valladolid, particularly since they all understood that they would have to travel to Madrid several times a month to participate in the design of the contents and activities. We took it as a significant indicator and proof of the high level of commitment they were willing to assume.

In the end, we selected six families according to criteria of heterogeneity: regional diversity,¹⁴ socio-economic profile and level of autism. Today, after seven years' experience, we can handle the challenge of creating accessible and inclusive activities for children of varying ages, interests and levels of autism, but that first year it was a different matter altogether.

The experimental programme of activities consisted of a cycle of eight two-hour sessions¹⁵ held at the same time as the sessions at Queens Museum. In keeping with the model of the New York programme, the families were the ones who designed the activities which they then did with their children in the workshop. During the weeks leading up to each session/workshop, they prepared the necessary materials and rehearsed the session, coming and going to the museum as if they had been frequenting it for years. The team of professionals took a back seat, allowing the families to take the lead (parents, aunts and uncles, grandparents, etc.).

When we started working with the team of families in Madrid, we implemented the Queens Museum methodology. We used the

March 2017: MEETING "Expanded Conversation", Medialab-Prado.
April 2017: PUBLIC PRESENTATION *Café Scientifique* programme.
Autonomous University of Madrid.

2017



May 2017: REPLICATION PROGRAMME Session at La Fábrica de la Luz. Museo de la Energía.
June 2017: MEETING "Expanded Conversation", Medialab-Prado.

2017



weeks prior to the session at the museum to design the activities and train the families, showing them how to create accessible resources and formats for their children. We also defined the roles that the families and professionals would play at the Saturday session.

Another objective that first year was to establish bonds between the families in the two countries, so we set up the necessary equipment in the workshop room at Museo ICO to be able to connect to Queens Museum every Saturday. In practice, the connection was never perfect because there was always some technical issue, but what we initially viewed as a setback ultimately became a relief for most of the Spanish families. Technology tends to act as a stimulant and distraction for children, and that was the case here as well: every time we turned the projector on in the workshop room, the session came to a halt and it was very difficult to get it back on track.

We bridged the gap between the two shores of the Atlantic by creating common contents for both museums and a postal art action in which each family in Madrid communicated with another family in New York about the works their children had made. The results of this action were exhibited at Museo ICO in July 2014 on completion of the first edition of *Empower Parents*.

Running, jumping and shouting...

On the Saturdays when we had a session, we would greet the parents in the museum foyer by hugging and welcoming them. Sometimes, they would be anxious and stressed because of the busy city traffic or the long journey from their own cities: Cádiz, Murcia and Valladolid in this first edition.

The children would enter the museum in an agitated state due to sensory overload, and they would have to adapt to the light, sound, touch, etc. without any possible mediation. So the first thing we had to do was explore the museum galleries with no other aim than taking a stroll together to get to know the place, allowing them the freedom to establish any connections they wanted with people, spaces and objects naturally, without forcing anything and respecting each child's individuality. These "connections" might be



challenging the motion sensor at the museum entrance, pausing to look at a work that had caught their attention, lying down in the middle of the gallery to feel the cold floor, noticing the shadows on the gallery wall cast by the pieces on display, and so on.

I can still remember how chaotic that first session was. The children raced around the galleries, shouting and touching the displays. In some cases, they even broke elements of the exhibition. The room staff didn't know how to react the first time they saw a group of children running, jumping and shouting without any restraint.

In any other circumstance, they would have immediately rebuked the educators, parents and children, but in this case they didn't know what to do. Their non-response was provoked by a condescending gaze that disappeared months later when the families had established a relationship with the museum professionals.

The other visitors were astonished and indignant when they saw a group of "ill-mannered children" not only breaking the silence



p. 38. First session led by an *Empower Parents* family at Museo ICO

Experience in the workshop with a group of mothers and their children

Phase 3 2017 2020 Rethinking

July 2017:

REPLICATION PROGRAMME Session at Espacio Fundación Telefónica, Madrid.
PUBLIC PRESENTATION *Cursos de Verano*. Autonomous University of Madrid.

2017



September 2017:

September 2017 / June 2018: fifth edition of the PROGRAMME OF ACTIVITIES for families affected by autism at Museo ICO. PUBLIC PRESENTATION *III Encuentro de Cultura y Ciudadanía*. Ministry of Education, Culture and Sport. AWARD *NICE Awards 2017, Networks for innovations in culture and creativity in Europe*, organizado por European centre for creative economy (ECCE).

2017



but some of the priceless exhibits as well. Both we the educators and the families tried, and failed, to bring the session under control while repeating mantras under our breath to help ease the anxiety. Some parents had to take their children outside, away from the stimulants inside the museum, to try and calm them down.

There were many reasons for this chaos, but primarily it boiled down to not having anticipated the session with the parents through a visual agenda, and not having a clear structure for the session, with set times and procedures. Those errors made us realise that there was no room for improvisation in the future family programme and that we had to structure the times and the space to ensure that the activity ran smoothly and the participants enjoyed it.

We incorporated the necessary changes into the following sessions, evolving from the running, jumping and shouting sequence of the initial session to a more measured sequence in which we greeted each other in the museum foyer and then started exploring the galleries together at snail pace, before going on to do a creative activity in the workshop. These sequences were gradually defined during the first edition until we reached a structure¹⁶ that was more sensitive to the children's needs. At the end, the educators and families met to evaluate the activity, noting what had worked, changing any aspects as necessary and finally defining the methodology we use today. This is described in Chapter 3, which focuses on the *Empower Parents* practice.

We soon discovered that sessions could only work if the families were calm, because with less stress and tension the children would enjoy themselves. Every Saturday we encouraged the parents to make themselves at home in the museum, to explore and connect with the space, sit on the floor, relax, discover every nook and cranny, etc. And little by little, though still quite self-consciously, at each session they seemed to gradually acquire these habits. By the end of the first edition, we were having afternoon snacks in the workshop, listening to music, dancing, chatting and, above all, laughing a lot, filling with liberating laughter the space they had initially viewed as hostile but had come to feel more and more at ease with.

After all, most of the families had had negative experiences when they had visited other cultural institutions, and this idea of



16. All the methodological aspects of *Empower Parents* are described in Chapter 3 (*Practice*).

the negative space was still at the forefront of their conception of museums.

In spite of the VIP bubble created in that first edition, with all its caring and excesses (the trips to New York, the catering for the afternoon snacks, etc.), we believe it was necessary because it allowed us to create a space of possibility that included the welcome hug, the conversation about the family in the museum foyer and numerous other invisible gestures that enabled us to build the *Empower Parents* community and ensure that it remains as active as ever seven years later. This VIP scenario may never have materialised if we hadn't incorporated hugs, bonds and emotions as the basis of the programme, because they may never have arrived at all or they may only have arrived much later.

p. 40. Dancing, jumping, laughing... End of a session at Museo ICO

p. 42. Miguel Fisac y Alejandro de la Sota. *Miradas en paralelo* exhibition Experience in the gallery with the families of the first edition of *Empower Parents*

p. 43. Group of parents preparing a replication session at Espacio Fundación Telefónica



February 2018:
MEETING "Expanded Conversation", Medialab-Prado.

2018



April 2018:
REPLICATION PROGRAMME Two sessions at Espacio Fundación Telefónica, Madrid.

2018

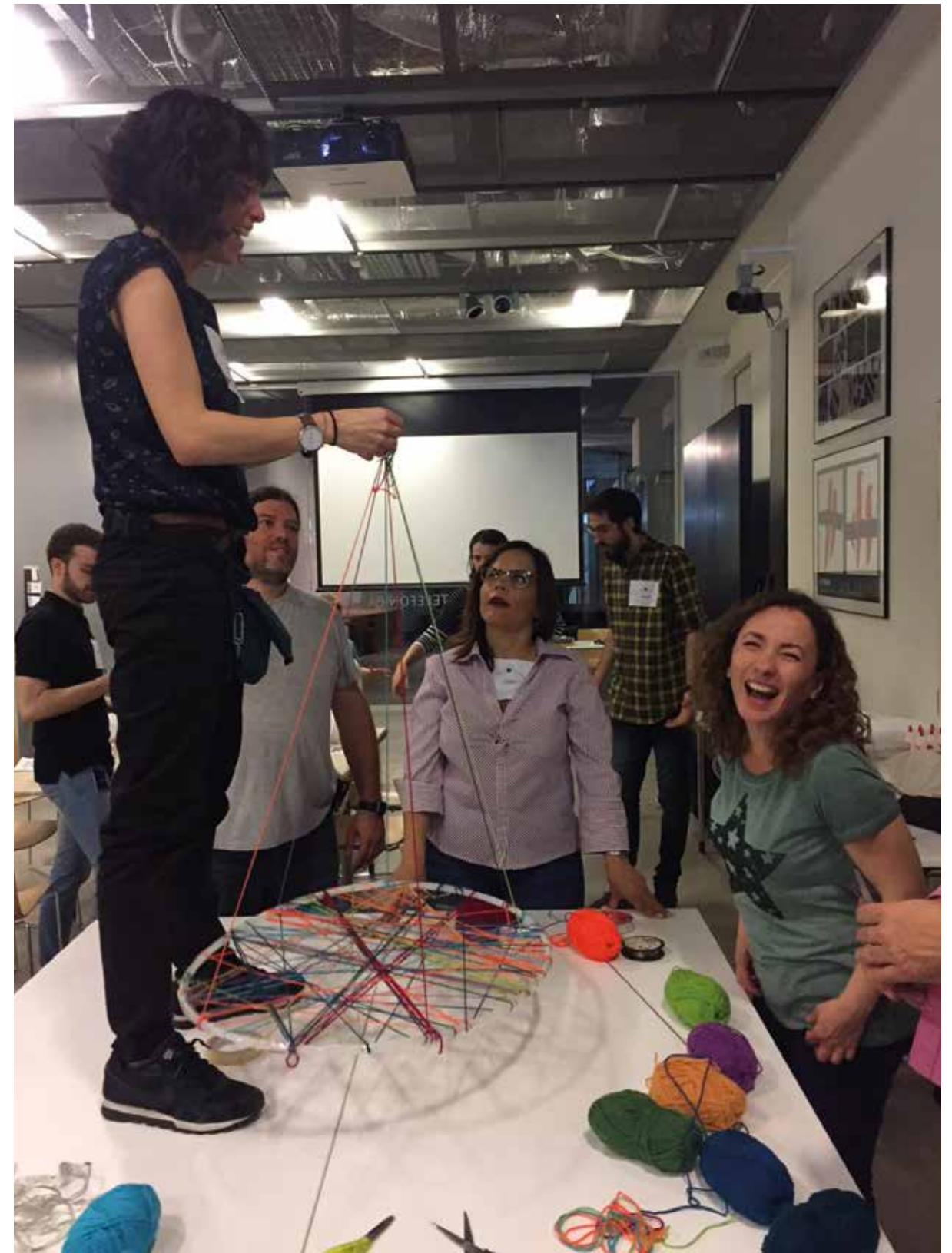


“It’s absurd, but when you have a child with autism, you often feel judged. Besides, there aren’t many spaces where a humane, sensitive and expert group opens its doors to you and invites you with open arms and all the professionalism in the world to take part in a project.

And there aren’t many leisure activities that the whole family, including siblings and parents, can do together and relate to other families in the same situation.

Empower Parents has made all of that possible through art and in a fantastic setting.”

Yolanda and her family have been involved in the programme since 2016



Phase 2: Dynamic Balance 2014:-2018

In 2014, having completed the first edition of *Empower Parents*, Fundación ICO and hablarenarte made the decision to continue the programme of activities at Museo ICO. This collaboration gave us the advantage of working at a small, relatively intimate museum and being able to develop a programme without having to reach a numerical target, which is quite rare in education and/or mediation projects with audiences and communities.

We had approached the first edition somewhat frenetically and with insufficient deliberation. Our primary focus was to meet the initial expectations: while we were busy with the trips, training and exchanges, we were simultaneously creating a bilingual platform for the Queens Museum and Museo ICO communities, designing a programme of educational activities adapted to the context, defining a working methodology, writing reports, making sure we were keeping within our budget, and dealing with the little incidents that arose every Saturday: trying to prevent the children from running around the galleries, pacifying the other visitors if they did, reassuring the security staff if they saw the children running around, putting the families at ease in spite of all that, and so on and so on. The education team was in the middle of all this stress and it was genuinely exhausting.

We met all these demands without questioning them until we finally had the opportunity to stop and think about the things we had been doing through sheer inertia. What was the point of it all? We'd adopted the work format as a legacy of the collaboration with Queens Museum and the award from the AAM but it was preventing us from focusing on what we viewed to be the essence of the programme: empowering families and building a community. We wanted the museum to become a place of social interaction for the families, were they could establish bonds and share meaningful experiences.

The beginning of this second, less challenging phase with Fundación ICO gave us the chance to ask ourselves where *Empower Parents* was headed in Madrid and what we wanted it to become.

The answers to these questions were translated into a set of objectives or a wish list that defined the lines of work for this new phase:

“We wanted the museum to become a place of social interaction for the families, were they could establish bonds and share meaningful experiences.”

- Transform the families' idea about cultural institutions. Encourage the appropriation of the spaces and the cultural habit.
- This automatically tied in with the notion of making the collective visible and changing the parents' role, with more activism and with staking a claim on a space they had been denied and had the right to access.
- Create a community of families by encouraging them to develop relationships and share experiences.
- Empower the parents and children by giving them the necessary tools to seize and occupy new museum and/or cultural spaces.
- Create a methodology that would enable the children, after eight training sessions, to internalise the lessons learned and apply them to other museums and cultural spaces.

The objectives for this new stage were therefore structured around three lines of action.

- Line of action 1. Community: Create and consolidate a stable and long-lasting community of families united around autism, culture and accessibility, adding an average of six or seven new families each session.
- Line of action 2. Empowerment: Through training actions for the families and a learning programme for the parents and children structured around eight sessions over the course of each nine-month edition of the programme.
- Line of action 3. Knowledge sharing and transfer: Define a working practice at the museum which other museum institutions can replicate.

May 2018:

REPLICATION PROGRAMME Session at Espacio Fundación Telefónica, Madrid.

REPLICATION PROGRAMME Session at Museo del Ferrocarril, Madrid.

PUBLIC PRESENTATION / *Encuentro Internacional de Mediación y educación Cultural*. Málaga City Council, Fundación Picasso, Colección del Museo Ruso and Centre Pompidou, Málaga.

2018



June 2018:

MEETING “Expanded Conversation”, Medialab-Prado.

2018



Line of action 1: Participation, collaboration, community

Participation, collaboration and community are terms that could be linked to a common theme but on this occasion they refer to connected concepts that define a process. The initial phase of *Empower Parents* was marked by a paradigm shift based on the experience with Queens Museum that enabled us to discover a more social type of museum model connected to its immediate environment. This idea was so attractive that we wanted to incorporate it into our own line of work and build a community around *Empower Parents* and Museo ICO.

The community concept has determined the pace of our programme in Madrid from the outset. In our case, however, “community” does not refer to a territory connected to the museum but to a group of people who share interests and motivations related to autism and culture.

We began by facilitating work processes and creating actions that would provide a space in which the families could participate with their children and play an active, leading role in our reflections about the changes required to turn the museum into a more open and accessible institution. This objective, which was launched in the second phase, is still in progress today but it opened up the possibility of creating modes of collaboration which, in Phase 3 (“Rethinking”), prompted a group of fifteen families to take the reins of the programme and create the *Empower Parents* association (EPA).

Our roles as educators, mediators, facilitators and fellow travellers on this journey have also evolved over these past years. In the first edition, the education team’s leadership was patently evident. We tried to make ourselves invisible during the sessions and allow the parents to take the lead, but although we managed to achieve that objective we were still the ones running the sessions. How could we establish a horizontal working relationship when we were in a position of power?

The decisive change came in the fourth edition when the families started organising themselves autonomously, assuming an ever-stronger group awareness and doing leisure activities outside the museum. Being able to appropriate new spaces and develop *EMPOWER* (as they call it) at other institutions is something that all the families have demanded since the second edition. Apart

“How could we establish a horizontal working relationship when we were in a position of power?”



from the replication sessions we held at other museums, we have not been able to persuade other institutions to commit to carrying out a stable programme of activities, so the space is limited to Museo ICO.

“Expanded Conversation” meetings

Conversation has been the core of *Empower Parents* all these years. However, it always seemed that we didn’t have enough time to discuss the different topics thoroughly enough, and the meetings ended up being simply the preliminary preparation for the sessions and the evaluations at the end of each one, so as the programme advanced it became more and more necessary to create moments for being at the museum with no other objective than to meet up with each other.

On numerous occasions we had to agree collective solutions to prevent the workshop space from filling up with the “noise” of the parents’ conversations as they got caught up in endless chatter, laughing and rejoicing at being together again.

In another context, that “noise” would be a marvellous indicator, but in this case it was a disruptor for most of the children with ASD, and sometimes it meant that we couldn’t carry out the activities in the desired conditions for them. At the same time, we didn’t want to curb their enthusiasm.

As an alternative, we decided to carry out actions in the museum galleries to free the workshop space from the parents’ voices and laughter. The music from the gathering flowed through every corner, inundating a usually silent space and making it feel more ordinary, filled with emotions and caring. Every Saturday this “noise” humanised the museum on Calle Zorrilla, filling it with life and spreading the sensation of “ordinariness” to the visitors and the museum professionals: whether information, security or cleaning personnel, they all ended up collaborating in the experience, establishing bonds with the families and calling each child by their name.

The evaluations we conducted at the end of each session provided a time for sharing. We talked about what we thought had worked and what had surprised us pleasantly or unpleasantly,

“Expanded Conversation” meeting at Medialab-Prado

August 2018:

PUBLIC PRESENTATION II Encuentro de Mediación Acción de borde, intercambio de Prácticas de Mediación Artística y Cultural. Chilean Ministry of Cultures, Arts and Heritage.

2018



September 2018:

Empower Parents featured on the *Conciencia Inclusiva* programme, CNN Chile. 2 September 2018.

2018



September 2018 / June 2019:

Sixth edition of the PROGRAMME OF ACTIVITIES for families affected by autism at Museo ICO.

2018
2019



and we discussed adaptations and changes to bear in mind for the following sessions. Above all, though, we used these sharing times to talk about their children and swap tips and educational, medical or therapeutic resources. We realised that these moments were very valuable for all the parents because they strengthened the relationships begun during the first year and reinforced the idea of a community. They began to discuss possible plans and actions outside the museum, and by the end of the second edition these started to materialise.

Having a child with autism is very demanding, and finding time to meet was always very complicated, so many conversations were left pending and had to be conducted through endless chains of emails. It was this need to share and carry on conversing that led in 2015 to the “Expanded Conversation” meetings.

Since then, we have held two meetings a year (February-March and May-June) at Medialab-Prado to provide the team of families with a new cultural space related to the various objectives of the programme of family activities that we were already undertaking at Museo ICO.

The aims of these meetings were to:

- Share knowledge, lessons learned, anxieties, fears and doubts.
- Operate as a space for discussing what had and hadn’t worked in the programme.
- Define future lines of work.

And the following topics were discussed:

- Rethink the museum: accessibility.
- Reflect on the different ways of interacting with and occupying spaces, taking into account each child’s individual needs.

“At the first meeting in 2015 we created three working groups: the promotion group, community group and education group.”

- Encourage a critical and reasoned approach to art and culture.
- Decide about aspects of the programme collectively, such as the budget, needs, team of professionals, methodological approaches, etc.

At the first meeting in 2015 we created three working groups—the promotion group, community group and education group—to organise the structure we had been using thus far.

The groups are still active and on average comprise ten families (the actual families have changed over the years but the number remains stable).

The promotion group is made up of six families who have been involved in the programme since it was first launched. Every year, they decide the lines of work, define the activities, seek partnerships with other institutions and take part in the outreach actions that have emerged over the years with the media and universities.

The education group helps to design the contents of the educational activities. And, on a completely autonomous basis but following the programme methodology, the community group organises meetings and activities related to art and culture, including visits to new cultural institutions.

It is the parents who contact the institutions, present the programme and organise all the necessary details to carry out the session/workshop at the venue in question. To date, they have worked with CaixaForum Madrid, Museo del Ferrocarril, Espacio Fundación Telefónica and Fundación Canal.

“It is the parents who contact the institutions, present the programme and organise all the necessary details to carry out the session/workshop at the venue in question.”

Line of action 2: Empowerment of families

It is difficult to talk about empowerment and limit it to a specific section of this publication because it has been a core strategy underpinning the entire programme. From the very first moment we met the families at the initial interview, our aim was to gain their trust and create a space where they felt comfortable, just as

October, 2018:

PUBLIC PRESENTATION *Perspectivas culturales I, educación y difusión en museos e instituciones culturales: Enfoques actuales y salidas profesionales.* University of Castile-La Mancha.
PUBLIC PRESENTATION *Jornadas sobre políticas culturales en la Comunidad de Madrid.* Regional Government of Madrid.

2018



November 2018:

REPLICATION PROGRAMME
Session at CaixaForum Madrid.

2018



November 2018 / January 2019

WORKSHOP “Exploring with the Senses”.
Artist: Lucía Loren.

2018
2019



when we put them at the centre of the family programme and let them take the lead in all the activities at all times.

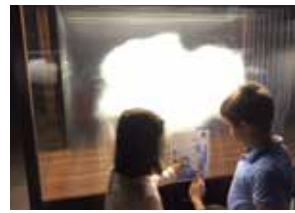
Hugging them when they entered the museum is an empowering action, as is encouraging them when they are running a session for a first time. The knowing glances shared in the museum gallery while carrying out an activity with other audiences build confidence and trust. Every detail and every step is related to the core idea of reactivating their agency. That is the basis of our empowerment strategy.

One general comment that the families voiced at the beginning of the programme was that they felt insecure about visiting a museum with their children, because whenever these behaved “unusually”, they felt uncomfortable with the “absurd judgement” they were subjected to by the other visitors or the museum personnel.

At the end of each eight-session cycle of the family programme, there were often families who commented that, thanks to the training, their child had managed to incorporate a session routine that they could apply to other cultural spaces or museums. In other cases, these changes will take longer to materialise, but I honestly believe that this is not the main achievement. Their children are the same as the first day of the programme, and how they express their happiness and frustration is also the same. Their ability to enjoy a new space hasn’t changed just because they have taken part in eight sessions at a museum. What has been genuinely transformative about the programme is that by the end of the sessions, the parents had come to realise that it didn’t matter if their children ran, jumped or shouted, even inside a museum.

At every session, we constantly repeated the phrase “It doesn’t matter, it doesn’t matter”, almost like a mantra, until we saw the most tense mothers stop clutching their bags and adopt a more relaxed posture, stop watching and controlling their child and instead look away and timidly strike up conversation with other families, or immerse themselves in the activity, exploring the museum gallery through play.

These meaningful moments are the true achievements of the programme. Besides, they tended to be contagious and spread: the words we used with one family were overheard by others at the same session, and that’s when the magic occurred.



Parents putting the final touches to a replication session at Espacio Fundación Telefónica (Image 1)

Experience in the gallery during the *Leandro Erlich. Certezas Efímeras* exhibition at Espacio Fundación Telefónica (Images 2 and 3)



Experience in the workshop during a replication session at Espacio Fundación Telefónica

Throughout all these years, we have encouraged the families to adopt a critical role vis-à-vis the institution, to collectively rethink the imposed relationship with the museum and how it should be. In these discussions we have talked about diversity and the need to devise new ways of occupying common spaces, taking into account each person’s individuality. As a space of resistance, this more political dimension has helped them to understand their role in cultural institutions and feel the need to claim it. For us, that is undoubtedly the greatest achievement.

Line of Action 3: Knowledge sharing and transfer

The aim of *Empower Parents* since the outset has been to appropriate new spaces for families affected by autism. The framework for our lines of action therefore includes creating replication programmes at other cultural institutions and museums. This has been one of the ways in which we have publicised the programme and demonstrated that it could be transferred and implemented in another institution, as well enabling the families in the *Empower Parents* community to discover a new cultural space.

Every time an institution has expressed interest in the programme, we have met with the education/mediation team to explain the methodology and the structure of the sessions, and then we have jointly prepared the necessary accessibility supports and assigned the roles to be played by each party during the session.

Between 2013 and 2019, we conducted replication programmes at Museo Thyssen-Bornemisza, Museo de la Ciencia in Valladolid, Museo del Traje. CIPE, Espacio Fundación Telefónica, Medialab-Prado and La Fábrica de la Luz. Museo de la Energía in Ponferrada.

January 2019:

PUBLIC PRESENTATION *Encuentro Internacional de Infancia+Arquitectura+Educación +Inclusión*. School of Educational Architecture, Autonomous University of Madrid. January 2019 / May 2019: **WORKSHOP** “Skin, Shell and Territory”. Artist: Lucía Loren

2019



February 2019:

MEETING “Expanded Conversation”, Medialab-Prado.

2019



Phase 3: Rethinking 2018-2020

By the beginning of the sixth edition of *Empower Parents*, we had achieved many of our initial objectives. We had created a relationship of trust between the museum and the community of families which had made it possible to appropriate the space and include cultural practices as a matter of routine. Even so, we still needed to introduce new challenges and directions.

We wanted to stop what we were doing, become more visible in the museum space and tackle the tension by generating gatherings conducive to active dialogue with the different agents of the institution. In short, we wanted to rethink the museum from a cross-cutting perspective and address the conflicts through new formats.

This edition represented a change of course and a departure in several directions. For one thing, we introduced new methods that questioned earlier processes and practices, placing a greater emphasis on working in the museum galleries to open up the possibility of establishing dialogues with audiences, professionals and the institution.

During the course of the previous years we had defined a session routine that allowed the group of children to explore the museum through play and tranquillity, and that gave the rest of us the opportunity to learn to look unhurriedly, to think about how we should move through the space, together identifying the cognitive and sensory overloads so frequently found in exhibition halls: the light, the sound, the relationships, etc. These excesses forced us to look for solutions to be able to carry out the family programme activities: in some cases they were resolved through creativity, in others by avoiding certain areas of the exhibition, and when that was not possible we started mediating with the institution, sometimes encountering an unexpected response.

Accessibility also generates tension. We can spark a debate with different agents and the majority of them will agree with the “merits” of introducing a line of work in this respect, but when they start taking the first steps and realise that it’s something that needs to affect every area of the museum, the differences of opinion and mental blocks arise. To what extent can initiatives like *Empower Parents* transform institutions?

“Accessibility also generates tension.”

“To what extent can initiatives like *Empower Parents* transform institutions?”



Experience in the *Espacio habitado* workshop led by the artist Lucía Loren

p. 54 Experience in the Museo ICO galleries

The fact of building a community around Museo ICO has prompted changes, leading to more work related to accessibility and the development of stable programmes in association with social agents like Plena Inclusión Madrid. The museum staff have received training in diversity and accessibility supports have been created for the exhibitions. The work in this area is ongoing, demonstrating a firm commitment on the part of Fundación ICO to these matters.

One of the initial objectives of *Empower Parents* was to “transform” the space, but although this is a small museum it has been difficult to achieve this aim outside the bubble of the programme. Even so, Museo ICO has become a meeting place for the families and it is friendlier, more sensitive and more welcoming than it was back in 2013. Its walls have expanded literally, to the point of being demolished during the second edition to create a more spacious and more comfortable workshop room. It’s complex because initially we weren’t very clear about what needed to be transformed, or whether what we initially thought should change was even possible within the time frame and resources at our disposal.

The list of objectives we drew up the first year was completely unrealistic in view of the programme time frame and resources: conceptualise and implement a programme of activities for families affected by autism that could be replicated in other institutions in Spain; design and create content for a bilingual platform to share experiences with the different social and cultural agents, etc.; carry out training and exchanges with Queens Museum; build a community around ASD and Museo ICO; and, to top it off, transform the museum.

All this is record time... starting now!... (and ending nine months later...). The resources amounted to just two part-time educators linked to a precarious structure outside the institution. If this text is your first insight into education in museums, welcome! For the rest of you, it must sound very familiar.

Seven years later, we realise that these excessive objectives were inherited as a result of the award from the American Alliance of Museums and we recognise how impossible they were to achieve, and not only because of the limited resources and time frame. To embark on a project of this nature, it was vital to establish a dialogue with the institution based on horizontality, which was

March 2019:

PUBLIC PRESENTATION European *Project Tandem (Tools and New Approaches for People with Disabilities Exploring a Museum)*. Museo de Arte Contemporáneo de Castilla y León and Mu-zee-um.

2019



April 2019:

PUBLIC PRESENTATION *The Museum for All People: Art, Accessibility and Social Inclusion*. Musaces. Complutense University of Madrid.

2019



“If they’d told us when our child was five years old that visiting museums would become one of his hobbies, we wouldn’t have believed it. Drawing, painting and modelling has been a form of expression for him from a very young age. He enjoys the sensations aroused by the materials, they calm him. Art in general has been very therapeutic.

In the last stage of the programme when we were working with artists like Lucía Loren and Irene Cantero, we really experienced the creative process with them, the influence of music and movement. It gave us a new, richer vision... There’s no need for verbal language because art has its own language, one we all have inside us and which in these children arises naturally, in spite of their difficulties. But we would never have managed to make art such an important part of his life without the support of *Empower Parents*.”

Carlos and his family have been involved in *Empower Parents* since 2014



difficult to do with an external team that first and foremost had to generate more horizontal internal relationships and create a stronger place from which to communicate as equals with the Fundación ICO team. This repositioning of powers, energies and weights paid off during the second edition of the *Empower Parents* when a collaborative relationship was created between the education team at *hablarenarte* and the Art Department of Fundación ICO, with which we have worked closely and as a single team ever since.

We know this is quite rare and we believe it's one of the reasons why *Empower Parents* has become a stable, long-lasting programme. Throughout, there has been clear recognition for the education/mediation work as a hybrid educational and collaborative programme. This has enabled us to approach it as a long-term process and secure an annual budget to implement it. If our analysis had resulted in a more simplistic view, seeing the programme as merely the implementation of activities within the framework of a programme with families, we may not have received the support of the Fundación ICO board of trustees and it may have ended after the first edition.

We have opened up new channels of dialogue with the institution and, together with different agents and adopting a multidisciplinary gaze, we have identified what needs to change for the museum to become a more humane space and operate as a shared meeting place. Assisted by the community of families, we have also detected the areas of discomfort and—a crucial preliminary step for us—we have learned how to look and therefore understand the need for change.

In this same line, the actions that we carried out in the exhibition space became an excuse to make visible and occupy what was once a hostile, prohibited place. The work in the gallery evolved from a preliminary sequence conducted before the activity in the workshop to a meaningful action in and of itself. The families didn't only leave their bags and coats in the foyer but their daily parental habits as well in order to become activists. We are not going to exaggerate and say that radical actions were carried out, but we do believe that the gestures that were already becoming more habitual in the families took on a new meaning: taking a stroll together with the freedom to be and express themselves from a place of individuality.

“We have encouraged the families to adopt a critical role vis-à-vis the institution, to collectively rethink the imposed relationship with the museum and how it should be.”



Experience in the *Espacio habitado* workshop led by the artist Lucía Loren

In this last edition, we wanted to continue exploring new ways of occupying the museum space by incorporating choreographies and new movements. We went from talking about art in earlier editions to introducing artistic methodologies that enabled us to research new practices and approaches through the work carried out by the artists Lucía Loren and Irene Cantero.

The education team designed the *Espacio habitado* [Inhabited Space] project which, based on the usual session structure, sought to create meaningful connections inside the museum by imagining and dreaming a new space that would accommodate other ways of being and relating to the museum from each identity. Within this framework, both Lucía and Irene conducted projects that started in November 2018 and ended in July 2019.

As part of *Espacio habitado*, Lucía led two workshops between November 2018 and May 2019: “Exploring with the Senses” and “Skin, Shell and Territory”. The workshops adopted a sensory-based approach, activating creative resources to use them as elements of communication and stimulation for people with ASD.

Irene took over in May 2019 and launched her “In Depth: Light and Body” project, using light in her pieces to connect the body, context and idea: diverse bodies in harmony with other bodies, with the environment, with objects and with concepts. Movement was the form of expression, conceiving dance in its broadest sense and always in relation to other languages or contexts that open up uncharted paths. The body and its movement were the protagonists, avoiding establishing hierarchies between disciplines, codes and spaces.

Perhaps the most transformative thing of all, now that major cultural institutions talk so much about emotions and caring, is that this is the line of work we launched seven years ago and it's enabled us to build a stable community beyond the programme actions and the museum itself, to the point of becoming a legally constituted association.

A group of fifteen families decided to create the *Empower Parents* association to continue the work conducted thus far at Museo ICO and other cultural institutions. This is the true accomplishment of the programme.

The idea of creating the association was first mooted in 2017 and re-emerged more forcefully at the last round of “Expanded

May 2019:
MEETING “Expanded Conversation”, Medialab-Prado.
NETWORKS European Network of Innovation for Inclusion.
Action Against Hunger and European Social Fund.

2019



May 2019:
WORKSHOP
“Light and Movement”. Artist: Irene Cantero.

2019



October, 2019:
Donis, L. publishes the article “Empower Parents, conquistando espacios comunes” in *Maremagnum* magazine.

2019



Conversation” meetings held at Medialab-Prado, but the real catalyst can be traced back to July 2019 and the end of the programme of activities for families affected by autism. This fact validated the work we had carried out over the previous years and the importance of continuing it through new channels. The first step would be to form an association to be able to apply for other sources of funding that would ensure the continuity of the programme of activities in the future as well as the development of new actions at other cultural institutions and museums.

Transferring *Empower Parents* to other institutions is one of the great challenges of the programme that we have failed to achieve. Why has it not been possible to implement it elsewhere? Why has it reached the doors of other institutions and, in spite of being viewed positively, has found those doors closed? We’ve asked ourselves this question internally on countless occasions.

From the moment we embarked on this adventure, we were very clear that one of the challenges would be to activate a network of organisations and professionals. We wanted to be able to share the lessons learned during the first year with Queens Museum and build on that exchange experience to create new partnerships with public and private institutions, but it has not been possible. In spite of the resources and time dedicated to that mission, we have not secured any partnerships beyond the replication sessions carried out at different institutions during these past few years.

Why? We believe the reasons are manifold. In some cases, the excuse has been financial, the institution in question arguing that this line of work would require a larger budget for educational programmes. However, although it is an initiative that proposes new methods, these are not associated with a larger budget if we compare them with the cost of any programme of educational activities on a similar scale. There is no need for personnel specialising in autism initiatives or special materials; all that is required is a genuine commitment and desire to open up institutions. We have offered our *Empower Parents* resources and experience, as well as a community of families that would have been delighted to collaborate with new institutions, but perhaps we haven’t been able to communicate it in a sufficiently attractive manner. Apart from sharing the work carried out to date, this publication also aims to provide a practical introduction to the

“From the outset, we have rejected exclusivity, and today we believe the challenge lies in blurring the boundaries between the programme for families affected by autism and all the other educational programmes at Museo ICO.”

characteristics of the programme with a view to its replication in other institutions which, thus far, do not appear to have grasped its possibilities for transformation.

The programme of activities for families affected by autism ended in July 2019 because it was necessary to stop and take stock of the work we have carried out over the years. This publication is the result of that process of reflection. We know that ASD requires specific support to be able to work with the groups autonomously and avoid top-down instrumentalised actions. We also know that there is a very fine line between an accessible programme and an exclusive one, and we are obviously very keen to stay clear of that ambiguity because of the risk it implies. From the outset, we have rejected exclusivity, and today we believe the challenge lies in blurring the boundaries between the programme for families affected by autism and all the other educational programmes at Museo ICO in order to guarantee the accessibility of all activities and transfer the lessons learned, supports and resources to other programmes and professionals.

There are many challenges ahead, but in the medium term we want to continue the work begun on accessibility; create a stable group to initiate multidisciplinary actions within the framework of a research-action programme in which educators, artists, curators, directors and audiences propose projects to address the tensions and conflicts surrounding this debate; reinforce the network of collaboration with social organisations, universities and cultural institutions; transfer the methodology and lessons learned to other cultural institutions committed to accessibility so that they can implement the programme, adapted to their own context; and continue with the welcome hugs and open doors, setting our sights on a more unorthodox type of museum occupied by different identities and without any labels.

October, 2019:

PUBLIC PRESENTATION *Xornadas de Cultura e Autismo*. Federación Autismo Galicia, Regional Ministry of Culture, Education and Universities and CGAC.

2019



February 2020:

MEETING “Expanded Conversation”, Medialab-Prado. A group of fifteen families creates the *Empower Parents* Association (AEP) to take over the programme and continue the work begun at Museo ICO at other cultural institutions and museums.

2020



Bibliographical references

AUTISMO ESPAÑA (2019). <http://www.autismo.org.es/actualidad/articulo/se-confirma-el-aumento-de-personas-con-autismo-identificadas-en-espana> [retrieved:10/03/2020]

AUTISMO ESPAÑA (2020). <http://www.autismo.org.es/sobre-los-TEA/trastorno-del-especto-del-autismo> [retrieved:10/03/2020]

AA. VV (2019). *Anuario de estadísticas culturales*. División de Estadísticas y estudios: Ministerio de Cultura y Deporte.

MÖRSCH, C. (2015). *Contradecirse una misma. Museos y mediación educativa crítica. Experiencias y reflexiones desde las educadoras de la documenta 12*. Quito: Fundación Museos de la Ciudad.

PADRÓ, C. (2003). *Museología crítica como forma de reflexionar sobre los museos como zonas de conflicto e intercambio*. Zaragoza: Prensas Universitarias de Zaragoza.

SIMON, N. (2010). *The Participatory Museum*. <http://www.participatorymuseum.org/read/> [retrieved:12/06/2020]

Conversations

When we began writing this book, we were very concerned about conveying the rich diversity of voices that made this collective experience possible. We thought long and hard about the best way to make those voices heard, and one of the options was to invite those who had been involved in *Empower Parents* in one way or another to express themselves in writing.

We felt it would be incredibly beautiful to create a multicoloured mosaic of individual narratives, revealing different perspectives, feelings and tones, but in the end we discarded that idea because it didn't reflect the dynamic nature of the programme and, above all, the living process of collective construction.

Conversation and dialogue have been the basis of this programme. Long hours were spent talking about inclusion, accessibility, culture and autism, laying a theoretical foundation that struck up a dialogue with practice every weekend. We talked about the difficulties that families face and the need for a more inclusive culture. We also talked about abilities, creativity and the importance of self-expression and visibility as a collective.

Empower Parents has essentially been one long conversation leading to different places. A conversation initiated by social outreach and culture professionals and sustained by the experience, emotions and lessons of 109 families who have helped us to grow over the years.

That's how this community was formed: sometimes around a table, over coffee or a meal, other times in a museum gallery, but always, always collectively.

For this reason, we decided that the best way to tell you what we've done over the years is by inviting you to join our conversations. Welcome.

Conversing

This chapter includes eleven conversations that Laura Donis, head of the *Empower Parents* programme, had with agents, artists and families between March and July 2020.

The selected talks touch on different aspects of *Empower Parents*. With Michelle López, manager of the programme at Queens Museum, we explored the history of *Empower Parents* from its inception in New York to its implementation in Madrid.

With Alicia Gómez, a member of the Art Department at Fundación ICO, we talked about the transformation of Museo ICO into a meeting place for the *Empower Parents* community of families.

Ana Lozano, a representative of Plena Inclusión Madrid, which runs one of Spain's leading inclusive culture and accessibility programmes, discussed the importance of making culture accessible to people with functional diversity and their families.

And the artists Lucía Loren and Irene Cantero explained their respective creative practices and the lessons they learned from working collaboratively with people on the autism spectrum.

Selecting the families was much harder. They all have a child with autism, but their situations are very different. In this chapter, we've tried to paint a picture of the collective by exploring its variegated nuances, stepping outside the programme's boundaries to show what life is really like for people with ASD and their families.

In these conversations, mothers, parents and siblings talk about their needs, concerns, interests and, in some cases, dreams.

Agents: ① *Michelle López*. Creator of accessibility programmes and initiatives for people with autism. ② *Alicia Gómez*. Art Department of Fundación ICO. ③ *Ana Lozano*. Coordinator of the Inclusive Culture Department at Plena Inclusión Madrid.

Artists: ① *Lucía Loren*. Artist. Art in the Territory. ② *Irene Cantero*. Choreographer, dancer and lighting designer.

Families: ① *Gemma Domínguez*. She and her family have been a part of *Empower Parents* since 2013. ② *Isabel Melguizo and David González*. They and their family have been a part of *Empower Parents* since 2013. ③ *Nuria González*. She and her family have been a part of *Empower Parents* since 2014. ④ *José Luis Morales*. He and his family have been a part of *Empower Parents* since 2014. ⑤ *Ana Gómez*. She and her family have been a part of *Empower Parents* since 2016. ⑥ *Marta, Fran and Miguel*. Siblings of children with autism who participate in the *Empower Parents* programme with their families.



Workshop experience.
Queens Museum
(Image 1)

Gallery experience
during a replication
session at Espacio
Fundación Telefónica
Jennifer Steinkamp:
Naturaleza digital
exhibition (Image 2)

Agents

1 Michelle López. Creator of accessibility programmes and initiatives for people with autism

A firm believer in art as personal growth and advocate of the universal right to create and experiment artistically, Michelle has worked at schools in New York City and Long Island and collaborated on accessibility programmes and initiatives for people with autism at institutions like Queens Library, Queens Museum and the Children’s Museum of Art, all in New York City.

For over fifteen years, Michelle has served children and families on the autism spectrum as an ABA¹⁷ instructor, counsellor and trainer. She has an MA in Creative Arts Therapy from Hofstra University.

In 2013, as Manager of ArtAccess Programs and Autism Initiatives at Queens Museum, she teamed up with Museo ICO and hablarenarte in Madrid thanks to a grant from the American Alliance of Museums,¹⁸ which marked the beginning of a collaborative partnership between Queens Museum in New York and Museo ICO and hablarenarte in Madrid.

Empower Parents was launched in Madrid thanks to a partnership with Queens Museum, where several years earlier you had introduced the Museum Explorers Club, a programme for families affected by autism. How did that programme get started?

Before I began working at Queens Museum, I worked with Jennifer Candiano¹⁹ on initiatives for Spanish-speaking families registered in the Young Autism Program at the Developmental Disabilities Institute in Ronkonkoma, New York. There were families who had children with autism, and we launched a pilot programme that taught us so much and helped us to understand the needs of people on the autism spectrum and their families.

What lessons did you learn from that experience, and how did you apply them to your subsequent experience at Queens Library and Queens Museum?

I think that working with kids with autism and being involved with their families gave me highly specialised knowledge which I applied to both programmes, as well as to the training I gave to professionals from other museums, libraries or art centres with an interest in developing a special programme for people with autism at their institutions. Specifically, working as an art therapist with people with autism made me realise the importance of expanding their visual vocabulary.

For example, Mary Temple Grandin, a person with ASD and world-renowned autism spokesperson, explained that children on the autism spectrum tend to “think in pictures”. And they’re very good with details and tend to be so focused on them that

17. Applied Behaviour Analysis or ABA originated in the United States as a therapeutic intervention (behavioural techniques and procedures) that aims to minimise inappropriate behaviour and increase appropriate conduct by learning new skills. This approach is used with persons with developmental disorders, including autism.

18. Grant awarded to *Empower Parents* by the American Alliance of Museums and the US Department of State as part of their joint initiative Museums Connect.

19. Jennifer Candiano and Michelle López co-authored the guide *Room to Grow*. In 2013, the year *Empower Parents* began, she was Associate Coordinator of ArtAccess and Autism Initiatives at Queens Museum, where she handled training and relations with participating families.

“Visual and sensory learning is very important for people with autism. They excel at remembering details but struggle to generalise that knowledge.”

sometimes they struggle to learn other things. This creates a feeling of frustration when faced with something they can’t control, and at times they become fixated on what they can control.

Experts say that a neurotypical person’s brain is more flexible, more capable of generalising learning. For example, we can adapt and extrapolate the things we learn to other contexts. This tends to be harder for people with autism.

On a social level, the idea that people with autism have difficulty generalising because they focus on details means they also have a hard time socialising, forging relationships outside their usual circle.

Moreover, as this inability to generalise creates frustration and anxiety in kids with autism, they often spend a lot of time playing alone or only with their parents or siblings, which doesn’t help them to acquire social skills and tools. So we work to offer them tools that will help them to function in society and make it easier for them to interact with others.

It’s very likely that this interview will be read by someone unfamiliar with autism. Could you explain, in simple terms, the cornerstones of these learning processes?

Visual and sensory learning is very important for people with autism. They excel at remembering details but struggle to generalise that knowledge.

That’s why, in general, they need to know what comes next in order to manage their anxiety so they can stay calm and be able to learn. Calmness is essential for acquiring new knowledge. Consequently, activities have to be structured so that any child, with a bit of practice, can understand the routine and expand his/her visual vocabulary through sensory learning.

It’s very important that they socialise with other boys and girls, and that their families remain calm so they can work with their children and help them to understand and enjoy the process.

What made you think a museum was a good place to develop your educational programme?

We were developing the project at the Long Island school, and we received a grant to work with children whose parents were predominantly Latin American: Honduran, Guatemalan, Panamanian, Mexican, etc. And they lived in a very isolated Long Island community: the kids had a 45-minute bus ride to school, and the mothers couldn’t attend the family training sessions. Plus, many of them didn’t speak English. We therefore realised that the school wouldn’t work as a space of integration.

At that time, accessibility was a hot topic in the United States, and there were plenty of resources available for developing projects with people on the autism spectrum, so we decided to look for funding to implement our idea in other settings.

We thought of museums, but it was complicated as their accessibility departments tend to be the most underfunded and understaffed.

So we had to come up with a plan that would eliminate the “no” from our conversations: museums telling us they had no resources, parents telling us they had no way to participate...

And that was when the ArtAccess²⁰ Department at Queens Museum and Queens Library launched a programme for families and children with autism in the Queens borough.

Queens Library was the number-one institution when it came to identifying resources that the immigrant community needed. Queens is a multicultural borough with a large migrant population that use libraries because there are many programmes and resources designed specifically for them, providing information in various languages, etc.

This institution is very sensitive to the community’s needs, and they were quite keen to launch initiatives for including boys and girls with autism in the library network.

The programme had to train professionals in the public library system, and we began with a training programme for 700 librarians to teach them how to work with children on the autism spectrum... They knew very little about autism, and we knew very little about how a library works! (*laughter*)

What was the biggest challenge they faced when developing this initiative?

Most of the librarians, who were almost always women, except at the executive level, didn’t feel prepared to do the programme. At the time, the United States was in the midst of an economic recession, and funding had to be found for these kinds of initiatives. They saw it as something they were obligated to do, and they were already short-staffed. There was a small group of librarians who had children or relatives with autism, and that group was more receptive, but as a general rule they didn’t have the energy to get involved.

So they didn’t really like us at first. But then a counsellor advised us to work with them by focusing on their interests. What interested those women? Books, children’s books. We thought, “Oh, let’s activate the books!” The books already had photos and visual vocabulary, so we began working at school, at the library, in homes, with parents, with educators, and later we made connections to the museum collection. The result of this effort was the *Room to Grow* guide, which provides the keys to launching programmes that work with boys and girls with autism.

Why did you decide to create a resource like *Room to Grow*?

To organise scattered knowledge: we saw that, when museums wanted to work with children with autism, they all took different approaches. Some museums had better training, a more dedicated team of professionals than others... And different practices were being developed. So we began to analyse all those different, diverse,

20. Since 1983, ArtAccess has served as a model for cultural institutions that want to improve their programmes for people with special needs. In 2009, the Museum Explorers Club was created through ArtAccess thanks to a three-year grant. The programme received the Mayor’s Award in Honor of the Americans with Disabilities Act (ADA) and two national awards for excellence from the VSA arts organisation. Its main proposals and contents have been shared with the Museum Access Consortium in New York, the Museum Educators Roundtable and numerous social networks for educators.



Michelle López and Jennifer Candiano in an Empower Parents session at Queens Museum (Image 1)

Workshop at Queens Museum led by a mother from the programme (Image 2)

scattered practices. Someone wants to create a programme but doesn't know where to begin? Well, let's put together a simple guide so that anyone interested in starting a programme for kids with autism can find out what worked for us.

It had to be easy to read, with simple vocabulary, something that could be used to launch initiatives even on a limited budget. It had to easily explain how to clearly convey the rules, the daily schedule, and give the kids some vocabulary—because when you're teaching someone to speak, or teaching them a new language, you have to give them some basic vocabulary, right?

We also wanted it to be useful for families. That way, if a mother signs her autistic son up for a workshop, she can give the educational team a copy of the guide.

What did you hope to achieve with this resource?

Professionals need resources in order to launch these kinds of initiatives and adapt them to their programmes and interests. That's why we felt it was important to create a set of common resources so that each institution could adapt them to their own style and format. For instance, if you're going to offer a painting workshop, you need to know what kind of working conditions are generally needed for children with autism: the rules have to be clearly communicated, and it's better to tell them what they can do than focus on what they shouldn't, give them visual information, divide projects into steps (at least three): And you have to bear in mind that the most important goal of every activity is to make them feel proud—and, in the process, for the families to feel proud as well. That's a form of growth. As art therapists, it's very rewarding for us when this happens.

How did you see the result of those adaptations in different settings?

Experimenting with different education professionals, we saw that it didn't matter who was teaching the class, where it was held, where the group was from, or what their native language or culture was. In fact, we had to set conventional American approaches aside and adapt to other cultures: Korean, Latino, etc. But the material is very flexible, and that adaptation is actually the key to making it more effective.

For example, one time we organised an activity about the "Day of the Dead", and we were teaching a class of predominantly non-Mexican women who associated the skeletons with voodoo (*laughter*). In that class, we had to deal with cultural adaptation problems. No matter how perfect we tried to make things, these kinds of situations always cropped up (*laughter*). We tried to make everything work for each culture, but those minor incidents were inevitable. However, the important thing is that we always worked with people who were willing to do it. Sometimes it didn't pan out, but at least we always tried. Never say "It can't be done". Our philosophy was "Yes, we can". We have to find a way that works, but it can be done, as long as we remember that the only behaviour we can control is our own.

“Professionals need resources in order to launch these kinds of initiatives and adapt them to their programmes and interests. That’s why we felt it was important to create a set of common resources so that each institution could adapt them to their own style and format.”

The programmes created for these families were bilingual, and they were implemented at several libraries in Queens and later at Queens Museum.

We started working with families affected by autism at the museum through the Museum Explorers Club programme. The same families usually participated, and some educators wanted to learn how to work with children on the autism spectrum. I asked them, "What do you want to teach?" and then they learned how to prepare a class and teach kids the routines of each session. And the sessions were adapted to whatever they wanted to teach: music composition, deejaying, things they hadn't expected to teach at first.

After that point, a stable group of families began coming to the museum on a regular basis, and every Saturday they would give us new ideas about what to teach the kids. One father taught music composition at New York University, another mum was home-schooling her children and always shared the ideas she had tried with her kids and what worked... That's how we began giving fathers and mothers a more active role in the programme, and they ended up being the ones who were teaching their children.

Was that when you went from training museum and library staff to training families?

Yes, at that point we decided to train the parents and let them be the children's coaches.

Most of the Spanish families in *Empower Parents* say that, given their children's situation, they had limited contact with art, as they found it difficult to access cultural institutions and museums. What kind of relationship did the families in the New York project have with art centres or museums prior to joining the Museum Explorers Club?

Some, if they were interested in art, didn't go because of their children's situation. Some came to the programme from schools, others from library programmes... They came to us for different reasons, but visiting a museum wasn't one of them: they hadn't entered a museum with their children before joining the Museum Explorers Club.

***Empower Parents* is a community programme. In this respect, we've noticed significant differences between our cultural institutions relate with the community and the model you have in the United States.**

That's true. Although the cultures of the United States and Spain aren't all that different, there are many differences in how we understand the concept of community. Those differences are subtle but significant if we're talking about a community programme.

Clinging to one particular culture or community is frowned upon in the United States. For instance, I'm Puerto Rican, and

“Empower Parents is a community programme. In this respect, we’ve noticed significant differences between how our cultural institutions relate with the community and the model you have in the United States.”

in my neighbourhood, Brooklyn, where there are a lot of Puerto Ricans, before there was nothing for our community, and later they began offering contents in Spanish and incorporating themes that made the museum more appealing to them. But it can't stop there, because soon another community comes along and demands that the museum pay more attention to its culture.

There's always a struggle for privileges. After some time, Puerto Ricans now have a series of privileges that other communities lack. And that creates conflict for the institutions, because many of them are supported by the city with public resources, and citizens argue that a cultural institution which receives public funds should reflect the entire community, not just the group with the loudest voice.

That's probably the biggest difference between the two programmes, the radically different understanding of what community means. Here, today, it's unthinkable that collectives who belong to historically excluded minorities could claim their place in an institution.

We, on the other hand, see that at practically every museum, except the private ones. But when they receive public funding, they have to change their philosophy, they can't continue to cater for just one group.

When you travelled to Spain, you had a chance to meet the families who participate in *Empower Parents*. Do you think the differences at the institutional level and how they are related to the concept of community were also apparent among families? Did you sense that there were major differences between families from different backgrounds?

They all share the culture of having a child with autism. For example, what I observed at Queens Museum is that families who have children with autism, no matter where they come from or what culture they belong to, share the same codes and method of organisation in their homes. That's what I call the culture of having a child with autism. I think that constitutes a unique identity. When I came to Spain for the programme, I had the chance to meet and interview the participating families in Madrid and other cities, like Cádiz, and what I found was that their homes were organised very similarly to those of the families in New York. It's like a common culture.

I think that's beautiful, the idea that families are united through their children, through the culture of autism.

For example, in New York, when we had the meal with American and Spanish families and they began talking about their families, we realised that they were very similar: they all wanted their children to be accepted and be part of the community. And that's something money can't buy: even the wealthiest families had that unmet need. And I think, economic differences aside, that was the heart of the project.

“[...] they all wanted their children to be accepted and be part of the community. And that's something money can't buy: even the wealthiest families had that unmet need. And I think, economic differences aside, that was the heart of the project.”

How did *Empower Parents* evolve at Queens Museum after the American Alliance grant ended?

I think that *Empower Parents* was built gradually by each of the individuals who were part of the professional team, in New York and in Madrid, and thanks to the challenges posed by the families in both cities.

When the grant ended in 2014, several changes transpired in the group of families at Queens Museum. Some of them moved to other areas of the city, and one family even moved to Florida. The children were getting older, and the new families who entered the programme had younger kids. At the same time, some of the mothers were beginning to explore their professional career options. I think the programme helped them to discover their own identities; for a long time, they had been absorbed in raising and caring for their children, and at that point they began to take an interest in their own personal and professional growth.

Internally, the ArtAccess Department felt that the programme needed to be modified and extended to people with a wider range of intellectual functional diversity, not just people with autism. The department professionals trained to work with other special needs, and today they work with functionally diverse adults.

For me, it was a bit sad to see that era come to an end, because we were deeply involved, but I didn't want it to be a stagnant programme; it had to be a movement by and for people, and I think we achieved that together.

In fact, that's one of the defining characteristics of the programme, and its positive results in this respect are proved by the fact that, for instance, every time an institution contacted me to train its staff, I would speak to the group of families and have the mothers do the training.

Yes, it's important for the families to take charge of the programme. In Madrid, since the second year, they've participated in the public presentations we gave at other institutions.

I really believe that if you want to change something in society, you can't think of yourself as indispensable.

Initiatives like this are living things and we need to help them become self-reliant. I feel very proud that the *Empower Parents* group in Madrid took the initiative to set themselves up as an association and continue the programme on their own, independently of Fundación ICO and hablarenarte. I think that's the logical consequence of empowerment.

Exactly. It's important for families to create groups wherever they want, depending on their interests. They should be the ones who decide what they want their children to learn.

The project allowed each of us to turn it into something else, and I think that helped us to grow professionally. This project made us cry, laugh and share; it connected us with other families

“I really believe that if you want to change something in society, you can't think of yourself as indispensable”.

in another part of the world. Who would have thought it could become something like this?

I was so proud when you won the NICE Awards prize in 2017. For me, the most important thing is knowing that the project changed and evolved in Madrid. You turned it into something so different to what I had imagined, and that makes me very happy. It's wonderful.

2 Alicia Gómez. Art Department of Fundación ICO

“Being in the right place is a rare stroke of luck, and for me it happened again with *Empower Parents*. We sailed into completely uncharted waters and learned unimaginable things, primarily thanks to the many families who helped to empower us as a museum and meeting place. The community that has grown out of this project is one of the great achievements we'll always remember.”

Since 2009, Alicia has worked in the Art Department of Fundación ICO, the foundation that manages Museo ICO and its collections. Her job involves organising temporary exhibitions and coordinating the museum's communications with the media and its audience.

Empower Parents began in 2013 as a cultural cooperation and exchange programme with Queens Museum. You've overcome many challenges and achieved many goals since then. Is there one of which you're especially proud?

More than anything, I'm proud of the fact that we managed to bring the idea of community that we saw at Queens Museum to Museo ICO. The exchange experience with the Queens Museum team was very positive. Seeing a museum that was completely alive and had become a gathering place for families made a deep impression on me.

After the whirlwind of launching the programme in Madrid, we set ourselves the goal of making Museo ICO a place where families could share their experiences, and we certainly achieved that goal. That's my greatest source of pride because it's a very hard thing to accomplish.

So far it hasn't been possible with the rest of the activities we offer at the museum, but with *Empower Parents*, because it's a long-term project, we've been able to see personal bonds and alliances form over time.

Seven years ago, hospitality and caring weren't the buzzwords they are today, and yet that was one of our primary focuses. We set out to build a community around *Empower Parents*, and we managed to fill the museum with hugs, emotions and affection every Saturday.

Turning Museo ICO into a welcoming social space for the families who participated in *Empower Parents* was very important. We created a community where families and professionals like me

“In Madrid, we set ourselves the goal of making Museo ICO a place where families could share their experiences, and we certainly achieved that goal.”

Welcome/introduction segment during an *Empower Parents* session at Museo ICO
Joaquín Vaquero
Palacios. La belleza de lo descomunal. Asturias, 1954–1980 exhibition



related and bonded on a personal level, allowing us to share their everyday lives, their joys and their difficulties.

Welcoming the families in the museum foyer every Saturday was so moving. We were eager to know how they were and what had happened since the last session. We had a genuine connection, and that was made perfectly clear every time we got together.

Families didn't just go to the museum for the activities; they came to stay in touch with each other. Very strong bonds were formed, and the fact that we were able to see this happen in a museum setting is, for me, one of the greatest accomplishments of *Empower Parents*, because it mirrors the sense of community and feeling at home that we saw at Queen Museum.

Every month, the warm embraces and greetings between families and museum staff confirmed our tremendous capacity for empathy. Real, meaningful relationships were forged, and we watched the families grow and bring new siblings to the programme. The security staff ended up knowing all the families and calling each child by name, and you don't often see that in an educational programme.

The *Empower Parents* community has been a fact since the programme first began, and the empowerment of those families eventually led them to form a legally chartered association. I can't think of a more eloquent testament to the programme's success. *Empower Parents* has outgrown Museo ICO to become something bigger and better than anything we could have imagined at first.

The fact that the families set up the *Empower Parents* association is one of the programme's greatest achievements, and its by-laws are proof positive of their empowerment. It's a milestone. We accompanied them and provided the resources, but it was really the families who were empowered and became motivated to fight for their children's right to enjoy the arts.

At Museo ICO, we felt it was very important to offer an experience that made art more accessible to families who find it difficult to enjoy because they have children with autism.

I think that was one of the most interesting structural aspects: being able to experience a museum, making it more social, more open... at least while the programme lasted.

In that sense, it's also very important to understand the difference between the concept of community in the United States and how we tend to see it here in Spain. Over there, communities form quite naturally. You have a church community, a school community, etc. Here we form islands, little clusters around a very specific issue or problem. And the fact that we managed to create that kind of community, based on a demand for improved access to the arts, seems like a big deal to me, precisely because it's so hard to do in our culture.

“The fact that the families set up the *Empower Parents* association is one of the programme's greatest achievements, and its by-laws are proof positive of their empowerment.”

Another major achievement was generalising acquired knowledge. People with ASD have a hard time applying what they learn in one context to another, which is why I think it's so important that the families began visiting other museums after participating in *Empower Parents*.

That was one of the most thrilling things for me: hearing the families explain in the early years how they had applied the lessons learned at *Empower Parents* in order to visit an exhibition with their children or take them to see a film or play.

Another big accomplishment was avoiding the “therapeutic” label. We knew that we didn't want the programme to be an extension of the families' regular therapy sessions, but we also didn't want that to limit our educational work.

Exactly. In fact, that was one of the doubts we had the first year. We knew how the programme worked at Queens Museum, but *Empower Parents* at Museo ICO went in a completely different direction.

The different training backgrounds of the staff at the two museums, as well as the differences in social context, explain why the Madrid programme went its own way.

The orientation of the two teams was quite dissimilar. The people at Queens Museum had more therapeutic training, but the approach at Museo ICO was more educational and social, leading the programme to where it is today, with a focus on building community.

I think we made the right choice, because all the changes made in the course of the programme were adaptations to our unique reality. Knowing and learning about other realities is very important, but the smart thing is to take what you know and adapt it to suit your needs.

In our case that adaptation was more like a total makeover; we made the programme our own, and in the end it bore no resemblance to the original at Queens Museum or the one that received the American Alliance of Museums grant. And that's one of its greatest strengths.

Moreover, the gradual changes made to the programme each year were very appropriate. The materials and resources were designed to meet the needs that families had at that particular time.

And now for a bit of self-criticism... What would you say were the project's limitations?

I think the biggest frustration was not being able to get other cultural institutions more involved and pass the programme on to them. Our intention was for other museums to benefit from everything we'd learned with *Empower Parents* and adapt the methodology to their institution.

I still can't understand the response we've gotten so many times: “It's a lovely idea, but no...”. That's been the hardest wall to

“Another major achievement was generalising acquired knowledge. People with ASD have a hard time applying what they learn in one context to another.”

tear down. Of all the goals we didn't achieve, that one pains me the most.

We also weren't able to bring the contents to more families. The first year, we designed a website for sharing educational materials and resources with the families in the programme and others who might be interested, even if they weren't participating. I think we did a good job, but even so our communication strategy failed because we didn't make as much of an impact as we had hoped.

Do you think there were other reasons why the programme wasn't picked up by other cultural institutions?

I don't know, because some of the institutions we met with had a fairly healthy annual budget for educational programmes. Maybe they thought that, as an initiative coming from another institution, they wouldn't have the freedom to run it as they pleased, or perhaps it was just too soon. But later we have seen other museums begin to develop accessibility initiatives, like easy-read texts, etc.

Honestly, there were times when we felt rather lonely. The only one that clearly told us no was Museo Thyssen-Bornemisza, as their education team was already developing an in-house programme and they weren't interested in pursuing another. But as for the rest of the institutions we contacted, I still don't know why they didn't want to collaborate. We had the methodology, the materials, even funding to get them started... I really don't understand it.

On the other hand, we were able to collaborate with different institutions²¹ on developing a replication programme to test our methodology. I have very fond memories of the sessions at the Museo del Traje and Espacio Fundación Telefónica.

Yes, in that respect we've had very good partners. At all the institutions we went to, they put everything at our disposal: space, workshops, etc. However, the degree of cooperation varied, and I think it's important to highlight the involvement of the education team at Espacio Fundación Telefónica in Madrid, who helped to design every activity we held there, although I still can't understand why we weren't able to find new venues to implement the project outside the halls of Museo ICO.

If *Empower Parents* started up again, what would you do differently?

I don't know, honestly. Maybe work on a less demanding schedule. We'd finish one edition and jump right into the next. If the timeframes had been more relaxed, I think we could have spent more time working with social agents and organisations, and perhaps the programme's ripple effect would have reached a much larger community of families with children with ADS.

It would have been a positive thing to work more closely with agents like Autismo España and other confederations.

21. Museo Thyssen-Bornemisza, Museo de la Ciencia de Valladolid, Museo del Traje. CIPE, Espacio Fundación Telefónica, Medialab-Prado and La Fábrica de la Luz. Museo de la Energy de Ponferrada.

“I think the biggest frustration was not being able to get other cultural institutions more involved and pass the programme on to them. Our intention was for other museums to benefit from everything we'd learned with *Empower Parents* and adapt the methodology to their institution.”

How has *Empower Parents* transformed Museo ICO?

It gave us a huge boost in confidence to develop activities and initiatives related to inclusion and accessibility.

Before *Empower Parents*, we'd made some tentative attempts, but this programme also empowered us as museum professionals, giving us the courage to pursue these kinds of projects. It opened the door to partnerships like the one we've had since 2015 with Federación Plena Inclusión Madrid, with which we're implementing a programme of activities for persons with intellectual disabilities.

I think that's something we wouldn't have done without *Empower Parents*. We've also invested in accessibility by promoting easy-read contents, sign language, etc., but the most important thing was changing the perspective of the entire museum staff.

The launch of *Empower Parents* was a real watershed. I remember the panicked looks on the faces of security staff in the beginning. Now the entire team is more sensitive to accessibility in general and autism in particular.

The fact that the programme coexisted with other museumgoers was also very important. Museo ICO has a very loyal audience of people who show up for each new exhibition. As a result, families and visitors crossed paths on a regular basis. We've seen their reactions evolve from exclaiming “What ill-mannered children!” in the first sessions to taking an interest in what we were doing and asking about the programme and its aims. I think that sharing and explaining the programme in real time was an empowering experience for everyone working at the museum.

What are the challenges that Museo ICO still needs to overcome?

Extending accessibility to the entire museum. Overcoming the cognitive barrier is important but, in my opinion, we also need to eliminate surplus content, because it excludes many of the people who visit museums.

Accessibility should permeate the entire exhibition. We strive to make the physical space accessible, but we need to do the same with its contents. For instance, we think that the museum's signage is easy for everyone to understand, but that's not true; for some people it's unintelligible. And from the perspective of inclusiveness and accessibility, it doesn't make sense to post signs of the “please don't disturb others” variety, or to put up labels with lengthy paragraphs written in a way that only an erudite few can understand.

That should be the ultimate goal for all museums: cross-the-board accessibility, not just in special activities for a specific audience.

A museum isn't acting consistently if it makes efforts and adaptations in the framework of an inclusive programme, but outside that framework it goes back to being a hostile environment in terms of accessibility.



Gallery and workshop experience during an *Empower Parents* session at Museo ICO

Joaquín Vaquero Palacios. *La belleza de lo descomunal. Asturias, 1954–1980* exhibition

It's no use creating inclusive activities for a particular audience if later those people can't participate in the rest of the activities we offer. We've tried to make our activities inclusive, and it's very difficult, but... when they turn out right, they really turn out right! *(laughter)*

It's very important to adapt activities so that everyone can participate. If children with disabilities can be included in mainstream classrooms with support mechanisms, why do we have to compartmentalise everything and create separate activities for special audiences at a museum? We need to promote the real, effective inclusion of all audiences.

Fundación ICO has made a strong commitment to inclusion and accessibility, and we've seen that in the board's unconditional support for *Empower Parents*.

Fundación ICO backed a programme with a small quantitative impact. The board of Fundación ICO gave us their unwavering support and provided substantial funding each year,²² even when times were tough. This allowed us to enjoy the programme in the intimate setting of a small museum, as well as to research and readjust it.

What challenges does the future hold?

We want to keep consolidating and increasing Fundación ICO's commitment to accessibility: finding new ways to make visitors to Museo ICO feel comfortable, and promoting the idea of the museum as a place where people can come together.

③ **Ana Lozano. Coordinator of the Inclusive Culture Department at Plena Inclusión Madrid**

Ana Lozano is the coordinator of the Inclusive Culture Department at Plena Inclusión Madrid, a federation of organisations that represent persons with intellectual or developmental disabilities. She also coordinates *Más Cultura, Más Inclusión* [More Culture, More Inclusion] a project developed with Fundación Repsol and awarded the Queen Letizia Prize for Inclusive Culture in 2017.

Plena Inclusión has supported *Empower Parents* from day one, keeping federated organisations informed about the programme and its activities. In 2015, Fundación ICO and Plena Inclusión Madrid signed a collaboration agreement to offer a programme of accessible, inclusive educational activities for persons with intellectual or developmental disabilities.

At Plena Inclusión Madrid, you're doing important work in the field of inclusive culture. When did the culture department and the *Más Cultura, Más Inclusión* project appear?

The Culture Department of Plena Inclusión Madrid was created after a meeting of professionals from different federated entities

22. From 2014 to 2019 Fundación ICO was the programme's sole sponsor, giving an average of €31,000 per year to the *Empower Parents* programme.

“It's no use creating inclusive activities for a particular audience if later those people can't participate in the rest of the activities we offer.”

in 2011, when it became apparent that there were certain organisations focused solely on the arts. In other words, they were not standard social services but spaces of cultural creativity for people with intellectual or developmental disabilities, such as Fundación Psicoballet Maite León, Debajo del Sombrero, Argadini or Afanias.

Various organisations advocated that some people with intellectual or developmental disabilities are also artists and felt that arts programmes should be given more attention.

At that time, the community art practices of the English-speaking world were just starting to enter our country, and in Spain there were already some initiatives that revealed culture's potential as an instrument of social change and personal growth. It was in this context that the *Más Cultura, Más Inclusión* programme appeared.

How would you define the *Más Cultura, Más Inclusión* programme?

It's a joint initiative of Plena Inclusión Madrid and Fundación Repsol that views culture as a vehicle of social transformation. Based on that understanding, we try to provide access to culture for persons with intellectual disabilities, whether as spectators, artists or workers, and develop standards of quality for cultural activities.

So at *Más Cultura, Más Inclusión*, you see culture as a fundamental element for personal growth and social inclusion. How did museums and cultural institutions respond to your proposals?

The first step was to prepare a document to publicly introduce ourselves to institutions in the culture industry, federated organisations, families and persons with intellectual disabilities.

We believed that the public sector would be more receptive to the idea of improving accessibility, so we established partnerships with Museo ICO and other state-owned museums, building a collaborative network to produce adapted materials and make museums more accessible.

We teamed up with Compañía de Danza, the Ballet Nacional and the Centro Dramático Nacional on joint projects like the celebration of International Dance Day for several years, and with CDN, a cultural volunteer work programme associated with the festival Una Mirada Diferente, which aims to make dance and the performing arts more accessible to persons with intellectual disabilities.

Through these partnerships, we introduced other federated entities that didn't have a specific art or culture department to new ways of working with culture.

For museums and cultural institutions, the traditional idea of inclusion means a single space where everyone fits in. But the

fact is that people with functional diversity often need special resources to access culture, and those resources are rarely available.

That's true. People with intellectual disabilities often find it hard to gain access to culture without some form of mediation, without adequate and accessible approaches and communications. There aren't many programmes prepared to meet those needs. They don't really consider us a potential audience.

There are interesting initiatives, like *Empower Parents*, and few more at other museums, but it's not the norm. One of the most important tasks of *Más Cultura, Más Inclusión* has been to publicise all the proposals we received from cultural institutions to encourage people to participate in and enjoy cultural activities.

Over the years, *Empower Parents* has become a forum for reflecting on how to make culture accessible to people with ADS and their families, working with participating families to form cultural habits. What are some of the things you consider at *Más Cultura, Más Inclusión*?

We believe that creating cultural habits is essential for people with intellectual and developmental disabilities, and we've been working in that direction since the beginning of the programme. In our view, this is something that needs to come from the public sector. Cultural institutions do it by compartmentalising audiences or creating educational programmes, but in the case of persons with intellectual or developmental disabilities, there's not a habit because it often isn't deemed a priority, and also because culture has long been seen as rather elitist or hard to understand.

We still have a long way to go, because creating cultural habits, in my opinion, is vital to broadening interests and increasing future opportunities for persons with intellectual disabilities. And this is especially true if we begin with children, because that opens up the possibility that they will end up working in a culture-related field in the future.

The collaboration with Museo ICO has always been very successful. The demand for those activities was always far greater than what we could offer. We'd experienced that before, at other times and with other museums and institutions. Those collaborations are very important to us, and maintaining them is essential because there's still so much left to do.

The educational practices of museums and art centres are creating new institutional models: more open, diverse and experimental. How do you see this paradigm shift? Do you think this transformation has triggered significant changes in cultural accessibility?

When culture industry professionals decide that they want to reach all audiences, they have to consider whether this is even possible in the initial phase: I think some measures or decisions take time to mature,

“People with intellectual disabilities often find it hard to gain access to culture without some form of mediation, without adequate and accessible approaches and communications.”

Workshop activity during an *Empower Parents* session at Museo ICO



and in the case of people with intellectual or developmental disabilities, I think it's important to design projects that specifically target younger groups or projects like *Empower Parents* that work with families. I feel that's very important because it addresses both fronts.

I think museums and other cultural institutions need to make an effort to train their staff and make them aware of the many different audiences they may encounter, so that the institution is prepared to welcome them. Visiting a museum should be a gratifying experience: we need to feel safe, know how to navigate the space, and then enjoy it. The learning comes later.

Accessibility departments are still ghettos at many institutions; accessibility needs to be a cross-cutting philosophy that permeates every area of the museum.

It's a slow process. I agree with you that bigger steps need to be taken. Museums are taking measures like creating accessible floor plans, easy-read gallery leaflets, adapted tours, etc. But they need to consider accessibility in a broader sense, build it into every new project they create and place it at the very core of the museum. Accessibility should be a standard of quality for every museum department and be factored in from the moment they begin designing each new exhibition.

Tying in everything we've discussed with *Empower Parents*, what would you say are the project's highlights?

The fact that it addresses a fundamental need: giving families with one or more members with disability the confidence and the tools they need to visit museums and art centres on their own, and providing support and training for professionals who work at institutions and haven't received diversity training. It's a very relevant project, not only for people with ADS but also for a large part of our society, which is incredibly diverse.

At times we've been criticised for working specifically with people with ADS. Our resources are limited, and we decided to focus on ADS because autism isn't always easy to detect, making this collective less visible.

Honestly, I think that kind of criticism has more to do with an ignorance of the real world of people with intellectual or developmental disabilities. In my opinion, *Empower Parents* meets a need of people with ADS and their families.

We need to help with specific support mechanisms and tools. Families have to lose their fear, own their right to enjoy culture just like everyone else, and demand that government institutions defend that right. This project is doing extremely important work.

Over the years, the project has received high praise from the culture industry, although we would have liked to receive more

“We believe that creating cultural habits is essential for people with intellectual and developmental disabilities, and we've been working in that direction since the beginning of the programme.”

collaboration or support from more museums and cultural institutions. What do you think is the next step?

It's an absolutely necessary project. It's been running for six years, and now other cultural institutions need to take the step you've taken with *Empower Parents*: make the museum accessible enough so that, if a person with intellectual disability wants to visit it alone, s/he can. Guided or group tours shouldn't be limited to a basic “one size fits all” format.

In order for that to happen, state-owned cultural institutions would have to step up and make a real commitment to accessibility.

Cultural institutions should implement a series of measures to ensure that anyone who goes to a museum or art centre and has a special need can understand all the information they're given, navigate the museum on their own, etc. They should guarantee the accessibility of tours and find ways to communicate and evaluate them. They should have a free support mediator on staff, something we want to see in every cultural venue, and a specific diversity mediator. Every public museum and cultural institution should have one or more professionals specialised in relating to diverse audiences. But right now that's not the case.

Having a specialised art and diversity mediator seems fundamental to us. When we launched *Empower Parents* at Museo ICO, we realised that we had to train everyone on staff at the museum, from mediators to security guards. We felt that they should all receive diversity awareness training because they interact with visitors.

Every museum and cultural institution should have that kind of expert mediator. How can anyone expect people with ADS or intellectual disabilities, who express their emotions differently at a concert due to lack of cultural habit, the absence of language skills, etc., to stay seated and silent for an hour in a music hall or theatre?

I think that, in many cases, the problem is that other audience members or museumgoers aren't well-informed. Many people have little or no idea of what diversity is, often assuming that there's only one right way to feel, express and appreciate culture or art.

Perhaps we need to rethink the established routines or patterns of behaviour in museums, theatres, concert halls, etc.

In the days of Shakespeare, Calderón and Lope de Vega, people went to the theatre with packed lunches and constantly commented on what was happening on stage.

Our latest experience at *Más Cultura, Más Inclusion*, in the world of music, was the “Big Bang” project which involved people with ADS: an artistic project that uses music as a language of expression. This experience proved that it's impossible for us to

“I think museums and other cultural institutions need to make an effort to train their staff and make them aware of the many different audiences they may encounter, so that the institution is prepared to welcome them.”

attend a concert. And that shortcoming is an opportunity for cultural institutions to launch innovative projects.

It's very important for us to be able to work in the museum galleries so that we can be visible, discuss access to art with the families, and practice certain cultural and social habits with the children. I think educating, raising awareness and debunking obsolete codes also contribute to greater accessibility.

People with intellectual or developmental disabilities should visit cultural venues from a very young age so that they can learn cultural and social habits. After all, those habits are what make us act a certain way in concert halls, museums and theatres. Habits that probably become ingrained if we practice them from early childhood. How can you acquire or even understand a series of codes if you haven't been exposed to them before?

As you've said in the course of our conversation, much work remains to be done. What goals should museums and cultural institutions achieve in the medium term?

I think some museums are rather skittish or afraid of incorporating accessibility and being criticised by part of their audience—those who visit museums on a regular basis and do so independently. I think the general public wouldn't object and would be fine with having more accessible texts and making everything simpler, to put it one way. There's still a great deal to be done in this respect. Find resources so that the museum can place accessibility at its core, envisioning a museum for everyone rather than just a few.

Part of that challenge is not doing this alone; museums should do it openly, with multidisciplinary teams who share their experiences with other teams. Thanks to this project, you've had a great experience that needs to be shared with other centres.

It's essential to create spaces where these issues can be discussed and considered.

Institutions have to create spaces for sharing experiences and needs, spaces for collectively seeking and finding possible solutions to create institutions for everyone.

It's very important to form working groups with a degree of stability and continuity in order to move forward and effectively construct a culture of accessibility from within. There are enough experiences and methodologies here, including yours, to work with people with intellectual or developmental disabilities, disability professionals, artists, communicators, etc. I think it would also be a challenge for how we work here in Spain.

Your decision to produce this publication is very important. I think it's quite necessary, because in the world of the arts, the world of culture, cultural mediation, sometimes there's a lack of written resources for sharing these kinds of collaborative practices.

“Institutions have to create spaces for sharing experiences and needs, spaces for collectively seeking and finding possible solutions to create institutions for everyone.”

Publishing them is also important because that way they can be replicated and build a learning community.

Finally, what would you tell the culture industry?

To count us in. It's important for institutions to rely on our professionals and on people with disabilities, who have a voice today, to advise them on matters of accessibility and inclusion.

Artists

1 Lucía Loren. Artist

Lucía's artistic practice explores how human beings interact and engage with the environment and the landscape. This bond has inspired her to stage interventions in different natural settings, using elements of nature to make minor variations that reflect on the very concept of cultural landscape.

In 2019 she collaborated with *Empower Parents* after having worked with people with diverse abilities on several prior occasions. One of those past experiences was a three-year collaboration with Federación Plena Inclusión Madrid on the *Arte en el Territorio* [Art in the Territory] project, which brought collective art creation projects for persons with cognitive functional diversity to different rural areas in the Sierra de Madrid.

Her line of work, based on tailoring educational proposals to personal abilities, is clearly aligned with the spirit of *Empower Parents*.

What inspired you to get involved with *Empower Parents*?

Working with persons with autism seemed like a challenge, and I was very eager to expand my work with people with different capabilities. I believe that creative projects based on the use of natural materials have tremendous benefits for everyone. Participating in this project was a way of reaffirming everything I had experienced with other groups.

What exactly did you do?

Between November 2018 and May 2019, I led nine workshops at Museo ICO for families who have children with autism. The workshops²³ were part of a project called *Espacio habitado* [Inhabited Space], which aimed to facilitate a collective creative process that would generate a new symbolic space, exploring the relationships that visitors establish inside the museum. Sensory properties and the use of materials from nature were key in these workshops, allowing each individual to explore different ways of perceiving the space.

In *Espacio habitado*, I brought everything I'd gleaned from the experiences I usually conduct outdoors, in the landscape and territory, into the museum. I wanted to convey an understanding of space through the use of natural materials like clay or wicker. In this way, we transferred the sensory properties of nature to the museum, things like sounds, smells or temperature sensations.

How did you plan that collective creative process, bearing in mind that nature is your habitual setting and that, on this occasion, it would take place inside Museo ICO?

For me, it was challenging to activate internal listening processes with the properties conveyed by natural materials. This is one of

23. Lucía offered two workshops ("Exploring with the Senses" and "Skin, Shell and Territory"), divided into 4 and 5 sessions respectively, during the months of November 2018 to May 2019.



Pieces created during the *Espacio habitado* workshop with artist Lucía Loren at Museo ICO

the basic tools I use for working in nature. First of all, we have to listen to ourselves, because we are also landscapes. And by learning to listen to ourselves, we can become more sensitive to the outside world, and then begin to listen collectively. Therefore, it was essential to use only natural materials, and that's why I insisted on it: nature helps us to bond on a sensitive level and connect with emotions and begin a much more honest listening process.

This process has its complexity: I remember that you would let the wicker soak in the river for several days so that it retained the scent of water and could be sensed in the workshops.

The truth is that it wasn't easy to introduce and prepare all those materials, because I had to bring the smell of earth, of river water, of flowers (which I collected on the morning of the day before so their scent was still potent) into the museum. But it was important, because those smells are so powerful that they can give us a very intimate connection with nature. We should never forget that nature is a part of life itself: even if we're in the city, we still live in the natural world, and I felt it was very important to draw attention to those listening processes. It was fundamental to me, and I think the people who participated in the workshops felt the same way.

How do you think the museum setting influenced the progress of the workshops and the families?

I felt like the space was a huge limiting factor, even though, for many families, Museo ICO had become a safe haven they could escape to when their children were feeling nervous. What we were lacking, in spatial terms, was the expansive capacity that only nature gives you, and that richness and diversity of places.

For you, it was very important to link your landscape-centred artistic practice with the creative process of *Espacio habitado*. How did you transfer that approach to the *Empower Parents* workshop?

In the workshop, the first thing I did was present the materials, giving participants time to explore and observe the materials on their own, with total freedom and intimacy: the aim was to let them imagine, but also to offer more opportunities for them to experience wonder or reject things they didn't like.

The creative proposal wasn't set in stone; everyone was free to choose their materials and find their own creativity. The fact that I brought lots of materials to the workshop and presented them in an orderly, structured manner paradoxically made it possible to use them in very unstructured, free, intuitive way.

I think the activity depends not only on what material you use, but also on how you introduce those listening processes: how we, before listening to something external (a piece of wicker that smells like water, like a river, and perhaps even has a little worm inside), take time to listen to ourselves, to figure out if we want and are prepared to

“I felt like the space was a huge limiting factor, even though, for many families, Museo ICO had become a safe haven they could escape to when their children were feeling nervous.”

explore with that material. I think the individual processes gradually linked up and merged to produce very open creative proposals that people were able to experience in many different ways.

What challenges did you encounter during the creative process with the *Empower Parents* group?

An obvious challenge was working out how to facilitate creative processes for that little tribe or community of *Empower Parents* families while also considering the specific needs of each family unit.

In certain situations it was important to reach agreements, communicate, understand the different creative proposals, etc. It was a big challenge for them and for me, considering the group's communication abilities and the fact that any collective creative activity, regardless of who is involved, can run into complications that force you to relinquish your own way of doing things, accept other people's decisions and understand the process as a group effort.

Did you learn from that challenge?

Orchestrating this collective process was very enriching; it was the most profound lesson I learned from this experience. The creative experience, on an individual level, is very different for every human being. You could say it's unique, no matter what kind of group you're working with. Therefore, the most complicated task was incorporating different proposals in one collective experience, finding a way for each person to contribute his/her knowledge and participate in the various listening processes.

It was very enriching and intense for me to be present without actually intervening, although I was facilitating all those communication processes among the different members of the group. Showing how we can step out of our roles, accompanying the listening processes of everyone in the group so that they had a chance to speak and contribute something to the creation. And knowing how to accept it if someone didn't want to create, letting him or her opt out at that time and simply watch. Learning how to handle all that was very intense.

You say this was one of your most intense learning experiences. What do you think made it different from earlier working processes?

On this occasion, I didn't have the tools to handle certain situations, which is why it was a challenging listening process for me; I had to pay close attention in order to assess situations that perhaps would be easier to interpret with direct verbal or emotional communication.

The learning curve was incredibly steep, because often I didn't understand the codes the families used to communicate with each other. It's been a tremendous learning experience.

Your role throughout the process was related to mediation, trying to facilitate a collective activity, but do you think there was a time when you took the role of artist in relation to the creative process?

“An obvious challenge was working out how to facilitate creative processes for that little tribe or community of *Empower Parents* families while also considering the specific needs of each family unit.”

My role was primarily that of a mediator, trying not to intervene during the creative process. I'd already done my bit as an artist by designing the workshops, where there were certain guidelines so that any proposal which might emerge could be coordinated with the actions of other groups.

That's why I think workshop design is very important in order to maintain an aesthetic direction. I try not to intervene in the creative process; occasionally I might answer questions or give an opinion, but never condition or direct the art projects, whether on an individual level or when working collectively.

Lack of balance is always a risk in collaborative practices. That's why it's important to review our role in the process, be self-critical and understand that we need to facilitate communication and collective decision-making. In this sense, I think it's interesting how you differentiate between your roles: you're an artist in the preliminary phase, curating the process, and once it's prepared, you relate to the group as a mediator whose job is to make the collective process run smoothly. Over the years, I've seen how artistic creative processes were liberating for many of the kids in *Empower Parents*. They were able to express themselves through the materials, regardless of their communicative abilities. Based on your own experience, would you agree?

The thing that struck me the most was how the kids with ADS were able to experience the process and experiment so freely, without eliciting an immediate or learned response. That ability to experiment in utter freedom and associate it with other senses is fascinating. I'm so glad that the families saw and appreciated that, too.

For example, I thought it was wonderful how, after I showed the children different seeds I'd brought from the country to generate working tools, they decided to pop them in their mouths (they were all edible, I made sure of that beforehand) and later spit them out and created things with them. I loved that the families experienced it as part of a process of free, suggestive experimentation.

Being inside the creative process, I've observed that the result is less interesting than the actual experience of those moments of connection, those powerful states of flux with the material itself, which I also experience in my everyday activity as an artist. In many cases I don't even finish those works; I'm far more interested in that highly personal process of learning and listening with the material. I found it fascinating how people with ADS internalise the creative process as an intimate, personal adventure.



Pieces created during the *Espacio habitado* workshop with artist Lucía Loren at Museo ICO

② Irene Cantero. Choreographer, dancer and lighting designer

Irene's working materials are the body and light. She pursues her own artistic endeavours, gives workshops and collaborates with companies, independent artists and cultural institutions. In her creative practice, she explores dance from the perspective of cross-disciplinarity and resistance.

There is no clear-cut division between the interior and its environs. Irene does not seek a pre-established formalisation. She touches on publishing, her own body, a bird's body, light or a walk with her dog Tristana.

You have experience working in context and with different groups. Had you worked with people with ASD before *Empower Parents*?

Not specifically, though I have worked with diverse communities. But I was thrilled at the opportunity and didn't hesitate, because I like working on projects where the way of doing things is completely different from what I've done before. For example, some time ago I did a project at a school in Rabat, and that experience was completely unlike anything I'd had before: when you put yourself in a different context, you encounter other working conditions and other rules. In that sense, I associate that experience with *Empower Parents*.

You give dance workshops for people with experience and for those who have no previous training. Which do you find more appealing?

Working with trained or professional dancers lets you have a very interesting dialogue, but personally I'm more attracted to the idea of working with people who've never had any training.

Dance classes can be a tad elitist. They're less so since public conservatories became an option, as now there's an excellent network accessible to everyone, but that elitism is still there, because the fact remains that children who take dance lessons tend to come from upper-middle class families.

What do you find interesting about working with dance?

Dance education has been trying to hybridise and broaden its horizons for a long time, but because training is based on classical ballet and technique, it creates profiles that, if you don't deviate from the norm, require people with very specific qualities. So when you work with people from other backgrounds, you find yourself dealing with bodies that are much freer, not restrained by that coding or those rules. That lets you work from any starting point, and I like to work with the body through movement, expression, the body as presence in a place which, in this case, is related to the work we did at *Empower Parents*.



Session segment with the artist Irene Cantero at Museo ICO

“People with autism have their own, more developed way of expressing themselves, one that perhaps doesn't follow the codes we're used to.”

I think it's very interesting that we talk about presence, because the “codes” of cultural institutions, museums, etc., condition how we inhabit spaces. And this in turn determines who the quintessential inhabitants of those places will be, just as dance requires a specific type of body with certain characteristics based on its canons.

That's right, we need to rethink all that. The curious thing is that, in our context, dance is one of the forgotten disciplines of the culture industry. Plus, dance training is deeply entrenched in classical canons. You have to do certain things with your body; it's all about measurements, and a lot of bodies don't fit that mould.

Was that quest for variety part of your motivation for working with *Empower Parents*?

I'm very interested in making dance available to other collectives, just as I want to see dance, as a discipline, be enriched by working with people who've had little contact with it before.

The case of *Empower Parents* was also a challenge and I was very curious. I thought, “Let's see what will happen with these bodies!” (laughter)

When I give workshops, my aim is to share the types of expressions that a body can contain, and in this case, with these kids, I realised that their bodies could contain everything and more.

“Contain everything and more” ... What a lovely way to put it! So what happened with those bodies?

Before talking to you, I reread the proposal we wrote for the workshops. We said that we wanted to “get in touch with the movement of our own bodies, explore expressive possibilities...”.

You write a proposal about the work you're going to do, but later it changes a lot depending on what you find and actually end up doing. The thing is, when I talk about exploring expressive possibilities, I mean that working with adults is nothing like working with children or, in this particular case, people with autism. It's like starting from a whole new place. The point of departure is different.

In what sense did you have to start from another place?

People with autism have their own, more developed way of expressing themselves, one that perhaps doesn't follow the codes we're used to. In the workshops, I saw a big difference in working with the group of brothers and sisters, for example, when giving an instruction and having them follow it or learn a movement by imitation, something that's used a lot in dance.

In that sense, children with autism were much freer.

You say that they had a more developed way of expressing themselves. Do you mean that they don't have the same kind of inhibitions as adults or children with typical development?

Yes, when working with them I felt that they used their bodies a lot. In general, I think we're all quite inhibited. From a very young age, we're taught to sit still for eight hours a day, and as you grow into adulthood that defines how you exist in your body and how you perceive the limits of what you can and can't do.

There are many very specific limitations and codes that the body learns gradually over time.

We also wanted to reflect on all these learned limitations inside a museum, a place where what you can and can't do is very clearly defined.

When you work with adults, you're very steeped in those codes; anything you propose seems outlandish to them. Oh my God, this is wild, rolling about on a museum floor! *(laughter)*

For me, perhaps, it's not that big a deal because I'm trained to push those boundaries, and for these kids it wasn't a big deal either, because they don't conform to the codes established by so-and-so, the institution or society in general ... and I was delighted.

What was the working proposal and what were your expectations of the group?

Well, as far as the institution went, the idea was a bit "punk".

Dancing in museums has become a kind of fashion or fad, but it's controversial. Lately there's been a lot of dance in museums. And it's an ongoing debate in the dance world. Some people are thrilled about it, but other, more critical people like myself aren't so keen. What is dance doing in a museum, or what are bodies in motion doing in a museum?

The work I did wasn't a performance, but even so I took that criticism into the workshops. On this occasion I wanted to reflect on how the museum-context relates to the children and, within that dialogue, push past the boundaries. We do the same thing in dance: we try to push past the boundaries of the body, as if skin were something permeable and we could suddenly turn into gaseous entities.

I wanted to find that delicate balance between what you can and can't do in a museum with the families. I really like that idea. Returning to codes, each child has his/her own limits regarding what can or can't be done. In my case, my instinct tells me that nothing is off limits. In that sense, the workshop can spin out of control, and that's what really interested me... But even so, it came close to getting too out of hand! *(laughter)*

What was the experience in the museum galleries like?

On this occasion, I had to take a more individualised approach. When I've worked with groups in the past, I've set guidelines that worked for everyone, but in this case I had to come up with a more personalised style of communication because it varied depending on each child and his/her needs, on whether or not they spoke, whether they wanted to stay with their families or be more independent, etc.



New ways of inhabiting space with the artist Irene Cantero at Museo ICO

“In the workshop we explored our boundaries, and so did the rest of the visitors, because from the outside they were probably judging if what we were doing was appropriate or not, etc. In such situations, ethics enters into the dialogue.”

A very interesting three-way dialogue emerged among the museum staff, who had a more rigid sense of what is and isn't allowed, me on the opposite end of the spectrum, and the families in the middle, accepting the proposal.

My role was that of facilitator, but I thought it was quite funny because I really wanted to make mischief with the rest of the kids. I don't mean to say that we did anything really outlandish or aimed at tearing up the museum. I'm talking about standing on benches or rolling about on the floor...

We who were in the workshop explored our boundaries, and so did the rest of the visitors, because from the outside they were probably judging if what we were doing was appropriate or not, etc. In such situations, ethics enters into the dialogue.

How did the gallery staff and other visitors react?

They didn't say anything, but we saw looks that expressed puzzlement and even distance, as if they were thinking, "I'm going to steer clear of that group, or they might make me roll about, too." *(laughter)*

The same thing happens when you dance. I always like doing things off-stage in order to work closely with the audience, and usually there's a kind of ripple effect that makes people move back as you approach them.

As for the museum's gallery staff, there wasn't much interaction. I completely understand that they're just doing their job, but they're more rigid, with no room for negotiation.

Every aspect of the workshop was designed with the utmost care and respect. I'm an artist myself, and I knew perfectly well that we wouldn't break anything. But a little bit of dialogue would have been nice.

Do you think that lack of dialogue limited your work and/or the group?

Yes, of course, it's something that's in the air, because there are lots of things we couldn't do, to be honest. Obviously, we could do more on a basketball court or a gymnasium floor covered with mats, but there wouldn't be much point in that. The interesting thing is working with that limitation and asking a series of questions: What can and can't be done? Who can do it and why? And who can't do it?

We felt it was very important to reveal the necessity of this dialogue, as it has to do with the need to rethink the institution and how spaces are inhabited, their codes or ways of being, etc.

Going back to the topic of dance in museums, if I come as an artist to give a performance, I'm allowed to do certain things you usually can't do if you come as a visitor.

What challenges did you face and what constraints did you encounter?

In my case, I always use improvisation as a very personal tool. I tend to leave workshop scripts wide open and change things as the workshop progresses, but here it wasn't possible because every detail had to be defined in advance so the families could prepare for it with their children, and so the kids would know what we were going to do at each moment.

That, for me, was a difficulty I had to learn how to manage. Knowing that I had to trust that structure and see how rhythm, attention and interest balanced out, making it fun, adding an element of searching or inquiry... I found it all quite hard, to tell the truth.

One of the challenges was maintaining balance so that things wouldn't get out of hand with the group. A little bit out of hand, but not too much. *(laughter)*

The families were very helpful in that aspect. If they hadn't been there, we might have broken the museum. *(laughter)*.

The families also played a very important role by identifying their children's needs: telling me when they were getting nervous and needed to leave the museum, etc. That was also important, because without them those needs might have gone undetected.

The challenge was balancing multiple factors at once.

Exactly! And my role was to facilitate the workshop and be attentive to those tensions or balances. The families looked to me as a figure of authority or responsibility, but that's not important to me and I don't mind not being in charge. However, I understand that, for the families, it was important to have that point of reference.

It's interesting you mention that, because people with ASD do need a figure of reference, a very clear and defined structure and routine. We who work in education try to overcome those limits and blur the boundaries between roles, but in this case that figure is essential because it gives them a sense of security.

That's why I think it was great that we had different types of people involved in the workshop: someone like Elena,²⁴ for instance, who knows exactly how the programme works and was able to explain the structure and be the liaison between someone coming from outside the museum and those who are part of it, like the security guards. I think that figure is essential, so that if you invite an artist from outside the museum, you can have a bit of chaos within the order.

In this case, the group really enjoyed that bit of chaos and the invitation to provocation. *(laughter)*

I think so. The families were very happy. The truth is that they all appreciated each of the actions we initiated in the workshops.

We have to see it from the families' perspective. For them, these small actions are major breakthroughs that become very meaningful because, after all, everything is happening in a place that's usually off-limits to them.

24. Elena Pavón has been a member of the education team at *hablarenarte* since 2012 and has worked with the *Empower Parents* programme since 2017.

“If I have to introduce myself, I wouldn't know where to begin, because I think I've become primarily the mother of a child with autism.”

We who want to inhabit spaces in a different way gain a lot from initiatives like this, but at the same time there's a strong component of activism, as you say, from the moment dialogue is initiated with other museum visitors and the people who run these institutions see that dialogue. Initiatives like this are a positive experience, not just for those participating in the workshop but for everyone involved.

Families

① **Gemma Domínguez. She and her family have been a part of Empower Parents since 2013**

“If I have to introduce myself, I wouldn't know where to begin, because I think I've become primarily the mother of a child with autism.”

Gemma's son is named Teo. When he was five years old, they joined the first group of families to participate in *Empower Parents* at Museo ICO. Teo is now twelve, but they both remain actively involved in the community of families and participate in the activities programme.

Teo has a severe form of autism that significantly affects comprehensive and expressive language skills: he only uses phrases and monosyllables to communicate with his family. His range of interests is very narrow, and only a few things appeal to him. What he likes best is to manipulate objects, and he tends to be obsessed with audiovisual activities like playing on the iPad or watching television, which have to be curtailed. It's very hard to get him interested in any non-audiovisual activity, and this has always worried Gemma because she doesn't want her son to be glued to a screen all day long, especially when that screen time is non-functional: watching the same video eighty times (literally) or the same film all day.

At age five, he was very hyperactive and unable to remain seated in a chair for more than fifty seconds: he was a bundle of pure energy. Now, at age twelve, he can last somewhat longer, but he is still a very restless child.

How did you hear about the project and why did you decide to join?

We heard about it through an association of parents in southern Madrid that we work with, and when I learned of the project, I knew I wanted to be a part of it.

Teo was diagnosed with autism when he was two years old. The first thing that came to my mind was the risk of rejection, and I knew that I wanted my son to be included in every possible social context. That's when the “fight” began.

The first context in which I had to fight was school, and later in recreational and cultural settings, as we had problems gaining access to the neighbourhood sports complex or the play centre. So

when I heard of the project, I thought it was important to be able to participate as a family and “fight” alongside other families to change the cultural context, which for us is particularly important. I wanted to make it so that my son could visit a museum and enjoy himself there. I initially thought it would be impossible, but I wanted to try.

Before *Empower Parents*, had you had any experiences with Teo in a museum?

We’d gone to Museo Reina Sofia and Museo Thyssen-Bornemisza on occasion, but the visits never lasted more than fifteen minutes.

Teo is highly visual and sensory and really enjoys everything that has to do with art. I felt it was essential to be part of this experience that aimed to make museums more open. That was what interested and surprised me, because there were no other projects like that, and for a group of professionals to understand that culture is a right and needs to be accessible to everyone, even my son—and I say even, because some people think my son doesn’t have the right to a lot of things, like access to certain cultural venues—and that he could do that and enjoy it is so important to me.

The only way we learn how to be in a space is by entering it. If we exclude people with functional diversity from cultural institutions, we’re denying them the chance to enjoy culture, to be part of its narratives, and also to learn certain social and cultural habits, even though many of our codes of conduct or “ways of being” in a museum need to be revised.

Teo liked going, but we also realised that other visitors didn’t accept a child like Teo, even though all he did was talk loudly and emit little shrieks from time to time. Now I can handle Teo just fine in a museum or a library. But years ago, what scared me the most were other people, more than the stress caused by certain situations with my son.

How hurtful is that lack of understanding?

You never get used to it, never. Even after all these years, those looks are still deeply hurtful. Feeling like you’re being watched, criticised, judged. Sometimes those looks are even accompanied by very harsh words that are deeply wounding.

To the extent that you stop doing things with your son?

Yes, those looks are very limiting.

Some people who read this interview may not understand how the lack of understanding affects your life and that of many other families. Some may think that this is no longer an issue, but unfortunately the feeling of rejection in different contexts, including the cultural context, is something all the *Empower Parents* families have in common.

“But years ago, what scared me the most were other people, more than the stress caused by certain situations with my son.”

“We’re limited by the inflexibility. In general, those spaces aren’t designed with children in mind, especially not children who see the world differently.”

It is still an issue, and it doesn’t just happen in cultural venues; you encounter it in many other settings, limiting your everyday life. Sometimes I want to think that it doesn’t bother me, but that’s not true. Those looks of judgement and blame still hurt, so much so that there are some places I simply don’t go because it’s too stressful. Sometimes you go home, and those people will never know the terrible effect their attitudes have on me and my son, because Teo senses an antagonism towards him and doesn’t understand what he did wrong.

In the specific context of culture, aside from the limitation of other visitors’ lack of understanding, what other barriers do you encounter when you want to visit a museum or cultural institution? How does the setting limit you?

We’re limited by the inflexibility. In general, those spaces aren’t designed with children in mind, especially not children who see the world differently. The very fact that there’s an itinerary you have to follow in order to see an exhibition, a route you can’t deviate from, is restrictive. The prescribed way of being in a museum is very limiting.

I think many of these limitations could easily be modified, for instance by using pictograms on signage, creating more flexible itineraries, etc.

I remember one show at Museo Thyssen where the itinerary to view the works was fenced off. Not being able to get out of there was horrible. You couldn’t enjoy it, because we don’t all see things from the same perspective, particularly a child with autism: you never know from what angle or what distance he’s seeing something.

The project enabled us to share experiences with professionals and families in New York, and to discover different museums and cultural venues. You were one of the families who went on the first trip. What were the highlights of that experience?

I haven’t visited all the museums in Spain, but what mainly struck me was the flexibility I sensed at the museums we visited in New York, specifically at Queens Museum, which had developed a methodology that let families truly enjoy a visit to the museum with their children. As the mother of a child with autism, something as simple as visiting a museum can be a nightmare, but it can also be wonderful if the museum is adapted to your needs and the families have access to a methodology like that of *Empower Parents*.

The methodology is simple: it’s all about finding out what the child or his/her family needs and providing it.

When we began the project, we felt it was essential to create a sense of community, forging ties and bonds among the Spanish families so you could later connect with the families in New York. What did you, personally, take away from this experience?

The greatest experience was being able to be a part of the *Empower Parents* community. In Madrid we’re a family, we’re a community,



without a doubt. We divide into working groups and, depending on each group's needs, plan different activities. We're a real community united by very intimate and powerful bonds.

In the working groups, made up of fathers and mothers, we organise visits to other museums and cultural institutions like Espacio Fundación Telefónica, CaixaForum Madrid, Museo del Ferrocarril, etc. We parents are the ones who make the arrangements with the institutions and design the activities.

Some of the families from the first year, including us, are still in touch with the New York families. It's really a community where we support each other, share resources, talk about our kids and give each other advice. I find it very reassuring to know that there are families who, even though they're far away, understand what's going on with my son because they're experiencing the same thing. It's reassuring because you don't feel so excluded and different. It proves that there are others like you, many others who have people with autism in their families.

We made the same connection with families from other Spanish cities that we met at the replications we've done. Four years ago, we went to Museo de la Energía de Ponferrada and there we met and worked with a group of fabulous people. I'm still very close to one of those families.

The sense of belonging is very important, being able to share experiences and forge ties gives you the strength to face everyday challenges.

For me, the most important thing was being part of a larger community, a community without borders, in which we share what's going on with our children and continue to support each other, even after all these years.

To outsiders it may look like we're just three or four families, but there's a lot of us and we've forged amazing bonds. There's a personal life and a family life.

Could you have imagined this seven years ago?

No, and it moves me to tears.

What were your initial hopes or expectations?

This was what I hoped for, but I didn't think it was possible. Another thing I hoped to achieve was feeling comfortable visiting a museum with my son and having him enjoy the experience and make it part of his regular routine. Being able to go to a museum at least once every two weeks or once a month. And that expectation was fulfilled.

I remember the last time a bunch of us, seven or eight families, met up to take our children to CaixaForum Madrid. We had all worked together to organise and prepare the visit. We had a great time, but the best thing is that my son enjoyed himself immensely.

“The greatest experience was being able to be a part of the *Empower Parents* community.”

For some families, a highlight of this project is that it gave them tools and a methodology for being able to visit other museums and cultural institutions with their children. Is this important for you, or would you say that the personal learning experience was more meaningful?

Undoubtedly, I benefited a lot more on a personal level. The project gave me more freedom and confidence. Years ago, going to a museum with my son was unthinkable. If we weren't welcome in other settings, just imagine a museum. Now I feel very confident; I can go with him and manage to keep him calm and have him enjoy the experience.

In Teo's case, the biggest benefit was the learning experience, because he didn't know those places existed and that he could enjoy them.

Every family had a role to play in *Empower Parents*. What do you think your role was?

My role was to be a part of the team and work with the other families and professionals to make sure the activities worked for all the kids. But the role I've enjoyed the most is one I began to play without being asked, starting the second year: the role of “greeter”.

That's turned out to be a very important role, because the new families started the programme with a lot of insecurity and tension. Giving them emotional support was essential.

Yes, I liked welcoming the new families, putting them at ease and explaining that if it had worked for Teo, it could work for any of their sons and daughters. I liked accompanying and building bridges between the families.

It was also highly stimulating at first to have to prepare the sessions and learn how to guide them, and that gave me a lot of strength which I now find useful in my daily life with Teo, when we visit another museum or in any other setting.

My son has autism, yes, and we have to adjust to that, but so does the rest of society.

It was a challenge knowing that on the Saturday when it was my turn to be “leader”, another family or professional had to look after Teo while I was running the session. Learning this was hard for me, because I thought that my son couldn't stay calm with anyone but me, and it turned out I was wrong.

How do you think the programme affected your family life?

It's been a tremendous learning experience. Teo went from simply being at the museum and handling objects to being able to participate in a programme of activities with other children.

Many people with autism enjoy manipulating objects, but they can spend many hours a day doing the same thing, and you have to draw them out of that repetition because their brains also need

“Years ago, going to a museum with my son was unthinkable. If we weren't welcome in other settings, just imagine a museum. Now I feel very confident.”

to work on other levels. The activities we did stimulated him, and he began to participate and really enjoy them. He didn't suddenly change from one session to the next. It happened gradually, in slow motion, over the first year. It was amazing to watch.

In terms of family dynamics, Teo doesn't have siblings, so he attended the sessions with his cousin Noa. It was fundamental for him to have his closest peer included in that space, which was intensely social for him. The fact that the whole family participated was very important for everyone. My sister understands Teo's needs and sees that we're not alone, and her support has been invaluable to me.

And on a personal level?

On a personal level, the programme gave me a chance to speak with other families in different tones, to feel understood and accompanied. You don't have to explain what you're going through and how it affects your family, because the people in this community understand it perfectly. Feeling understood, embraced, sometimes just a look has given me so much encouragement.

The confidence the programme gave me has helped me to establish ties with other families and professionals and feel confident enough to leave my son with them. Teo was fine with that because he had already connected with that person, he felt safe and secure, and so did I.

What do you think Teo has learned over the years?

The social aspect was the most important, the highlight for me. Also the generalisation of learning. We can use what he's learned at the museum in other contexts.

Before participating in *Empower Parents*, Teo's life was very confined: home, school and his grandparents' house. The programme let us expand our world to include Museo ICO and other cultural venues, as well as the new places we went after leaving the museum with the rest of the *Empower* families.

Some of the people who read this interview may not understand the kind of social limitations that a person with autism can have. Could you explain why it was so important for you, and especially for Teo?

Teo sometimes isn't aware of the people around him, and from the beginning the programme focused on developing personal bonds and relationships so that the children could interact with each other. I think that's the context in which he most enjoyed the social part, without a doubt.

At first, he was oblivious to those around him, but over time he acknowledged that there were other boys and girls and even began to hug them and enjoy the physical contact, which was the hardest thing for him.

That was the context that really boosted his social abilities, because he learned that interacting with a peer could be a positive



Gallery experience during a replication session at Espacio Fundación Telefónica

“Cultural institutions have to understand that our children need very specific assistance in order to have access to and participate in a cultural institution.”

thing and generalised that knowledge to establish contact with other children outside the programme.

I think the social bonds forged at *Empower Parents* would have been impossible in other settings. Teo has attended a mainstream school for the last five years, but we haven't seen this kind of progress in the educational context because it hasn't been addressed on the social level.

Now, when I tell him we're going to the museum, he understands me perfectly; it's something that he has generalised. At first, the museum was “painting” because he knew there was a creative activity, and he also said the names of his peers.

What do you think was the key to making the programme work?

The material investment was very small, but the team worked for inclusion with passion and conviction. That's important because part of our society thinks that kids with autism, like Teo, should be somewhere else—I don't know where, but not included in mainstream society.

Do you think it may have become an exclusive programme because it specifically caters for families affected by autism?

Autism is the great unknown. People with ASD are still invisible. Cultural institutions have to understand that our children need very specific assistance in order to have access to and participate in a cultural institution.

Do you think it was important to do the programme in a museum?

Yes, because it's not a place you can go every day, so if you learn that once a month you're going to be in a museum, doing activities and learning a work methodology, in the end it will make you feel more confident about visiting other museums with your child, without fears or insecurities, and generalising what you've learned in other surroundings and spaces.

What would you change about the programme?

I'd like it if we could schedule more sessions. In recent years, we had the same resources but a larger number of families, so the range of activities available to each group was smaller and took longer to complete. It's important to increase the number of families, but resources also need to increase so that more activities can be offered.

Another criticism is that, because of the limited workshop area at Museo ICO, we always had to pack a lot of people into a very small space. In recent years they tried to make it so that the children could work with fewer people around by having us parents do other activities in the museum galleries while the kids were in the workshop, but I confess we were so eager to see each other and share that we never ended up doing that, we all stayed together in the workshop.

What are some of the most positive aspects?

The whole initial methodology. Involving the parents like that and inviting families to help design the activities, the team meetings to prepare the sessions in advance, all of that was very positive.

And the learning experience for the children, not just mine but everyone's, because at each session you could see how the rest of the kids were evolving. It's been a tremendous learning experience for all the families.

And the community: I'd highlight the community of families that grew out of this.

Also the real empowerment: now I can say that I'm going to an exhibition with my son, and I know what I have to do to make sure that Teo is calm and enjoys it. If other visitors give me "looks", they're the ones who have to learn; we already have. That's very positive, and I think it was one of the programme's goals—not one of mine initially, because I didn't think I needed it, but the programme made me realise that I did.

Years ago, I didn't think having access to culture was all that important, or maybe I did, but sometimes daily life is so busy that you always have other concerns and don't stop to think about the important things. Now I do understand the importance of giving my son access to culture, and I learned that at *Empower Parents*.

What would you tell cultural agents, managers and professionals?

I'd tell them that I'm afraid of rejection, and that it's very hard to think my son can't have access to culture, and unfortunately at some institutions that's still the case, not because their visitors reject us but because the people in charge do. That's what frightens me, the fact that there are institutions which deny a large part of the population the opportunity to experience and enjoy culture.

“It's very hard to think my son can't have access to culture, and unfortunately at some institutions that's still the case, not because their visitors reject us but because the people in charge do.”

25. Stereotypies are repetitive movements often associated with ASD. They can be movements such as hand or arm flapping, repetitive hopping, rocking, peculiar hand and finger movements, etc. They are usually responses to emotional excitement or sensory over-stimulation, helping people with ASD to cope with situations of anxiety. In some cases they are also a way of expressing joy and euphoria.

📍 **Isabel Melguizo and David González. They and their family have been a part of Empower Parents since 2013**

“David is adopted, and when we filed the international adoption papers, we knew that he might have a special need. When he was one year old, we went to Bulgaria to meet him, and at eighteen months we were able to bring him to Spain; that was when we realised there was something different about him. He hadn't been diagnosed yet, but the early signs were there.”

David has been diagnosed with autism. His mother, Isabel, calls it a “textbook” case of autism.

They joined *Empower Parents* the first year, when David was eleven. Now he is eighteen, and he and his family have to embark on a new stage: preparing him for adult life.

Isabel, what is David like?

David is a very active and affectionate boy. He loves being with people, enjoys interacting with others and never forgets anyone he has spent time with: he remembers every detail, good or bad. He doesn't often get angry, but when he does, we have to try to negotiate with him, because he gets very frustrated and can become violent and harm himself.

Empower Parents was very good for him. He's very active and has a lot of stereotypies,²⁵ but at the museum he remained calm and attentive, following the routines and always keeping up with the activities. Plus, it gave him the opportunity to interact with more people and enlarge his social circle.

What were your first years with David like?

The early years were very difficult. Until you sort it all out and see that he's making progress... It's very hard, but it is what it is. You have to rise to the challenge and do the best you can for him and for everyone else.

Sometimes we'd have childminders who had no idea how to deal with a boy like him. They'd come one day, and the next they'd tell you they weren't coming back. And he was still very small then.

At first, David had difficulties with language, and we assumed it was because he didn't know Spanish and couldn't understand or speak to us. Later we learned that it was because of his autism.

He was enrolled at a preschool operated by the Regional Government of Madrid and the staff there noticed that something wasn't right. After that, they had him tested and they told us he had autism. We already suspected it and had come to terms with the idea, because we'd taken him to an early childhood development centre and they'd already told us that he probably had autism.

How do you handle the news that “your child has autism”?

Well, doing whatever you can to ensure his wellbeing—what else can you do? There's nothing you can do about it. It's not something

that can be solved, so all you can do is try to improve his quality of life. And ours, of course.

If he can manage on his own and develop in the best possible conditions, it's better for him and for you.

At first, living with him was very difficult. We both worked, we had no support or assistance, and it was very hard to find someone who could stay with him.

David doesn't ask about his autism, but he is aware of it. If he sees another child, he'll say, "He has autism too, he's like me." He doesn't feel like people discriminate against him.

Many children with autism study at mainstream schools with ASD units to guarantee their inclusion. Was that David's case?

When he finished preschool, we enrolled him at an ordinary school with an ASD unit, but soon afterwards they told us he couldn't stay on there. He happened to be in a more aggressive phase at the time and had a lot of behavioural problems, breaking everything and throwing desks and chairs, so we decided to move him to a special education school, and that's when he started at Asociación Pauta, where he stayed until this year.

Now that he's eighteen, we're weighing the options open to him, because we'd like him to attend a vocational school so that he can learn a trade and be as independent as possible in the future.

So now your efforts are focused on helping David to become increasingly self-reliant.

David is already quite independent: he's learned to read and write, he knows his way around a computer, he uses the phone... And we want him to learn something else he likes that might be useful to him in the future. He has possibilities, which is why we don't want to send him to a day centre. We're looking for a vocational school where he can become even more independent and lead a happy life.

Isabel, how did you hear about *Empower Parents*?

The people at Asociación Pauta told us about it. David was going to school there, and they told us about this programme and we signed up. We sign up for everything.

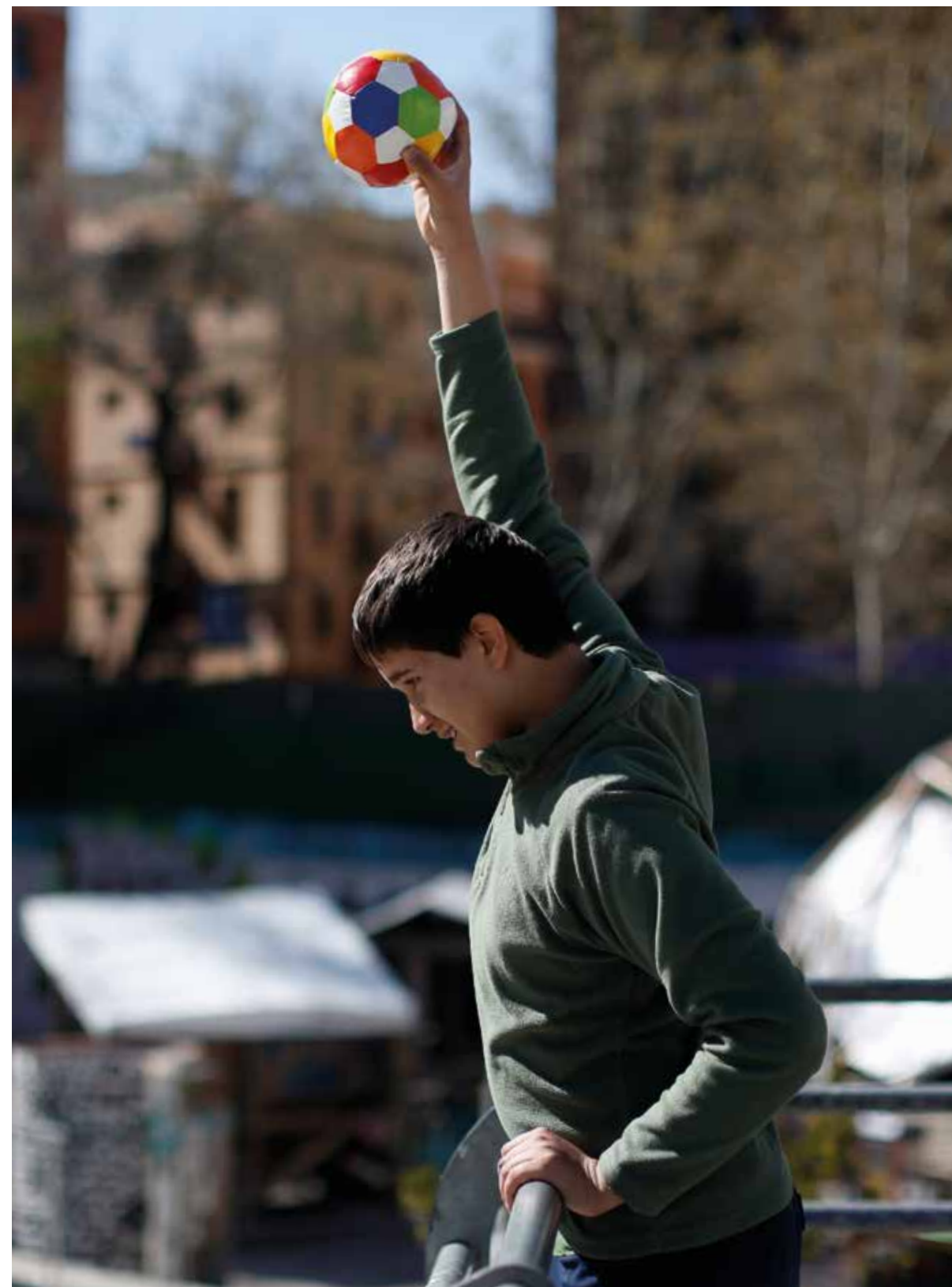
It sounded like something new, a chance to get out, be in a different setting and mingle with a different group of people. In fact, that was six years ago and we've never missed a session. *(laughter)*

David loves it, it makes him very happy. Plus, every time we go to the museum, we have a treat: a stroll through the city centre and a bite to eat.

David: Yes, and at Christmas time, after the museum we go to buy wigs. I like wigs and crayfish a lot.

David, I still remember when you told me how you caught crayfish over the phone. Your mother and I were together in New York, do you remember?

David during the workshop with the artist E1000, in Campo de Cebada



David: Yes, and I was in Burgos with my father the whole time. I had lots of fun because we went to catch crayfish with Uncle Santi and with Dad.

Isabel: *(laughter)*

You catching crayfish, and meanwhile your mother and I in New York meeting the families of *Empower Parents*.

Isabel: What an adventure! We also had lots of fun. *(laughter)*

Isabel, what did the experience of seeing the Queens Museum programme and meeting the New York families mean to you?

It was a good experience. I really liked it, though honestly it was nothing like I had imagined. I loved meeting the group of families, we got on famously and forged a lot of close friendships.

The Queens Museum programme was different from what we were doing in Madrid, and the New York families had a different way of participating and being in the museum. There the parents had more independence from their children and were much more active. Here, sometimes, you had to give us a nudge to get us to participate. *(laughter)* There it seemed like the parents were very aware and knew exactly what they had to do at every moment.

David, you've been participating in the activities we do at Museo ICO for many years now. What do you like best?

I like going to Museo ICO because I do a lot of stuff there and I see the kids: Teo, Fran, Nacho, Miguel, David, Javi, Noa. I also like seeing Daniel and Victoria. I've made a lot of friends at the museum, but Noa is one of my favourites. We play and do projects in the workshop.

Would you like us to change anything?

I like going to the museum with my parents, my grandma has gone too, but now I'd like to go to the museum with you. I want you to pick me up at home so we can go to the museum together.

David, a few years ago you began explaining the activities to other boys and girls. Did you like the experience?

Yes, a lot. When I got to be the teacher at the museum, I felt very important. They even paid attention to me when I was explaining things. One time I had to explain about these architects called the Antonios.²⁶

Isabel: When it was his turn to lead the sessions, he felt very good. He really liked the experience, and I think he did it quite well; he knew the museum and everything he had to explain because he had practised with the team beforehand.

26. Antonio Cruz and Antonio Ortiz, from the studio Cruz y Ortiz Arquitectos. In autumn 2016 we saw the exhibition *Cruz y Ortiz 1/200...1/2000* at Museo ICO, a show produced by Fundación ICO and curated by Jesús Ulargui.

“For us, it was very important to get to know other families who had children like my son. Being part of a community is a great help.”

Would you like to continue doing more activities at the museum?

David: Yes. I want to go back and I'd like to paint a picture. I'd also like to go to other new museums. In Valladolid we went to the science museum and I liked it a lot. I also liked going to the railway museum and doing the catwalk at the fashion museum.

David, what's the best thing about going to the museum for you?

I like greeting everybody and it makes me very happy when I see the other kids. I miss them, I want to see them again.

I think a lot about Asier, who lives in Valladolid, and another friend who lives in Cádiz and is named Dawit. I also remember Ethan who came in the early years.

Isabel, what inspired you to get involved with *Empower Parents*?

For us, it was very important to get to know other families who had children like my son. Being part of a community is a great help. However, I did notice that there were families with children who were more severely affected than David and were much more tense and stressed than we were.

You've been an example of optimism for many of the families at *Empower Parents*.

Well, you have to be optimistic! If you just sit back and mope when the going gets tough, you're in for a bumpy ride. You haven't got any choice but to accept it and press on. I mean, if you stop to think about all the problems, life is very hard, it's cruel.

You can't let yourself be overwhelmed by thoughts of the future. David doesn't have any siblings and he only has us, but we can't think of the future and worry about that now, because if you do, you'll break down. You just have to take it one day at a time and try to prepare so that, when he's older, his future will be assured. We know that all our preparations can't guarantee he will be treated with affection, respect and love, but how can I worry about that now? I can't. I prefer to live in the present moment and try to make our lives as good as possible and enjoy this time with him.

3 Nuria González. She and her family have been a part of Empower Parents since 2014

“Often the rejection is your own doing. You don’t want your son to annoy others and put you in an embarrassing situation, so you avoid it. You have to be really combative, and that’s the big change of *Empower Parents*: I was combative in other areas, and now I’ve become a combatant of culture. Now I take my son to the Reina Sofía, Museo del Prado, etc., and if anyone doesn’t like it, that’s their problem.” Nuria is the mother of Nacho and Miguel, ages 15 and 11. They have been a part of *Empower Parents* since 2014. She originally joined in order to be able to visit different museums and cultural institutions with her older son Nacho, who has been diagnosed with autism. Based on her first-hand knowledge of the needs of people with ASD and their families, in 2017 she and several other parents founded Asociación Trastea, which provides assistance, care and support to families affected by autism. She is also on the board of directors of the *Empower Parents* Association, created by a group of families who participated in the project. Their goal is to continue the programme’s lines of work at other cultural institutions.

What is *Empower Parents* to you? What has the project meant for your family?

Empower Parents has “restored” my son’s humanity. I like art and culture, I think it’s a fundamental part of human history. Human beings have always felt the need to express and enjoy themselves through art, through something that seems to serve no functional purpose. If I deny my son that, I’m denying him that part of his humanity. Everyone is capable of enjoying art, regardless of their level of education or culture. That’s why I think *Empower Parents* is a genuinely inclusive project. Firstly, because of where it’s held: a public place, with ordinary museumgoers who aren’t warned that they’re going to encounter an activity involving kids with autism. We’re there and they can see us. It’s inclusive because it’s open to siblings, friends, cousins, etc. and makes no distinction between those who are neurotypical and those who aren’t: everyone participates in the same way and on the same level. At the same time, it convinced me that I’m capable of accompanying not just my son but others as well, and of finding new strategies for myself in the strategies I use for others. It’s an inclusive, human art and culture project that gives visibility and conquers new territories.

I think it’s very important to conduct these interviews individually, because when we talk about *Empower Parents*, we assume that all the families see the project the same way, and that’s not the case. Some families focus on the importance of empowerment, of the methodology, on how they’ve learned new skills and how that’s given them the courage to take their children to other cultural institutions, etc. You, on the other hand, talk about the right to culture.

“You have to be really combative, and that’s the big change of *Empower Parents*: I was combative in other areas, and now I’ve become a combatant of culture.”

Nuria leading a programme session during the *Gabriele Basilico. Entropía o espacio urbano* exhibition at Museo ICO



Of course, because the question isn't why it's important for our children to participate in these types of projects. The real question is, why shouldn't they? Why should my child be prevented from enjoying a cultural activity simply because he has autism? Art is fundamental for everyone because it's about expression; art is made not only by the person who creates it but also by the one who perceives it. Art only becomes meaningful in the presence of the other.

I get the impression that art and culture are very important to you and your family, am I right?

Yes, they're very important. Culture is what brought us out of the caves. Not formal culture—it doesn't matter if you know what the Baroque is, for example. Culture is the vision that lets us enjoy the artistic experience, and anyone can do that. The ability to see beauty in the expression of another and to express yourself is universal. No disability limits our capacity to enjoy art and express ourselves. Blind people do it with their ears, hands, etc.; deaf people do it with their eyes; and people with autism do it by painting, through movements, by jumping in excitement... There's no disability that can limit us in this sense.

Do you think your son Nacho was able to express himself through art?

This project lets you observe and create at the same time, because the kids who participated in the project expressed themselves artistically. At each session, after seeing the exhibition, the children were given a chance to express themselves based on what they had experienced in the museum galleries. Through art, my son expressed what he couldn't say in words. The important thing is for people with autism to communicate, and *Empower Parents* helped them to discover new channels of communication.

What was Nacho's relationship with culture before participating in the project?

The truth is that Nacho had barely set foot in a museum before participating in the project. We'd attempted some brief introductions, but we ran out after just a few minutes, because the fact is that, unfortunately, museums are still associated with elitism. I absolutely refuse to accept that. I believe museums exist to protect art, to make sure it's not lost and, once they have it safely stored or locked up, to show it to everyone. But I don't put it in a cage to make it off-limits; I lock it up to preserve it. Museums have an obligation to be open to everyone. I would take Nacho, but in the end the elitist message always sinks in because you think it's a quiet place for erudite people, and you start thinking that your son is going to bother others. I ended up doing the opposite of what I believe.

That tendency to see museums as elitist or "high-brow" cultural venues is something that many of the *Empower Parents* families have mentioned. On various occasions,



they've told us that their relationship with culture was very limited because they felt they weren't welcome at a cultural institution or because they'd experienced rejection when they took their children with autism to a museum.

Absolutely. For that very reason, there were times when I would take Nacho to a museum, be inside with him for five minutes, and when I thought he was beginning to disturb others, we'd leave and he would stay outside with his father while I went back in.

Have you ever experienced rejection?

Often the rejection is your own doing. You don't want your son to annoy others and put you in an embarrassing situation, so you avoid it. You have to be really combative, and that's the big change of *Empower Parents*: I was combative in other areas, and now I've become a combatant of culture. Now I take my son to the Reina Sofía, Museo del Prado, etc., and if anyone doesn't like it, that's their problem.

In addition to making you more combative, has it changed anything else in you and your family?

Yes, it's helped me to show my son Miguel that his brother is capable of doing things just like him, understanding that he has different abilities and may even be more creative than him and have a greater artistic ability. It's helped me to meet other families and become the richer for it, and to know that together we can achieve more.

Do you think *Empower Parents* gave you something you weren't getting from therapy?

My son Nacho had his needs met in terms of speech therapy, music therapy, etc. But we all need to learn from life and experience, so informal learning is fundamental. Consequently, after all that therapy, we needed something that would provide an informal learning experience, a way for a child with autism to develop and grow on equal terms, because autism limits us socially and in some cases may even limit us in language, but we can still perceive and experience art. Plus, *Empower Parents* placed Nacho on an equal footing with everyone else. He and his neurotypical brother were exactly the same! *Empower Parents* also gave me new perspectives on family: for instance, after the first meeting, Nacho's father decided not to continue, but that gave me the wonderful opportunity to get my sister involved in the project, which has been very enriching. It really empowered her with Nacho, showed me sides of my sister that I'd never seen, and brought us closer, and it turned out to be a totally magical experience.

Did it live up to your expectations?

It exceeded them. The biggest miracle was discovering that when you don't pull, push, explode or demand, things just flow naturally. *Empower Parents* came along at exactly the right time for us and transformed

Gallery experience during an *Empower Parents* session at Museo ICO

Nacho in many ways. I remember the first sessions—I think we should have recorded them on video—when my son arrived at the museum in hysterics. He was all worked up because we'd just ridden a bus crammed with people, but the moment he stepped inside the museum he changed completely. That museum setting, that calm, that acceptance, that absence of demands (because we're demanding things of them all day long) made him feel relaxed, and that relaxation worked wonders. The results were amazing.

I think that transformation has to do with a lot of things, sometimes it has to do with the ordinary and with everyday life. That's why we tried to make it so that, when you and the other families entered the museum, no one was tense or worried. Jumping, yelling, running were just part of how each child expressed him/herself, letting all of them communicate their feelings at any given moment and never questioning the appropriateness of their actions. We wanted the families to know that it was all right, to reduce the anxiety that parents of children with ASD often have, and to not make you feel judged.

The wonderful thing is that this happened in a very hostile environment. In a café everyone raises their voices when they talk, but not in a museum. That's why I didn't take my son to museums, because the environment felt very unwelcoming. And yet that miracle of transformation occurred in a museum, which is why I think we're a success story.

What role did you play in the project?

Because it's a living project, our roles changed over time. Sometimes I played the role of leader, and other times I simply watched other families take charge of my son in the activity, which is wonderful, because it gives you time to rest and observe from the sidelines. It also made me see that other people are capable of caring for my son and that I'm not irreplaceable in his life. Having a son with autism makes you a slave in a sense, because he's very dependent and that gives rise to unhealthy co-dependencies. So the project allowed me to step out of that role from time to time, to care for others and know that others were caring for my son and that there was no problem—quite the contrary. Therefore, the project was a living, changing thing, letting me be the leader in some cases and an observer in others. But in every role, I've always been enthusiastic about the project.

You managed to convey that enthusiasm when you took on that leadership role in a session: you mediated with the group, adapted your explanations and the contents to the children's needs so that they could participate in the workshop independently, you organised the creative activity segment with the education team and, above all, you encouraged everyone to approach the activity with excitement and enthusiasm.

Yes. *Empower Parents* has borne very positive fruits, even after the programme of activities at Museo ICO ended. This is a long-term project, because we're still seeing the results in our kids even after it finished.

“Nacho discovered something new that he likes. People with autism have a very narrow range of interests, and it's very important to broaden that range. His brother Miguel discovered that his sibling is capable.”

How did *Empower Parents* benefit Nacho?

Nacho discovered something new that he likes. People with autism have a very narrow range of interests, and it's very important to broaden that range. His brother Miguel discovered that his sibling is capable. We always talk about disabilities, limitations, inabilities, and for once we were talking about achievements, abilities and potential; that was very important. I've always been more focused on weaknesses, and thanks to *Empower Parents* I began to see my son as someone capable of producing rather than simply demanding pleasure. It allowed me to see his full range of abilities, to enjoy him, and for the two hours the session lasted I saw that it was true.

What would you have changed about the project?

We should have done more marketing and taken better care of the families who gradually dropped out of the project. We should have left the museum more often, like the day we went to paint the wall at Campo de Cebada.

Do you think it was important to do the project in a museum?

I think it was important as a starting point, but it's time to get outside. If we keep it locked up inside the museum, we're creating a ghetto: comfortable and cosy, but a ghetto nonetheless.

Visibility is a primordial concern for me, which is why I often repeated that phrase about conquering new spaces, because I really felt it was a necessity. One of this project's future challenges is to reach more cultural institutions. So, if you had the chance to address the directors of a cultural institution, what would you say?

Well, I'd say three things. First, I'd ask them why they work in the culture industry. If art means anything to them, they should realise that it also means something to everyone and that, if their institution receives public funding, they have an obligation to make it available to all of society, including my son. I'd also ask them about corporate social responsibility. Every company, even capitalist enterprises, dedicates part of their efforts to social responsibility, so why not support projects like *Empower Parents*? And there's a third aspect that seems very important to me. Museo ICO may be well known in art and architecture circles, but I think the project that really boosted its social visibility was *Empower Parents*. A small, financially modest project that appeared on television, in the press, received international awards, etc. Do you want publicity for your museum? Then keep on doing these types of projects!

Is there anything else you'd like to add?

I'd tell the people who are reading this to set my words aside and come to a session and watch the magic happen. Come and see for yourselves.

④ **José Luis Morales. He and his family have been a part of Empower Parents since 2014**

“We’re a family of four, although we were only three when *Empower Parents* began. At first, we joined the programme with the idea of forming a community, of doing something fun together as a family. But it ended up being something much bigger. The family fun is there, but it’s not the most important part. It made me grow as a person.”

“I liked being in the museum gallery more than in the workshop because everyone could see us and we made disability visible, that’s what I liked best about the entire programme. Leading the sessions was hard for me at first, but I actually ended up enjoying it.”

José Luis is the father of Alonso, a boy with ASD who joined the programme at age seven. Now, in 2020, Alonso is 13 years old. They joined *Empower Parents* in 2014, eagerly making the trip from Talavera de la Reina to attend every session, meeting, gathering, meal... The family is very active in the association movement. In fact, Vanesa, Alonso’s mother, is chair of the local ASD organisation, Asociación TEA Talavera.

You began the project in 2014, when Alonso was seven years old. Who is Alonso today?

When we started out, in 2014, Alonso loved to draw. I always remember this huge drawing of a dog that he made at school, which we still have. Over time that interest faded and his narrow range of interests shifted to other things like watching videos online, especially cartoons like *The Simpsons*, although he still draws occasionally.

His social communications were very limited, and the project helped him with that. Being comfortable with other kids in an environment where all the families knew the score and were at ease in that respect also helped to put him at ease.

Before participating in *Empower Parents*, we’d gone to visit a few museums, but we were always tense, not knowing what would happen, if he would start screaming or take off running. This project gave us the tools we needed to, as a family, engage in leisure activities that include him and all of us, and be able to calmly visit a museum.

I remember that when Alonso started out in the programme, he had a great talent for telling stories through drawing, and that made it easier for him to communicate.

At the time, we thought that Alonso had a standard form of high-functioning autism, but lately it’s been looking more like he has “pure” autism and that his intelligence is slightly below average, bearing in mind that it’s very difficult to test his intelligence quotient as communication is one of his weak points.

How did you learn of *Empower Parents*?



“Expanded Conversation” meeting at Medialab-Prado (Image 1)

José Luis leading a session at Museo ICO (Image 2)

The social worker at the ASD association in Talavera told us about it, and they in turn had heard of it from Autismo España. And it sounded really interesting to us. When you called us for the first time to do the interview, afterwards we waited with bated breath for several days until we finally got the news that you'd chosen us.

What initially appealed to you?

We thought it sounded different. It wasn't conventional therapy and it had a new approach that would let us do something we normally couldn't, like visit a museum: go together as a family and enjoy it.

We also liked the fact that it tied in with Alonso's interest in drawing at the time.

After the interview, when we learned that we parents were going to play a central role, leading the sessions and such, we liked it even more.

Do you find it tedious to think that every activity you do with Alonso has to be some kind of therapy?

The majority of the offers we get have the word "therapy" tacked on the end. Something that for any other child would be an after-school activity with a mixture of fun and learning is always presented to us as a form of therapy.

It's true that you need to work a lot with these kids, but they have the right to just have fun without thinking of anything else, with no ulterior motive or goal—at least not at first, although later they might achieve certain things.

I think what you just said is very important, that they're entitled to just have fun.

For example, a kid goes to play football. Why does he play football? Well, because he's going to play football. And what does he get out of it? Well, he learns teamwork and social skills. But those aren't the goals. The child's goal is to play football. Full stop.

What kind of relationship did you have with museums and cultural institutions before participating in *Empower Parents*?

We'd never participated in any educational activity at a museum with Alonso before. We'd visited the odd museum or gone to an exhibition we thought he might like or that appealed to us. But you went with that fear of not knowing how he would react, with no tools other than the ones you find online or some simple pictograms to give the tour a bit of structure.

Could you explain how those tools have made you feel more confident about taking your son to a museum?

For starters, it's the fact of knowing how I need to structure the visit. I can see what the museum is like, explain what we're going to do to

“We thought it sounded different. It wasn't conventional therapy and it had a new approach that would let us do something we normally couldn't, like visit a museum: go together as a family and enjoy it.”

my son, give him a routine so that he knows what he has to do when we go to a museum: speak softly, walk slowly, pay attention at certain points... things Alonso didn't know before participating in *Empower Parents*.

And do you think he's been able to generalise that learning in other settings? I'm thinking of a library, his school...

Yes. When you tell him he has to behave like at a museum, he already knows what to do and that he mustn't yell or run. He's internalised things he hadn't fully registered before thanks to repetition, the act of going to the museum every month and following a strict calendar. That regularity, after all, is a routine, and it put him at ease.

What were your expectations when you started *Empower Parents*?

First of all, acquiring tools to be able to visit a museum or do a cultural tour. And later, being able to extrapolate those tools to other contexts, outside the museum.

And were those expectations met?

Beyond our wildest hopes. Initially we just wanted to acquire those tools, but we ended up getting so much more from *Empower Parents*. We got to build a community. Before, we didn't know how to handle situations that might occur in a museum, but now we have—and he has—that ability. And that applies to the museum visit as well as to the part of creating materials. But we also gained that sense of community, with the replications of the visits we've organised outside Museo ICO: that's conquering and claiming other territories, making disability visible to the rest of the population.

Many people think culture is already accessible, that institutions are inclusive and this is no longer an issue, but we who work as mediators with people with special learning needs know that's not the case.

Cultural institutions have a highly theoretical discourse that often conceals practical shortcomings in the area of accessibility and inclusion. That's why highlighting the difficulties and challenges that still exist is so important.

I completely agree, accessibility and inclusion are still largely theoretical concepts in Spain. Our society isn't prepared for 100 percent inclusion. For instance, right now they're talking about eliminating special education schools, but society isn't ready for that. I still see it when Alonso has a tantrum; people stare at you in the street and think he's just misbehaving. It doesn't occur to them that he might have a problem. Now, because he's older, perhaps they might think that a bit more.

That's why showing autism, making it visible, is so essential. We still have a long road ahead of us.

One of the mothers I talked to for this publication spoke of how “those looks can be so hurtful”, to the point that she wouldn’t do certain things, like going to a museum, just to avoid them. As a father, how do you cope with that lack of understanding?

The last episode was on the 104th birthday of my wife’s grandfather, celebrated at the retirement home where he lives. A television crew came and they had a little party for him. The director of the home told us we had to leave because Alonso was having a tantrum and upsetting his grandfather. Our inner circle knows how a child with autism can behave. But every child is unique, and autism is a disability that *doesn’t show on the face*, so it’s very complicated. A lot of times you just feel like turning round and saying, “What’s your problem? Why are you staring at me?” Usually you don’t say anything, but sometimes you do. There are times when you just say, “I’ve had it.” We still have so many obstacles to overcome. Inclusion is just a word.

Speaking of inclusion, Alonso is enrolled at a mainstream school. What has your experience been?

In his inner circle, with his classmates, Alonso is totally included. But when you leave that circle and Alonso exhibits behaviour unlike that of neurotypical people, he sticks out.

Alonso finished primary at a mainstream school and now he’s going to switch to special education.

Why did you decide to make the change to special education?

Because we and part of the teaching faculty agreed that Alonso’s abilities aren’t suited to a mainstream secondary school. Because of everything secondary education entails: it’s not just one class, you have to move about and change classrooms, and the instructors at that level aren’t teachers, they just go and deliver their spiel and that’s it. The form tutor may be a bit more knowledgeable about special needs, but the instructors are experts on their respective subjects. It’s not like primary school, where the entire faculty is much more involved in the child’s education. And a special education school will provide the kind of tools he needs to become more independent, to help him be capable of doing whatever he can or wants to do. In other words, making him calculate derivatives or solve an equation... those are things he’s not going to use in his daily life. He says he wants to be a forklift truck driver when he grows up.

Our goal with Alonso is for him to be as independent as possible in the future, and special education will give him the tools he needs to make that happen.

Perhaps we should ask ourselves if the educational system has sufficient resources to ensure effective inclusiveness and, if not, what needs to change.

At a special school, Alonso will be in a classroom with four or five pupils and a specialised teacher, plus any additional support he needs.

“Our inner circle knows how a child with autism can behave. But every child is unique, and autism is a disability that *doesn’t show on the face*, so it’s very complicated.”

In a mainstream classroom, he would be with anywhere from twenty to twenty-five pupils. He’ll receive much better attention at a special education school. Because any child with special needs requires more attention. And mainstream schools don’t have the resources to provide it. Society isn’t prepared for what they want to do.

And this means that, once again, minorities must work twice as hard to be included in a space that’s not prepared to include them.

Of course, society isn’t making an effort to include the individual. The individual, or his/her family, are the ones who make the effort to be included in society. And it should be the other way round.

How do you think *Empower Parents* influenced your family?

Because it’s something you do as a family, it affects all of us. Bruno less than the rest of us, because he was born towards the end of the project at Museo ICO. But it taught Alonso how to behave when he has to be calm and still. Just being with other families and seeing how the other children behave when they’re doing it right, that’s how they learn. If the rest of the kids, or most of them, walk slowly through the museum, or remain seated when they’re doing an activity, or wait their turn... all of that really helped Alonso. It also helped us to devise useful tools, and it even taught me how to speak before an audience, which was something I found difficult.

What do you think your role was in the programme?

I’ve played every role, but the mothers were really the ones who participated the most.

The first time I led a session, it was only because I was next in line. (*laughter*) But after that, I began to enjoy speaking in public.

In families affected by ASD, it’s often the mums who shoulder most of the autism burden and devote more time to caring for the kids. That’s also true in our case: Vanesa spends a lot more time with Alonso than I do, and she’s been more active on the autism front.

What are the highlights of *Empower Parents* for you?

The best part was the community formed by those of us who were involved from the early years. The energy generated during and after the sessions brought us closer together. When each session ended, I was already looking forward to the next one because something magical happened there.

It was this feeling of peace, of comfort and ease, of knowing that you were doing something in a place where everyone understood you. You were in a museum, but you were with other parents who knew exactly what your son was dealing with and what each person needed to do at every moment—because we ended up having a familiar structure and we knew what we had to do. That eliminated the uncertainty we usually feel in any activity of life. And the

“It was this feeling of peace, of comfort and ease, of knowing that you were doing something in a place where everyone understood you.”

enjoyment you got out of it, because you were drawing, or playing and dancing in a museum gallery, or looking at a scale model or a sculpture, in the end it gave me that: a sense of peace so deep that when one session ended, I couldn't wait for the next to begin. I remember that we were very sad to think Alonso would soon be too old to participate in *Empower Parents*. Last year the age limit was raised to 16, so that took a weight off our minds. *(laughter)*

Something that seems so simple, just knowing that other people understand you, can be incredibly meaningful.

And something fundamental for us was the fact that we weren't just receiving, being *given* something; it also involved us *doing* something. We internalised it and made it *ours*, knowing that we were the ones who made it happen at the museum.

Yes, that's one of the secrets to the success of *Empower Parents*, the fact that it came from all of you, even though we were there to provide support. And the families like you who understood it that way are the ones who most enjoyed the programme.

Of course, we understood that Museo ICO was our home, that you all structured each session for us and helped us to come up with the contents, but that we were the ones who actually ran the sessions. I see us as the stars of the show. *(laughter)*

We felt it was very important to make the museum a place for coming together, to transform it, eliminating sensory overload and anything else that might be distracting for the kids... We've managed to change some things, but there's still a lot of work to be done before accessibility permeates the entire museum structure. Even so, did we succeed in making you feel at home?

Yes, for many reasons. For example, the museum staff, from Alicia in the Art Department of Fundación ICO to the security guards and information desk staff. They all joined in and made us feel welcome, each doing their jobs. The security staff, making sure that the kids didn't touch a scale model... and at the same time, they saw people with disabilities coming to the museum every month, and I'm sure they learned a lot about us from that.

But the main reason was the work done by the education team.

Another good thing about Museo ICO is that it changes completely from one exhibition to the next. With each new show, it could go from a brightly lit environment to a dark one, from open to labyrinthine spaces. The same venue was different every time, and that may have helped us when we did the replications.

Yes, in the end the museum became a laboratory where we were able to experience all sorts of things. And leaving that space allowed us to test our methodology and put it into practice at Museo del Traje, Espacio Fundación Telefónica...

“We understood that Museo ICO was our home, that you all structured each session for us and helped us to come up with the contents, but that we were the ones who actually ran the sessions.”

Do you have any criticism of *Empower Parents*? What do you think we should change in the future?

In the last two years, I get the impression that the programme has lost some of its steam, because the new families aren't as involved as we were in years past.

We've acquired tools for visiting museums on our own, we've made ourselves more visible and formed a stable, lasting community... The challenge now is to get more institutions to open their doors to us like Museo ICO has done.

What would you say to those institutions?

That they don't know what they're missing, because this project creates a wonderful magic and energy in any setting. Initiatives like this are immensely enriching, for the institution as well as the families, and such projects, in addition to creating a sense of community, shine a spotlight on often invisible issues like autism.

Cultural institutions can be catalysts of change, generating synergies that could lead to a larger social transformation. Families affected by ASD struggle every day on multiple fronts: education, healthcare, etc., and participating in this programme made us realise that we need to take that fight to the cultural arena as well.

Empower Parents was a huge step forwards for us: on the one hand, it made us part of a very beneficial, active and proactive community, and on the other, it gave us the tools we need to enjoy any museum or cultural venue as a family.

5 Ana Gómez. She and her family have been a part of Empower Parents since 2016

“My perfect family photo changed when Pablo was two years old and they told us he had autism. Our lives were turned upside-down, and the entire family had to adjust to the new situation. I’m an architect, and I decided to leave my job to care for my children.”

Ana is the mother of Marta and Pablo, ages ten and eight. Pablo has been diagnosed with autism, and in 2016 Ana, her husband Miguel and their children embarked on this adventure.

In February 2020, they and other families decided to create the *Empower Parents* Association in order to continue the programme and conquer new territories.

How did Pablo’s autism diagnosis affect your lives?

Paradoxically, when we received Pablo’s autism diagnosis, I was busy mapping out my children’s future. The diagnosis took me completely by surprise. It was a sudden and totally unexpected blow. I had no clue what autism was or what it meant, and I hadn’t seen any of the signs in Pablo. It never even crossed my mind that my son could have autism.

In a split second, all my plans fell apart and I had to learn to take life day by day and stop thinking ahead—maybe the current academic year, but no further.

But you know, the diagnosis eventually made me realise that all I want for my children is for them to be happy, regardless of their studies, their jobs, etc. I just want them to be happy.

How did the word “autism” change everything?

The biggest change for me was giving up my job. When Pablo was diagnosed, they told me I needed to start working with him as soon as possible, so we began going to the therapy sessions he needed, which were usually at midday. I was constantly running late. I raced about all day long, driving up and down the M30 ring road, from therapy to work to school and back again. I remember those were very stressful years, and my stress took its toll on the kids, so one day I made the very painful decision to stop working. It was very hard for me, because I’m an architect and I loved my job.

It took a long time to come to terms with that decision, but I don’t regret it. I’ve made my peace with it, because I think that choice allowed me to care for my children, but I also know that it cost me my professional career.

Autism changes family expectations, but it also changes personal ambitions. In your case, you stopped working and focused on raising your children.

In my profession, it’s hard to keep up with the latest architectural trends and the new software. I don’t know if I’ll ever be able to go back to work.



Ana and Pablo participating in an *Empower Parents* session at Museo ICO (Image 1)

But having children is a choice, after all, and I chose it. I don’t regret leaving my job, because if I hadn’t, I would have been in a constant state of anxiety. Now I have the peace of mind that comes from knowing I’m doing the right thing.

Initially I attended all of Pablo’s therapy sessions, and I learned a lot about emotions, pictograms, etc. Pablo couldn’t speak, but he evolved dramatically and quickly because we worked with him constantly. I took everything I learned in therapy and later applied it at home. It was also very important to make sure that Marta, while growing up with the reality of autism, didn’t feel ignored or neglected. She was five when we received her brother’s diagnosis, and we had to explain to her that, even though we couldn’t give her the same amount of time, she was every bit as important to us as her brother.

It’s a job that requires constant dedication, and I’ve had to work on my emotional balance in order to cope with everything.

How did you hear about the programme?

Pablo began to develop speech, and seeing that his cognitive ability was good, we decided to send him to a mainstream school with an ASD unit so that he could study in a more inclusive environment. There were four other children with autism, and over time we began to socialise with their families.

One of them was participating in *Empower Parents*, and they always told us about the activities they did at Museo ICO. They knew I was an architect and that I was very interested in being able to do activities with my children at a museum, and an architecture museum at that... it was like the programme had my name on it! (*laughter*) One day they invited us to participate in an activity they were going to do in Campo de Cebada, and we went.

Just think, our first contact with the programme was painting a wall with spray cans, getting all stained... Everyone was happy, the families were there, and you could tell that the adults had this special connection, everyone was relaxed, the kids were having a ball... It was such an impressive experience!

So I said, “I simply must be a part of this! It’s tailor-made for me, and I have to be a part of this group, whatever it takes!” (*laughter*) And the truth is that I was fascinated by the programme, the concept and the atmosphere I sensed from the very first day.

What else made you want to join?

I’m from Albacete, and one of the things Madrid offered me was the chance to participate in a wide variety of cultural activities with my kids. My daughter has been going to activities at different museums since she was three years old, and when I first got Pablo’s autism diagnosis I wasn’t sure if I would be able to do these kinds of activities with both children, which was very important to me. So the *Empower Parents* programme at Museo ICO was the perfect opportunity to start doing that. What I didn’t know is that it would also give me tools so that

“For us, it’s a community of families where we’ve learned, thanks to the training we received, how to enjoy cultural institutions independently with our children.”

I could visit other museums and do activities there outside the programme.

For example, a year ago, Fundación Canal had a Lichtenstein exhibition that I loved. I contacted the foundation, made a schedule and arranged my own adapted tour, using what I'd learned in the programme. That was hugely gratifying for me; it made me realise how much I'd learned and how empowered I'd become.

What does *Empower Parents* mean to you and your family? How would you define the project?

For us, it's a community of families where we've learned, thanks to the training we received, how to enjoy cultural institutions independently with our children. It's a cultural and social programme: cultural, because it gave me the tools I needed to participate in museum activities; and social, because it created a community of families that exists outside Museo ICO.

What do you mean by "it gave me tools"?

I mean that, after participating in *Empower Parents*, I feel like I have enough tools and resources to ensure that my son can enjoy an activity in virtually any setting, preparing a schedule and other materials in advance, and above all I've learned that it's all right if my son gets nervous. You just have to know how to make others see that some children are more active than others and that it's OK, that we need to accept everyone for who they are and have a more open mind. Thanks to these tools acquired through *Empower Parents*, I know that I can use what I've learned to organise a family activity with both children, something I was once very afraid to do but which has always been a priority for me. These tools have given me the ability to participate in cultural activities in practically any setting, with confidence and peace of mind, knowing that it's going to be fine, even if my son gets upset.

What scared you about visiting a museum with Pablo?

I was afraid that Pablo wouldn't be interested in the activity and that he'd begin to behave inappropriately so he could get out of doing it and we'd be invited to leave the museum. *(laughter)*

Pablo has no boundaries, and if something doesn't interest him, he'll do anything, invent the wildest antics you can imagine, just so he doesn't have to keep doing it. He's a very active child with a very short attention span. His form of autism is verbal, and getting him hooked on an activity is very difficult. He finds it very hard to pay attention and follow through on an activity or a talk; he stands up, fidgets and may even yell in order to leave when he's tired of it. And that makes it hard for him to participate in a programme like this, as his behaviour distracts the rest of the group.

Workshop with the artist E1000 in Campo de Cebada, Madrid



Before *Empower Parents*, I didn't dare take Pablo to a museum, much less do an activity with him. I was afraid he would take off running, pitch a fit or get us reprimanded.

That's why the schedules we worked with in *Empower Parents* were so important, because they gave us a script to follow, so we could keep up with the pace of the activity and not get too far off track. Knowing how much time was left and being able to set a pace was fundamental. Thanks to that, Pablo was able to participate in all the activities we did without a problem.

It's important that you were able to generalise the things you learned in the programme and apply it to your everyday life, with some adaptations, but using it in other places with your son. That's the goal of *Empower Parents*.

Being able to do all those activities, at Museo ICO or any other museum, and doing them with both of my children was very important to me. In my case it would be easier to just take Marta, my eldest, and leave Pablo at home. But it's important to make that extra effort, because I think it's really going to benefit his development and that we're going to have a lot of fun as a family.

Receiving that diagnosis also means a change for families in their social circles. Support networks and friends often fall away, either because they don't know how to deal with these children or because it requires too much effort. Was that true in your case? Has autism made you feel alone?

No, not in our case. In general, we've found that our good friends really are good, far better than we could have hoped or imagined. Sometimes there have been situations where their children have had a bad experience with Pablo, but they've addressed it and talked to their kids, explaining what Pablo is like and how they should treat him. We've made some very positive discoveries. In other cases, not so much.

Also, Pablo's autism has given me the chance to forge true friendships, and that's a very positive thing, because when you socialise with families who understand your son and how to treat him, it gives you tremendous peace of mind. You can relax because the other families are never going to judge your son's behaviour. That's a wonderful thing!

I recall the sessions at the museum as moments of enjoyment and peace, especially when it wasn't my turn to lead the session. I could relax and just let myself go. Sometimes I could even see the exhibition without a care in the world, because there was always someone else watching my son, and if he misbehaved it wasn't a problem... I knew some other kid was probably behaving even worse. (*laughter*)

“[...] after participating in *Empower Parents*, I feel like I have enough tools and resources to ensure that my son can enjoy an activity in virtually any setting, preparing a schedule and other materials in advance, and above all I've learned that it's all right if my son gets nervous.”

“Before *Empower Parents*, I didn't dare take Pablo to a museum, much less do an activity with him.”

Did you feel like an important part of *Empower Parents*?

Yes, I think that if we parents hadn't been so involved in the programme, I wouldn't have had the same feeling of empowerment.

What are some of the project's most positive aspects?

The tools we acquired, the families we met, shared interests with other parents, experiences at a museum where you're enjoying yourself and feel totally relaxed, and the people we met. A high percentage of the families were deeply involved, making an effort to come every week, to get together, etc. Their main interests are the same as yours, and what's most important to them is also what's most important to you. In those sessions, each child's individual quirks and traits were respected and treated as completely natural, and that gave us a lot of peace so we could enjoy our time there.

You and several other families have set up the *Empower Parents* Association. What is your intention and where do you want to go with that?

We had been wanting to set up an association for a long time, but the catalyst was when the activities at Museo ICO ended last year. That made us realise how necessary the programme was and we decided to get organised.

As a chartered association, we could apply for funding to take the programme to new settings. That's very necessary, and there are a lot of families who need initiatives like this. Having a child with autism is very demanding on so many levels and requires different types of therapy which many families can't afford because they're so expensive, and I think these kinds of learning experiences are so positive that their benefits extend beyond the museum. The lessons learned at *Empower Parents* are things you can apply in your everyday life.

They're strategies that work for everyone and we need to keep it going, we have to take *Empower Parents* to new places and expand the community of families.



⑥ **Marta, Miguel and Fran are 10, 11 and 13 years old, respectively. They've participated with their families in *Empower Parents* since they were very small, long before they knew what this thing called autism was. They all have something in common: a sibling with this diagnosis. And they each have a lot to say on the subject.**

Marta: "I didn't know my brother had autism until I was older. When I was younger, maybe five or six, it was harder for me, to tell the truth. My brother was also small, and my parents were with him all the time."

Miguel: "Autism is just the way you are, you're born with it. It's not a disease, because there are people who think it is."

Fran: "I think doing this interview is important in order to show the point of view of those who, like us, live with people with autism, in this case our siblings."

If you had to explain what autism is to others, what would you tell them?

Miguel: I'd tell them that autism is just the way you are, you're born with it. It's not a disease, because there are people who think it is. It's not a problem, it's something you're born with and it has advantages and drawbacks.

Fran: It's a way of being, like Miguel said, that makes you behave differently, and that behaviour draws the attention of others.

In what sense does it draw attention?

Fran: Well, in the sense that people with autism act in an unusual way and others think it's weird.

Have you ever encountered someone in the street who called your brother's behaviour "weird"?

Fran: No.

Miguel: They don't say it, they just stare at us.

Fran: They stare at us in a strange way, not like they usually look at people who don't have autism. I don't like it, because they look at us like they're saying, "What's he doing here?"

Marta: My brother is different. Sometimes, when we go somewhere, he'll pitch a fit over anything that seems strange to him or that he doesn't like. People start staring at you because they think there's no reason for him to act like that. It's very uncomfortable when everyone stares at you, because you think, "Why am I in this mess if I didn't do anything wrong?"

"When I see other children acting like my brother does, I know it's because they have autism or some other disability."

They look at you like you're a problem. In my case, when I see other children acting like my brother does, I know it's because they have autism or some other disability.

As siblings of a person with autism, you have the ability to understand not only your brothers but also other kids in the same situation. What would you say to those who judge people like your brothers?

Miguel: I'd try to explain the situation, and if they keep giving us odd looks—which would be unlikely, because I doubt they'd keep looking at us like that once they know my brother has autism—I wouldn't care. I'm not ashamed to be with my brother, people can stare as much as they like. But if I had to do something, I'd explain his condition, and if they can't understand it, too bad.

Those who refuse to understand are the ones with the problem...

Miguel: Right.

Marta: I'd ask them, "Why are you staring at us?" Ask them to put themselves in our shoes and think about our feelings. Sometimes I find it a bit embarrassing when everyone's staring at me.

Fran, have you ever had to explain what was going on with your brother?

Fran: Yes, at a few birthday parties this or that friend would ask me, and I'd explain why my brother behaves like that. After explaining, they never brought it up again.

What does having a brother with autism entail for you?

Miguel: In my case, it's been a very positive thing. It's helped me to understand and comprehend more, and to be friends with everyone. Also not to judge anyone by their appearance or how they act.

In fact, one of your best friends has autism.

Miguel: Yes, and I also get on well with another kid in my class who has autism too. I've learned not to judge. They've helped me to understand kids with autism and everyone better, to not judge or stare at anybody just because they're different. It's helped me to be more caring and helpful.

Well, I think a lot of "adults", who sometimes don't act their age, should listen to people like you more often, because you've got important things to say. (laughter)

Marta: I didn't know my brother had autism until I was older. When I was younger, maybe five or six, it was harder for me, to tell the truth. My brother was also small, and my parents were with

"Living with Alex has been good for me, because it helped me to understand how things sort of work in today's society, that not everyone is the same and that's totally fine."

him all the time. Plus, he had bigger tantrums than he has now. Sometimes I'd go to my parents and ask them to play with me, and they'd always tell me, "Not now, dear, we're with Pablo," and I'd walk away alone. It upset me that they spent all day with Pablo and not me.

Fran: Living with Alex has been good for me, because it helped me to understand how things sort of work in today's society, that not everyone is the same and that's totally fine. And that everyone deserves respect, no matter what they're like.

What is everyday life like for you? How do you handle the fact that your parents may have had to give your brothers more attention, as Marta explained, or times when their tantrums were aimed at you?

Miguel: Honestly, it's never bothered me that my brother gets more attention, because my parents have given and still give me all the attention I need. Sometimes I don't need their attention; I'm not a baby anymore and I can do things on my own. I don't need to hog all the attention. Attention should be given to the one who needs it. To me it makes perfect sense that they pay more attention to my brother, because he needs it more than I do, I can take care of myself.

Who talked to you about all of this, Miguel?

I've always asked my parents a lot about why my brother couldn't do certain things, why he didn't come to Scouts with me, etc. So my parents explained all these things to me, which helped me to understand that he gets more attention because he needs it, not because they wanted it that way.

Would you change anything about your brothers?

Marta: No.

Not even the tantrums, Marta?

Marta: No, because I like him the way he is, I don't want him to change.

And what do you each like best about your brothers?

Marta: Well, when he doesn't have those tantrums and when he wants to be, Pablo can be very good, and sometimes we do things together, although we almost always have to play what he likes. *(laughter)*

Fran: I wouldn't change anything either. What I like best about him is his laugh. When I'm feeling down, he laughs and cheers me up.

Miguel: I think things can't just change overnight, so I would try to make people understand more about what autism is and help

Miguel and Fran participating in an Empower Parents session at Museo ICO (Image 1)

Marta during the workshop with the artist E1000 in Campo de Cebada, Madrid (Image 2)



Nacho, my brother, to open up to people more, because of course my brother is in his own world and does his own thing, but it can't always be that way. In the future he'll have to communicate with his boss, his caregiver, his wife, his friends, me... Although he already communicates with me in his own way.

Miguel, how do you communicate with Nacho?

Miguel: Well, sometimes he wants to play with me, other times he makes signs with gestures, other times he lies down beside me, at times we give each other kisses... not everything has to be talking. Our relationship is more non-verbal than verbal, we lie down and give kisses more than we talk.

Do you think your life would be the same if your brother didn't have autism?

Fran: It would change quite a bit, because my brother would act differently at home and we'd play together more. My brother is very independent and I spend most of the time alone in my room. If he didn't have autism, I imagine we'd play more and spend more time together. We could share more things.

Miguel: My brother has influenced the way I am, so without him my life would be totally different. He's helped me not to judge anybody. I also feel alone, but that's not because of my brother. I feel alone because people, without meaning to, exclude you from the group. They look at you funny and keep their distance because of the disability and that makes us feel lonely, because we think we're the only ones and it's not true. People often judge you and push you away, they don't even bother to get to know you.

Marta: If Pablo didn't have autism, maybe he would be ruder or nicer than he is now... I don't know. He'd be different, and I don't want him to change.

How important was it for you to meet other kids who have siblings with ASD at *Empower Parents*?

Miguel: For me it was very important, honestly, meeting other people in the same situation, because it helps you to not feel so alone, and it's nice to know you're not the only one. It helped me to come to terms with it and discover new sides to my brother. I've also seen how being able to interact with other people helped my brother. I think that's important, because maybe my brother feels alone because he has autism, and he's not the only one.

Marta: Meeting other siblings at Museo ICO also helped me to realise that I'm not the only one who has a brother with autism. For example, at my school I don't know if there are more kids who have siblings with autism. We do have an ASD unit, where there are five kids with autism who, depending on the subjects, change

“The best part of the museum was what Fran said. Because more than the activities, which were really fun, what I liked best was the fact that we could all get together and do things that involved all the kids, with or without autism.”

classrooms to be with other kids and be able to talk to them. I think that's really good, because that way they can interact with more people.

Fran: I basically feel the same as Miguel and Marta. Having a brother with autism can be tough at times, but knowing there are other people in the same situation helps a lot. It puts your mind at ease.

What did you like best about *Empower Parents*?

Marta: I really enjoyed the activities, they were very cool and you got to be with other kids. Before we couldn't really go to a museum with Pablo, but now he likes it more and he's more focused on doing the things we learned there.

Fran: What I liked best was being with other kids who have siblings like mine and who ended up becoming my friends.

Marta: When we left the museum, we'd always go for lunch or a snack with other families. I really liked being with Teo's family; Teo and my brother became friends.

Miguel: For me, the best part of the museum was what Fran said. Because more than the activities, which were really fun, what I liked best was the fact that we could all get together and do things that involved all the kids, with or without autism. Before I didn't do anything with my brother, but now we've learned to do activities and make plans together, trying to choose things that aren't boring for either of us.

If you could change anything about *Empower Parents*, what would it be?

Marta: I would have liked us to change museums. For my brother, going to a new place every day can be stressful, but once in a while we could go to other museums so we're not always at the same one. I'd also like it if there were kids of all ages in my group, so I could make friends with people who are older or younger.

Imagine that the people who decide which projects to do at museums are listening to us. What would you say to make them understand how important this kind of activity is?

Miguel: I'd tell them that it's essential for us to meet other families and for my brother and I to be able to do things together. That it doesn't matter if we have a disability or not. I think it's very unfair that kids like my brother aren't given the same opportunity. I think it's very wrong and unfair because my brother was born with autism, he didn't choose it. It seems so unfair to me that he's judged just for being different and that he doesn't have the right to enjoy the same opportunities.

“It's essential for us to meet other families and for my brother and I to be able to do things together. It doesn't matter if we have a disability or not. I think it's very unfair that kids like my brother aren't given the same opportunity.”

I'm going to bring all of you to my next meeting at a museum so you can explain why museums need to be more open, social and accessible spaces. (*laughter*)

Fran: Well, museums should adapt to people with autism because, in the end, that will bring them more visitors and prove that they welcome people from every walk of life.

Practice

27. [Room to Grow](#) is a resource that Michelle López and Jennifer Candiano developed when they worked in the ArtAccess Department of Queens Museum. It is aimed at professionals interested in developing art programmes for people with autism in community spaces.

The *Empower Parents* methodology and resources are the result of six years of learning and participatory research based on the work carried out with more than a hundred families and the collaboration with cultural institutions and social action organisations.

During the course of these years, Museo ICO has provided the *Empower Parents* team with a space for experimentation that has facilitated the collaborative development of a working methodology with its routines, structures and accessibility supports. In all six editions of the programme, every Saturday we would evaluate the successes of the session we had just completed and make the necessary adjustments to anything that hadn't worked. This has been our logic throughout: we introduced an entirely experimental method the first year and have pursued it to this day.

The aim of this chapter is to share our practice, just as seven years ago Queens Museum shared its experience of the Museums Explorers Club with us, the methodology of which is described in the *Room to Grow* guide.²⁷

We hope this publication will also become a space to grow and share with professionals, institutions and families committed to creating learning spaces that are inclusive, accessible and adapted to the needs of people affected with ASD.

“At the age of fifteen and with very narrow interests, Alex hasn’t only discovered art as a form of expression. He’s also discovered the pleasure of finding out what exhibitions can offer him. He goes right up to the labels and reads them out loud carefully, looks closely at the exhibit on display and then says exactly what he thinks of it. And then he calmly continues his tour of the gallery, with an occasional jerky movement and a ‘strange’ expression on his face that sometimes upsets the security guard and has caused us a headache now and again. But he manages to get to the end of the marked itinerary in spite of the crowds and the security rope that invites him to give it a gentle prod and watch it sway. The *Empower Parents* family has not only made this possible but has enabled us to take part in cultural activities as a family again. The emotional support we’ve found has given us confidence in ourselves. It’s been a therapeutic process for all of us... even for our younger son who didn’t understand what was wrong with his brother but now says he goes around ‘being careful not to upset anyone’, observing the differences, being more sensitive and aware of the fact that there other people with those differences.”

Esther and her family have been involved in *Empower Parents* since 2014



Action!

The programme of educational activities is aimed at families (parents, aunts and uncles, grandparents, etc.) with children between the ages of six and twelve who have varying types and levels of autism. It takes place over the course of nine months, coinciding with the school year, and consists of eight sessions held on one Saturday each month at Museo ICO. At each session, we carry out accessible activities with all the children, irrespective of their abilities, interests and ages, aiming to generate positive experiences in the museum space and encourage a cultural habit.

Running the programme in a social context like the museum means that we can incorporate multidisciplinary learning in social, communication and interpersonal skills, as well as specific habits in the museum context: walking slowly, speaking calmly, waiting for one's turn, etc., so that by the end of the cycle of sessions they can apply all these skills to other social contexts, such as with their family and at school.

In relation to the families, the museum acquires a whole new meaning, evolving from a “prohibited space” to a “conquered space”. At each session, we reactivate their agency, enabling them to appropriate the space and therefore transform the notion that many of them previously had about cultural institutions.

To guarantee the families' immersion in the programme, at the beginning of each edition we run a training session with the parents to provide them with the necessary information, such as the aims and structure of the sessions and the role that each participant will play during the family programme. We explore the space together so that it starts to feel familiar to them and they can find their way around, and we introduce them to the museum staff.

Each session lasts an hour and a half, and it's the parents who take the lead. Assisted by the educational team, they design the contents and activities as well the necessary supports for each child to be able to enjoy the experience autonomously. The sessions take place in the museum galleries and the workshop, and they all have the same structure: welcome gathering, exploring the exhibition space while respecting the presence of other visitors, and making the programme visible while discovering the exhibition. This is followed by an activity in the workshop related to the theme of the exhibition.

These activities enable the families to genuinely engage with the museum through contemporary artistic languages that vary from corporal, sensory-based proposals to different approaches that allow us to communicate with each child using the range of expressive languages. All the activities are prepared in advance to ensure a structured routine and the appropriate educational resources and accessibility supports. This means that each child knows beforehand what the activity involves and can take part in it as autonomously as possible.

At the end of the session, the team of families meets with the education team to evaluate the activity and pinpoint the successes,



failures and areas of discomfort so that the following sessions can be adjusted as necessary.

As well as the family programme, the parents take part in a training programme designed to encourage participation and the appropriation of the museum as a space for learning, and to provide them with the tools they need to be able to visit other museums and cultural institutions with their children confidently and autonomously.

Key data:

- Duration of the programme: 8 sessions
- Number of educators/mediators per session: 2
- Duration of each session: 90 minutes maximum (it's important not to make the sessions too long)
- Participants: children with autism spectrum disorder and their families (parents, siblings, aunts/uncles, grandparents, etc.)
- Recommended age: 6 to 12
- Maximum number of participants: 6/7 families per group (20/25 people)

Explore, learn, make visible

Over these past years, Museo ICO has become a space to enjoy, rediscover oneself, experiment and learn. The community of families has made autism visible and transformed the museum, and this transformation has generated opportunities to meet, establish dialogues and communicate with other audiences and the museum professionals.

Thanks to our presence at Museo ICO, we have been able to enjoy each and every one of the eighteen exhibitions we have explored over the years. But above all, we have resignified the museum space by introducing in each session new ways of being and relating to the museum galleries.

The family programme fulfils two objectives: it represents the possibility of carrying out an activity as a family, and it provides a site-specific learning experience that enables the parents to acquire the tools they need to visit a museum more confidently once they have completed the cycle of eight sessions.

It's important for the families to feel calm and confident, and for each person to appropriate the space in their own time and way. For example, there are parents who feel home from the very first session, while others adopt a more distant relationship with the institution, space and group, even though the mediation strategies used are basically the same. Many families have had negative experiences at other cultural institutions so instead of looking for automatic responses we need to observe them and let each person engage with the experience at their own pace.

Sequence of a session led by the parents during the programme at Museo ICO
Gabriele Basilico. *Entropía y espacio urbano* exhibition

We put into practice with the families all the elements included in the sessions, we jointly design the materials and supports that their children use during their experience at the museum, we show them how to communicate the activity to the group when they take the lead, and we put the structure of the session into practice.

Putting the learning into practice in context is vital because it helps the parents to incorporate the sequences naturally. During the cycle of sessions, they play different roles, from helping with an activity in the workshop to running a session and taking responsibility for explaining and supporting the group of children as they explore the gallery or do the activity in the workshop. The idea is that by the end of the cycle of eight sessions, all the parents in the group have played at least one of the roles.

The training for parents focuses on communication, the preparation of adapted materials and the practical implementation of the session structure.

Communication

The family programme involves children with different levels of autism, and the same group may include a child who needs augmentative and alternative communication (AAC) systems to communicate. The aim of these forms of expression, which consist of graphic symbols such as photographs, pictures, pictograms, words and letters, is to assist people with communication difficulties and language impairment.

In general, communication needs to be clear at all times, speaking slowly and using simple language, avoiding abstract concepts. During explanations, it's important to look at each child to capture their attention and make sure they understand, and nothing should interfere with the communication. It's useful to ask simple questions to check whether they have understood the explanation.

As we pointed out in the previous chapter, people with ASD are great visual thinkers. They have an excellent memory: they can remember numerous details with great precision, details that most of us probably wouldn't even notice. We use this sequence of abilities, images, memory and details to present the information during the sessions, and all the materials we prepare include real images and/or pictograms to present the information visually.

We use the ARASAAC²⁸ pictograms because these are the ones that the parents and children tend to use.

Adapted materials

At all times, the materials have addressed the needs of each group of children who have taken part in *Empower Parents*. In their design, we take into account the individuality of every child while ensuring that they are accessible for most of the group.



28. Aragonese augmentative communication portal that offers a complete database under a creative commons licence.

When preparing materials, it's important to bear the following in mind:

- Use pictograms and real images.
- To communicate actions through images, it's best to keep the sequence short—no more than three actions—so that everyone can understand it.

In all the sessions, we used the following materials:

- *Rules and presentation of the museum:* We explained visually how to behave and used images and pictograms to introduce the idea of the “museum”.
- *Visual agenda:* We sent this material to the families a few days before each session so that they could explain it to their children. As a minimum, the agenda should answer the following questions: Where are they going? When is the session? Who will they see at the museum? What are they going to do? How long will it last? What happens at the end of the session?
- *Visual guides:* We used three visual guides during each session.

General routine guide: to explain the different sequences and activities. We used it throughout the session, verbally repeating the things we'd already done and the things we still had to do so that the children knew where they were on the session timeline.

Gallery activity guide: to explain the specific sequence of activities in the exhibition space.

Workshop activity guide: to explain the specific sequence of in the workshop.

- *Evaluations:* to obtain an impression of each child's relationship to the activity carried out: how they felt, what they liked, who they felt comfortable with, etc.

There are two types of evaluations:

- One completed by the children with the most advanced communication skills, where they draw pictures and use coloured crayons to indicate the aspects of the workshop they've enjoyed the most as well as their emotions with respect to the activities carried out.
- And a tactile alternative used for the same selective purpose as the first evaluation but for children who find it easier to communicate their responses by physically manipulating plasticised pictograms and stencils.

Collective preparation of contents and materials at Medialab-Prado

pp. 152/153: Evaluation of the session by children at Museo ICO



Structures and routines

Routines help people with ASD to understand and predict what is happening around them, reducing the stress of the unknown



“Routines help people with ASD to understand and predict what is happening around them, reducing the stress of the unknown and helping them to develop skills.”

and helping them to develop skills. In some cases, the absence of routines can prompt them to develop their own, which may be less appropriate or unsafe. Children with ASD learn through repetition, and it’s therefore important to create structured routines in every context that they can rehearse and repeat.

Routines such as entering the museum, greeting people, leaving their coat in the cloakroom and proceeding to the space for the introduction assembly can help to reduce or eliminate less appropriate routines like shouting and running around. The repetition of these routines at every session helped the children to internalise them, associating them initially with the context of Museo ICO and then applying them to other museums and/or educational or other environments.

When we speak about routines, we are referring to the definition of a structure that is predictable for children with ASD but can be followed by the whole group (siblings, friends, neighbours, etc.). It’s important for the routines to be fairly flexible so that they operate as a lesson in reality, where change is constant.

The sessions are structured around three sequences carried out in different spaces with specific objectives and routines:

- Sequence 1: Welcome and introduction
- Sequence 2: Experience in the exhibition space
- Sequence 3: Experience in the workshop

Evaluation using material designed to facilitate manipulation and selection

Breaks and transitions

The transitions last approximately five minutes and take place between sequence 2 and sequence 3, coinciding with the switch from the activity in the exhibition space to the one in the workshop room. The transitions and their duration should be announced in advance.

It’s important to have a “quiet zone” in the museum for situations when the children need to calm down, away from noise and stimulants.

Session evaluation

At the end of the session in the museum, a group of parents should meet with the educational team to evaluate the following aspects:

- How did the leaders feel? What aspects should be improved and what works well?
- How did the families feel? Were there any incidents?
- Successes and failures?
- Collective decision about what needs to be changed before the next session.

The session at the museum

The *Empower Parents* sessions are structured around three sequences (described below), supplemented with brief notes for the education team that is going to put them into practice.

In this section, we share the methodology for the programme of activities, but we view it as a flexible format that can be adapted as necessary. We used complete sequences but, depending on the programme needs, the entire session can be carried out in the exhibition space or workshop according to the objectives and contents of each activity.

Sequence 1: Welcome and introduction

The welcome is a time for hugs, meeting again after the previous session, and catching up on how things have gone since we last saw each other. It’s a special caring space because it provides the foundation for building bonds and relationships with the families.

Actions:

- We sit on the floor, in a circle, and use play to introduce ourselves.

“The *Empower Parents* sessions are structured around three sequences.”

- After the group introduction, the people who are going to lead the session introduce the activity, using the visual resources and materials.

Objectives:

- Introduction of the participants.
- Explanation of the activity sequence by the leaders.

Location:

It's best to use a large space, such as the museum foyer, that accommodates the assembly of six or seven families, approximately 20/25 people. Other visitors to the museum should be able to view the space chosen in order to make the programme visible.

Duration: 10 minutes

Materials:

Rules and presentation of the museum:

Visual guide: general routine. This support should be used throughout the session, verbally repeating the things we have already done and the things we still have to do so that the children know where they are on the session timeline.

Note for educators:

People with ASD don't handle waiting very well, possibly because of the difficulty of understanding social contexts. It's therefore important to start the activities at the designated time.

Beginning with the group introduction is a way of starting the activity and also allowing families who arrive late to settle in naturally. The session can get under way without interruption, so there is no unnecessary waiting and the settling in part is more flexible.

To keep the group introduction short, it can just involve the children. This will depend on the number of participants in the session.

Some children may be nervous or agitated when they arrive at the museum, so it's important to begin the activity slowly and calmly. The activity explanation is the moment to tell the children what they are going to do, where they are going to do it and how long it will last. Starting like this allows them to settle down and connect with the space and with other visitors at their own pace and without any demands.



Sequence of a session: welcome and introduction

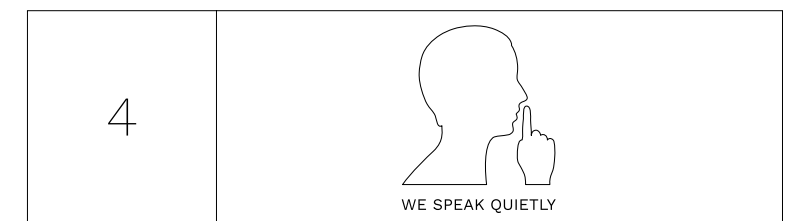
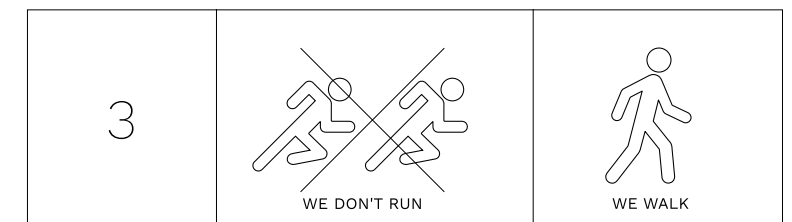
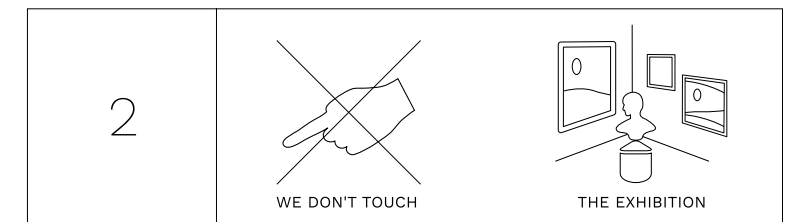
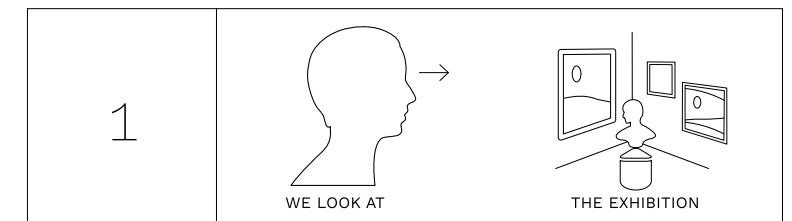


Welcome sequence at Museo ICO

Sequence 2: Experience in the museum galleries

The body, movement, sound... the sensations that the space arouses are the resources that will be used to explore the museum in a playful manner. Occupying it, strolling through it, dancing, listening to it... The exhibition space as a place, separate from its contents. On another level, the exhibition offers a resource for establishing a dialogue between the group and other visitors.

Exploration and play lead us to the selected pieces, located at different points of the exhibition space.



“This support should be used throughout the session, verbally repeating the things we have already done and the things we still have to do so that the children know where they are on the session timeline.”

Actions:

- Explore the exhibition space, following an itinerary through the galleries and communicating with the other visitors.

Objectives:

- Create a positive experience that enables each child to connect to the space from their own individuality.
- Encourage meaningful learning experiences inside the museum space which they can apply in their everyday life.
- Communicate and dialogue with the other visitors and the museum professionals.
- Find different ways of inhabiting the space.
- Make autism visible.

Location: Museum galleries

Duration: 20 minutes

Materials: Visual guide for the gallery activity

Note for educators:

Before the session, the families and professionals should check the museum galleries to identify any sensory distractions (audios, videos, etc.).

The itinerary through the exhibition space should be planned to avoid improvisations, changes and unnecessary waits. Like the activities carried out in the gallery, the itinerary must appear on the visual agenda sent out beforehand to the families.

Select an average of three pieces to establish a meaningful connection, creating supports with images for each explanation.

Keep explanations short and don't ask the children unnecessary questions.

The educators should be invisible, observing the session while the parents lead it.



Sequence of a session: experience in the museum galleries

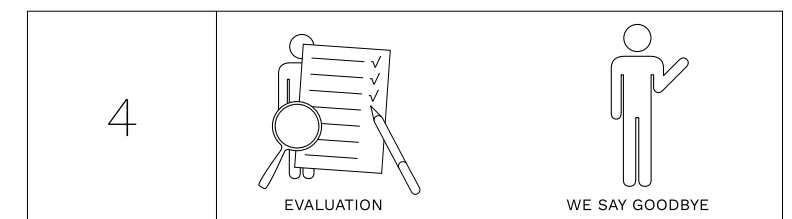
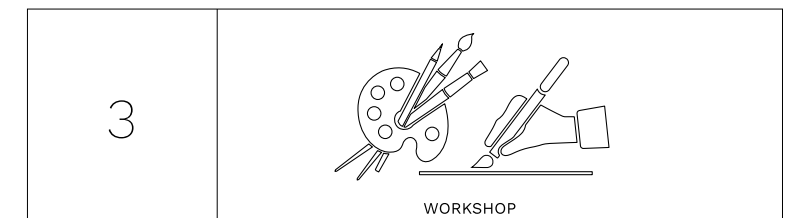
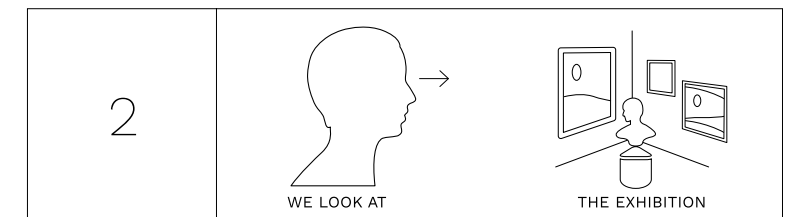
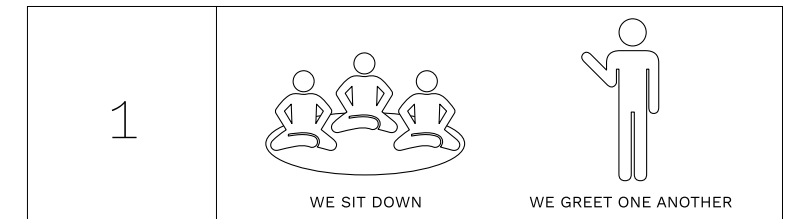
Sequence 3: Experience in the workshop

Regardless of the creative activity carried out, it's important to create a space for experimenting and feeling. "Sensory" is the essence. Allow enough time to explore the materials and feel them, and then move on to a collective task that helps them to develop an interpersonal connection. The group work is the



Group of mothers leading an Empower Parents session at Museo ICO

perfect moment for bringing everyone together so that they can share and bond.



“Explore the exhibition space, following an itinerary through the galleries and communicating with the other visitors.”

Actions:

- Carry out an activity designed and led by the team of families.

Location: Workshop room/exhibition space

Duration:

Activity: 35 minutes

Reinforcement: 5 minutes

Tidying up and saying goodbye: 15 minutes

Materials:

- Visual guide for the workshop activity: activity in three steps with the option of marking each step as it's completed, managing the activity autonomously and following a specific procedure.

Notes for educators:

The educators should be invisible, observing the session while the parents lead it.

This is the most creative part and continues the work carried out in the exhibition space.

In the workshop, the children should sit at designated tables based on the work groups defined in the gallery. These groups can vary from one session to another to encourage greater interaction. Depending on the session, the work can be carried out at a table or on the floor in the workshop room.

It's important to create the necessary supports so that the children can work as autonomously as possible according to their individual abilities.

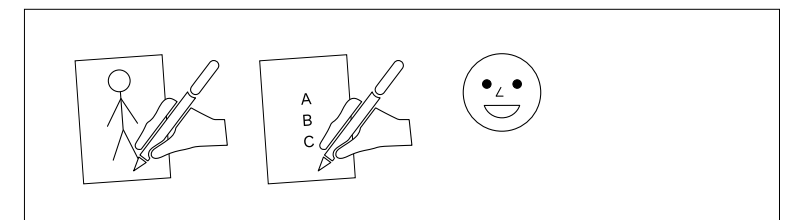
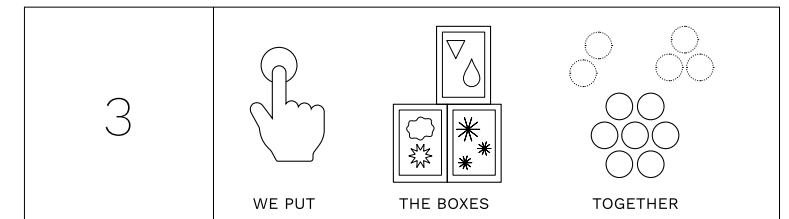
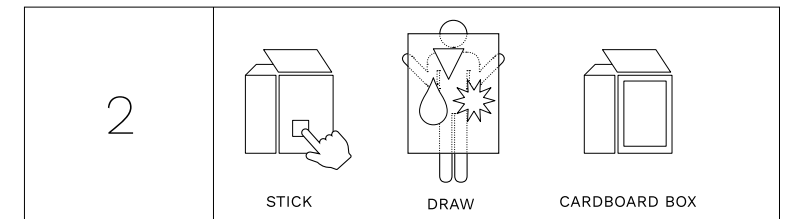
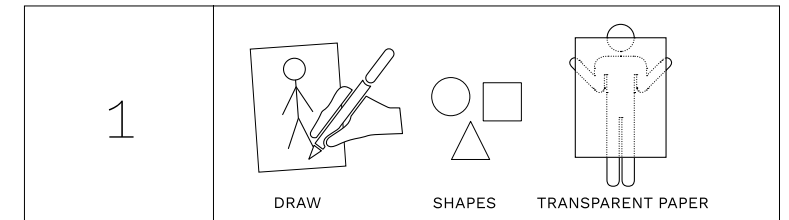
At the end of the activity, reinforce the work each child has done. It's important for them to feel proud of their work and for each child to have enough time to explain what they've done. The reinforcement should be public, visible and immediate.



Sequence of a session: experience in the workshop



Using the visual guide during a workshop activity at Museo ICO



“Activity in three steps with the option of marking each step as it's completed, managing the activity autonomously and following a specific procedure.”

NAME _____ DATES _____

Evaluation form used at the end of each workshop. The children can select what they like best about the workshop and indicate their emotions with respect to the activities carried out.

HOW DID YOU FEEL TODAY AT MUSEO ICO?

THE EXHIBITION HAPPY SAD NERVOUS

WORKSHOP HAPPY SAD NERVOUS

DRAW OR NAME THE FRIENDS YOU WERE WITH

Bibliographical references

[Autismo diario \(2020\). *El método Teacch*. https://autismodiario.com/wp-content/uploads/2011/03/resumenTEACCH.pdf](https://autismodiario.com/wp-content/uploads/2011/03/resumenTEACCH.pdf)
[retrieved:15/05/2020]

[Autismeurope \(2019\). *People with Autism Spectrum Disorder. Identification Understanding Intervention*. https://www.autismeurope.org/wp-content/uploads/2019/11/People-with-Autism-Spectrum-Disorder.-Identification-Understanding-Intervention_Spanish-version.pdf](https://www.autismeurope.org/wp-content/uploads/2019/11/People-with-Autism-Spectrum-Disorder.-Identification-Understanding-Intervention_Spanish-version.pdf) [retrieved:16/05/2020]

MESIBOV, G. and HOWLEY, M. (2011): *El Acceso al currículo por alumnos con trastornos del Espectro del Autismo: uso del Programa TEACCH para favorecer la inclusión*. Ávila: Autismo Ávila.

LÓPEZ, M. and CANDIANO, J. (2010). [Room to Grow. A Guide to Arts Programming in Community Spaces for Families Affected by Autism](http://www.hablarenarte.com/uploads/proyectos/155_1314.pdf). Nueva York: Queens Museum of Art. http://www.hablarenarte.com/uploads/proyectos/155_1314.pdf
[retrieved:15/05/2020]



Chairman:
José Carlos García de Quevedo Ruiz

Director: Lucinio Muñoz Muñoz

Head of the Art Department:
Gonzalo Doval Sánchez

Art Department:
Alicia Gómez Gómez
Silvia Consuegra Rodríguez

Published by: Fundación ICO

Texts, editorial concept and general coordination:
Laura Donis Quintana

Editing: Feliciano Tisera
Proofreading: Ignacio González
Translation: Polisemia
Fundación ICO Coordination: Silvia Consuegra
Gráphic Design: Jaime Narváez
Printing: Brizzolis
Binding: Ramos
Images: Andrea Beade, Maira Villela, hablarenarte

Acknowledgements: We would like to express our sincere gratitude to Michelle López, Jennifer Candiano and Mitra Dejkameh of the Department of ArtAccess at Queens Museum in New York, Sofía de Juan, Tanit Lagüens and Álvaro Molina of hablarenarte, and Alicia Gómez of Fundación ICO. Without their determination, this adventure would not have become a reality.

To Mónica de Linos, director of Fundación ICO from March 2012 to 2016, for her generosity and constant support for the programme.

To the education team at hablarenarte who have been involved in *Empower Parents* since the outset, for their diligence and commitment.

We are equally grateful to the Embassy of the United States in Madrid, Confederación Autismo España, Federación Plena Inclusión Madrid, Asociación Pauta, Asociación Trastea, Asociación TEA Talavera and Asociación Aleph. Thank you for your constant cooperation and for forming part of this network.

To the interviewees (Michelle López, Alicia Gómez, Ana Lozano, Lucía Loren, Irene Cantero, Gemma

Dominguez, Isabel Melguizo, David González, Nuria González, José Luis Morales, Ana Gómez, and Marta, Fran and Miguel), for supporting this publication.

To the vast community of *Empower Parents* families associated with Museo ICO in Madrid and Queens Museum in New York, and to the families who took part in the replication programmes at Museo Thyssen-Bornemisza, Museo de la Ciencia de Valladolid, Museo del Traje. CIPE, Espacio Fundación Telefónica in Madrid and La Fábrica de la Luz. Museo de la Energía in Ponferrada. Thank you for your enthusiasm and commitment.

To the team that accepted the challenge to create the *Empower Parents* Association to bear witness and take the magic of the programme to new spaces.

And very especially to the small and great artists, plant enthusiasts, photographers, budding palaeontologists, music lovers, dancers, inventors of unimaginable cities and experts in urban mazes. Boys and girls with a gift for navigating unknown places, many of whom would live under the sea if they could... Thank for you showing us how to look at the world in a different way and, every Saturday, set ourselves the challenges that have taught us so much over these last few years.

Thank you.

© of this edition, Fundación ICO and hablarenarte 2020
© of the texts, the authors
© of the images, the authors

The texts in this publication are protected by the terms and conditions of the Creative Commons licence "Attribution-NonCommercial-NoDerivatives 4.0 Spain". The material may therefore be copied in any mechanical or digital format provided that it is not used for commercial purposes, is not modified in any way, and the authors are credited and cited correctly. Any other use requires the express permission of the authors and publisher.

The authors made the decision to use gender-neutral expressions in the texts.



ISBN: 978-84-948744-4-4
National book registry number: M-30805-2020

The contents of this publication can be downloaded from the following websites: empowerparents.net/fundacionico.es/hablarenarte.com

This book is a pause to organise and reflect on the work carried out since 2013 through the *Empower Parents* programme, an innovative experience in Spain with families affected by autism that enabled us to create a stable community and define a practice, described in this publication, which we hope will serve as a tool for the implementation of similar programmes at other museums and cultural institutions.

The book is also a space to converse and to thank everyone who has participated in the programme over the years. It includes eleven conversations held with different social and cultural agents, artists and families who represent a collective voice through their accounts of their experiences, sharing their concerns and wishes but above all explaining why they believe cultural institutions need to adopt a more transformative gaze and become common spaces that we can all enjoy from our different identities.

Transforming cultural institutions into genuine spaces for all is the essence of the EMPOWER community. We invite you to come in and join us.



MUSEO
ICO

hablarenarte: