TRANSMEDIA LEARNING FOR PREVERBAL CHILDREN WITH AUTISM:

TAKING ADVANTAGE OF DIGITAL CULTURE AND DEVICES

Nohemí Lugo

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About the Author

Nohemi Lugo holds a Ph. D. in Communication from Pompeu Fabra University, earned a Master of Arts in Spanish from Western Michigan University, and a Bachelor of Communication Sciences from the Tecnológico de Monterrey, Mexico.

She is a full-time researcher and professor in Tecnologico de Monterrey, at the Department of Media and digital culture of the Querétaro Campus, the Online Master in Educational Technology, and the Doctorate in Humanistic Studies of the Monterrey and Mexico City Campus.

She belongs to the research group in *Art, media, and digital culture* of the Tecnológico de Monterrey and the *MEDIUM* group of the Communication Department at Pompeu Fabra University. She is part of the media literacy network, *Alfamed*, (Mexico chapter), and belongs to the scientific committee of *Virtualis*, a journal of the Tecnológico de Monterrey dedicated to digital culture. She also belongs to the scientific committee of *Contratratexto* published by the University of Lima and the National System of Researchers in Mexico.

Currently, she does apply research and projects that promote inclusion, health, and education, especially for the population with autism through the study of digital culture, digital storytelling, and interactive communication.

She was a junior researcher of the international Horizon 2020 *Transmedia Literacy* project. She has published several scientific articles, the book *Relato digital, Continuidad y Rompimiento en la Narrativa* and is currently in the process of *publishing Diseño de experiencias de aprendizaje: Transalfabetización, cultura e innovación educativa.*

She is co-author of the Learning Management System *Aprendiz*, which bases on game principles, mastery learning, peer to peer learning, and contributions of digital culture frames.

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Acknowledgment

I would like to express my deep and sincere gratitude to everyone who has been there as a motivator, companion, facilitator, and guide. This book was imagined and published thanks to you.

First, thanks to Andrés, my 10-year-old son with autism. His condition has changed the course of my life and has profoundly changed me. The challenges we have faced as a family, especially those related to his education, have revealed the need for innovation in the long-life learning process of persons within the spectrum, the unfinished work on social and educational inclusion, and, especially, the validation of all kinds of differences. He has made me question what "diversity" means and look for strategies to be respectful towards the development of all children. He has taught me that every act of teaching and learning needs an intentional design and implementation that is respectful, ethical, loving, honest, curious, and creative.

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I would like to thank Diego Reza and Luis Padilla. They are the kind of therapists that all children and families should have. They gave me hope when many discourses about the future of my son were very negative. Besides, they taught us the essential skills to raise Andres. Their therapy approaches were the inspiration for me to look for sources behind their approach to autism therapies such as Vigotsky. One of the Vygotskian theories' most empowering concepts is the zone of proximal development. I was an educator with 15 years of experience when I discovered we have the same foundation for education. Developmental

Socio-pragmatic approaches to autism resonated with my vision very quickly.

I would like to thank all of the *Centro de Estimulación Infantil de Barcelona's* sensory integration therapists, who were also very sensitive and caring with my son. They made me discover the fundamental role that sensory integration plays in the quality of life of most people within the spectrum, an aspect that I later researched and have observed in all persons within the spectrum that I know. Taking sensory challenges into account is an integral part of the proposal of this book in chapter 4.

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This book was inspired by the challenges that many families with autism face. I thank my friends from the autism community in Queretaro, Mexico. They have also let me discover the unique challenges that every family has. They have been a motivation and informed my vision of autism. They have trusted me and have been collaborators in different autism research projects. In this work, I would like to thank especially Eli, who allowed me to enter her family intimacy and document the case of Emi, her son, which is presented as a case study in chapter 3. I am sure that his case and the way he learns will resonate with many families.

While I don't know them in person, I would like to thank the most meaningful authors cited in this work, whose works made me feel that I was not alone in my view about autism. I learned from their critical vision, approaches, and theoretical frames: Themistoklis Pantazakos, Eva Kittay, Chandra Kavanagh, Majia Holmer Nadesan, Marion Quirici, Thomas Armstrong, Aiyana Bailin. Their meaningful ideas are explained in chapter one and work as the ethical standpoint of this work.

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From Transmedia Storytelling to Transmedia Learning (Foreword)

Carlos A. Scolari, Depart. of Communication Universitat Pompeu Fabra, España

cscolari@updf.edu   https://orcid.org/0000-0002-7792-0345

Since its introduction by Henry Jenkins in an article published in 2003, the concept of 'transmedia storytelling' has gone through different mutations and interconnections. From the early reflections on transmedia fictions, researchers and professionals moved to transmedia documentaries and journalism, and from there to transmedia branding and marketing. At the same time, educators and media literacy practitioners discovered the advantages of thinking their research and activities from a different perspective: transmedia literacy, transmedia education… and now, transmedia learning. In all of these combinations, two characteristics emerge as distinctive traits: many media and platforms are involved in the communication process, and the subjects actively participate in the creation and expansion of the storytelling.

Nohemí Lugo Rodríguez is a pioneer of transmedia education in Ibero-America. Her Ph.D. thesis ('Design of transmedia narratives for transliteracy,' 2016) studied the application of transmedia storytelling for the teaching of transliteracy across the curriculum, that means, while teaching literature, arts, sciences or other topics. Beyond this early interest in the crossroads of transmedia and education, in the following years, her work expanded to new research areas and applications, including the object of this book: the learning processes of preverbal children with autism. As the reader will discover in the following pages, educational research on autism is not as intensive as it should be (one percent of the population around the world is on the autism spectrum). Only 16% of the funding was dedicated to research about educational projects, and 5% went to occupational, physical, and sensory-based therapies research.

In this context, Nohemí Lugo Rodríguez proposes a series of cases and proposals for fostering the learning of preverbal children that are

inspired by the principles of the transmedia logic. As indicated in the preface, the purpose of the book is to offer a practical, adaptable, multidisciplinary, easy to apply, and inexpensive contribution to foster the learning of children with autism in general and, especially, preverbal children at home, public, and semi-formal learning spaces. The research behind the book situates in the intersection of a dense network of theoretical references: representation studies, new literacies, fan studies, disability studies, neurodiversity, educational technology, and, obviously, transmedia studies. the volume presents itself at the same time as a map of emergent research and a set of opportunities under a new key concept: Transmedia Learning Design.

A few words about Transmedia Learning Design: this intervention proposal stems from a series of fundamentals, from the ethical and humanistic perspective that validate people with autism to the learning possibilities of multimodal and ubiquitous mobile devices, going through the use of technology as a cultural activity and the integration of popular media in the learning process of children with a disability. The book includes different activities that could be developed under the 'umbrella' of Transmedia Learning Design, for example, the critical adoption of commercial transmedia narrative worlds for personal use or the development of practices based on characters, fictional worlds, or personal experiences. The original spirit of transmedia storytelling –that is, the combination of different media and platforms with the participation of subjects in the narrative construction- is present in each one of those activities.

In a few words: this book is another step in the expansion of the concept of 'transmedia' beyond its original environment (the fiction) into the territory of learning. In this case, it refers to working with preverbal children with autism. As indicated below, this volume is at the same time a map and a tool for researchers, educators and families. If someone thought that transmedia storytelling was just a brand new fashionable concept or the last Hollywood business, please read the pages that follow.

Preface

Autism Spectrum Conditions and Quality of Life of Preverbal Children

One percent of the population around the world is on the autism spectrum. In a study performed by the Autism and Developmental Disabilities Monitoring Network where participants were 8 year-old children, from eleven cities of the United States, the prevalence reached 1/59 in 2014 (Wiggins, Christensen, et al). A previous study where the total number of children of South Korea was sampled, 55,000 children, the prevalence was 1 child in every 38 (Kim, Leventhal, Koh, Fombonne, Laska, Lim & Song, 2011).

There is a discussion about whether statistics imply a growing number of people with autism, or different diagnostic methods among countries or, differences in the methods used in the present in comparison with the past. Nevertheless, autism is among the most prevalent disabilities in children and is a lifelong condition.

People with autism face challenges in reciprocal and social interaction, communication and language. In order to have an diagnosis of autism, children should present what in medical terms is described as "deficits" in the aforementioned areas, as well as repetitive behaviors, and what is described as "narrowed interests" (DSM-V, 2013).

It is a condition that has several comorbidities: persons within the spectrum may have one or more conditions or illnesses along with this main condition. Among them are attention deficit, epilepsy, gastrointestinal disorders, sleep disturbances, anxiety and depression (Autism Speaks, 2018).

While sensory disintegration is not considered as part of the diagnosis, according to Iarocci & McDonald, (2006) who reviewed at least another fifteen research papers:

> The earliest, as well as the most current theories of autism, are based on the premise that persons with autism process sensory information in a way that is different from others" The authors add that autobiographical accounts of their subjective sensory experience "refer to difficulties in the reception (input) and processing (making sense) of sensory information. The personal accounts include examples from vision, sound, taste, smell, proprioception, and kinesthetic stimulation of sensory distortions, sensory tune-out, and overload, synesthesia difficulties processing information from more than one modality concurrently, and difficulties identifying the source modality of sensory input (no page).

Sensory disintegration and reactions and behaviors caused by it are some of the factors that most affect the quality of life of children and their families.

The reason to study autism is frequently cited as a public health issue born of what has been perceived as a growing prevalence. Economic issues are also mentioned. In a comparative study between the US and the United Kingdom, it was discovered that parents of children within the spectrum spent more money on health and special education than regular parents, and they lose productivity. Other costs include the attention that people with autism conditions (ASC) might need as adults, such as residential care or supportive living accommodation and their reduced possibilities to work as well as medical expenses that increase in adulthood (Buescher, Cidav, Knapp & Mandell, 2014). Those costs are not just for parents but for governments.

While these arguments are true, in this work, I would like to put aside economic and productivity arguments and shift the focus to the quality of life of children with autism and their families as the main reason to do research. I will especially focus on the people labeled, until now, as

"nonverbal". Some sources consider them to be between 25% and 50% of the autism population (Yee, 2012). In the US, Autism Speaks (2018) declares that they are about a third of the population within the spectrum.

Among the population of children with autism, "Nonverbal" children have the least possibilities to participate in any sphere in society and are the most vulnerable. "Nonverbal" is not only used as a descriptive adjective to indicate someone does not physically speak. It implies that

"Nonverbal" children have the least possibilities to participate in any sphere in society

they are unable to express and communicate, frequently classifying them in a category that until 2013 was described as "low functioning" in the diagnosis groups by the MSD.

The field of alternative and augmentative communication has done valuable research for fostering communication through digital or not digital communicators for "nonverbal children", but in general, families face great challenges for their communication and learning. The process and cost of alternative communication is not always affordable and the effort and competencies required for parents are additional barriers.

As the mother of a child with autism, and an autism researcher, I have listened to many stories related to the role of parents and learning. For instance, three years ago, a single mother of a 5 years-old preverbal child narrated that sometimes she did not have money for gasoline or lunch and would not send her child to the special education school he attended. She was partially maintained by her brother and had to work just to have enough money to send her child to school or take care of him during his after-school hours. She did not know about the existence of alternative communication. At that moment she was busy trying to find out how to make her child stop using diapers and allow his hair to be cut. Finally, the child left the school and stayed at home. She told me she wished to know how to help him to learn because she also lacked knowledge and resources to teach him at home.

This story seems dramatic, but many countries face challenges implementing inclusive education and special education, and their social services are not enough. This happened in Mexico, but to different degrees, even in countries that are considered to have an advanced inclusive education policy in Iberoamerica such as Spain, parents face many challenges, which they publish in newspapers and activism blogs.

School inclusion for children within the spectrum frequently does not happen. Even when it does, it is less likely to be a meaningful learning experience when children do not speak, show severe sensory responses to the environment or engage in disruptive behavior. What is typically done is integration: the child is at school. This, however, is not an authentic inclusion. The participation of children is very limited, as is their learning experience. In addition, children with disabilities are more likely to suffer bullying. In a country like mine, and maybe in others, special education faces different challenges such as the number of children in attendance, the number of teachers, lack of training and interpersonal skills of professionals, assigned resources, and so on.

Lack of Research Focused on Promoting Learning of Preverbal Children with Autism in Different Settings and with New Strategies

According to a report by the Office of Autism Research Coordination of the US, in 2015, which is the most recent report, just this country spent 342 million dollars in autism research. This money is mostly dedicated to the medical field, especially to research autism biology, 34%, etiology, and risk factors 32%. Treatments and intervention receive just 20% of the total funding. That funding covers interventions including pharmacological, behavioral, educational, occupational, technology-based, and alternative/

Treatments and intervention receive just 20% of the total funding

complementary/ integrative medicine approaches. Out of the 20% total budget for treatments and intervention research, only 16% was dedicated to educational project research and 5% to occupational, physical and sensory-

based therapies research. Siegel (2018) argues that "present spending in autism research has almost no practical value".

While most of the budget in non-medical research was dedicated to "development of model systems targeting areas for new interventions'' (25%) these are therapeutic projects. There are several problems derived from this. First, Therapy is not the same as learning. The objectives of therapy may differ and be focused on remediating a specific challenge. Assumptions about autism and child expectation may influence the design. Second, therapies that can be conducted only by a specialist and in a therapist office, may not be a viable option for many parents. Third, the existence of research is not equal to the community receiving the input of research: "Efforts to apply research findings in public services and professional support have not always been forthcoming, raising serious questions about the utility of past and existing models of practice in autism research" (Fletcher-Watson et al, 2019). Fourth, the perspective of research can be problematic too and may not reflect the needs, vision, and experience of the autism community. There is a lack of participatory methods that include the perspective of the community (Fletcher-Watson et al, 2019) and there is a need for more phenomenological approaches in researching autism. (Pantazakos, 2019).

Potential Solutions for Fostering the Learning of Preverbal Children: A Space for Digital Culture and Devices

Not many researchers are currently looking at the practices of children within the spectrum that have access to technology. However, children within the spectrum are using their own, or their parents' digital devices in the same way children with typical development are: at home, in the car, planes, and restaurants either to watch their favorite cartoons, listen to music or be entertained. A few of them may use their device as a speech communicator device. Parents and caregivers may be concerned about the time of consumption, or use them to have a little free time while they are entertained. Teachers might be worried about use of time too, but both

may need to go further and consider what to do with this time and how to take advantage of these devices to foster involvement, interaction, and learning.

Access to digital technologies and Internet stills varies not just among countries but within the areas of each country, the cost of mobile devices is cheaper than many other technologies and they can work without Internet access, are portable, resistant, have the capacity to host or stream videos, music, podcasts, and children's digital books, apps, communicator speech applications, edutainment and learning applications, and images. All of them can be connected to children's tastes, preferences (and learning needs). Mobile devices allow interaction and production without speaking. If used in libraries or community centers they can be shared.

Mobile devices allow interaction and production without speaking

In addition to children's use, parents are chatting about treatments, practices, nutrition, personal challenges and more, in digital affinity spaces such as private parents groups in Facebook or WhatsApp, open pages, blogs, and so on. Parents upload their experiences on YouTube channels and Youtubers on the spectrum explain their life experience. All this, which may promote collective intelligence in the community and is a great source of information for researchers, is unfortunately mixed with fake cures and fake news. Discussions about different beliefs concerning how to deal with disabilities and treatments are common, and may even feature aggressive comments because of these ideological differences (Antunes & Dhoest, 2018).

The practices of children within the spectrum around digital devices should be formally investigated

Even so, platforms and social media offer a window to families' experiences and discoveries. The practices of children within the spectrum around digital devices should be formally investigated and the parents' experiences too.

In a closed group for parents on Facebook, many years ago, I saw a video of a "nonverbal" 12 years-old Mexican girl that started singing at the funeral of her grandfather. The girl sang the same song for three weeks. She did not speak, she just sang and cried. Later, she started to talk. She said "thank you", her first word. For a few weeks, her mother shared videos of how she started dancing and helping in the kitchen and saying phrases.

A few months ago, I saw a viral video and an account on Instagram. Jaime, a Spanish preverbal boy on the spectrum who started talking at 21.

Navigating, years ago, I also discovered the Alternative Teaching Center in California where children with "severe autism", sensory and behavioral challenges are taught their numbers, letters, and many other topics and skills. They do not speak but they do write and they can count on their tablet or throughout visual strategies. It was a project initiated by parents that were told that their son would never communicate and learn. Their son Ethan has never spoken but he has finished high school's average learning curriculum.

As a mother and researcher, the previous findings have made me question the idea that my son will not communicate, and has made me treat him under the assumption that he understands more than he demonstrates. I grasped that I had to teach him. As a media and education researcher, and an avid user of a tablet, I started to practice without having formal research intentions at first. I started to upload private videos of these practices to YouTube, leaving some of them open, whenever my child's privacy was not compromised. I started to share my observations in a Facebook private family group. As a previous second language teacher, I discovered that many strategies to learn a second language were useful for my son. Our story is not a miracle. While he is 10 years old, he does not speak (yet) but his receptive language is advanced and this has a very positive effect on his quality of life and meaning of life.

This is one of the reasons to use the term "preverbal" instead of "nonverbal" in this work. Some children will speak later in their life, others

will never speak using oral language but hopefully will be able to communicate in different ways if stimulated. I took the idea of using "preverbal" instead of nonverbal when I listened to Daniel Comín mentioned it in a course (2015). He is the father of a child within the spectrum and also an activist and coordinated one of the most important projects in the Iberoamerican region: the *Autismo Diario* foundation and specialized blog.

Calling them preverbal, has another meaning in this work: implying that their communication skills are in process and evolving. For me as an author and mother, it is essential to avoid adjectives that deny their possibilities and potential to communicate and their actual strategies to communicate, either by yelling, singing, doing echolalia, showing, taking people where they want to go, taking objects, looking at something, crying to show frustration or selecting an icon on a tablet. While some of this is said not to be intentional communication, we should not forget that communication is a bidirectional process and we always make efforts to understand others when they speak a different language. We achieve more if we make an effort to understand and assign meaning even if we make a mistake. We should not forget that language is not just productive but receptive, and that verbal language is not the only way to communicate.

Purpose and Theoretical Frames

Theoretically, the book is based on the intersection of the cultural communication studies field: representation studies, new literacies. fan studies and, transmedia studies; the humanities: disability studies, neurodiversity, the ethics of care and, the educational technology field. The Transmedia Learning Design proposed in this work has four main foundations:

- The ethical and humanistic perspectives that validate people with autism, a fair representation that avoids stereotypes and stigmas. This contributes to recognizing the ability in people with disability

and to make sure that any strategy designed for them is based on a recognition of their needs, rights, interests, and potential.

- The learning possibilities allowed by mobile devices. Especially the multimodal reception and multimodal production capabilities of mobile devices and the selective interactivity features (Ryan, 2015) which provides opportunities to interact, learn or show learning without using oral or written language as a predominant or exclusive medium to communicate and learn. This may foster communication and learning anywhere because of ubiquity. This can be an essential game-changer for children who do not speak. While this has been explored by studies of alternative and augmentative communication, there might be additional contexts and strategies in which mobile devices can be useful for learning.

- The use of technology as a cultural activity. Awareness about the fact that users appropriate devices and content as cultural objects within specific contexts. This context mediates use and meaning.

- The integration of popular media interests in the learning process of children with a disability. From the medical point of view, people with autism have "narrowed interests" which hinder their social interaction and learning. From a cultural point of view, children within the spectrum can be understood as fans. Recognizing their transmedia literacies (Scolari, 2018) might allow integrating their interest in learning as the connected learning frame proposed by Ito et al (2010, 2018), who has claimed is possible and necessary for children and young people in general.

Organization of the Book

Chapter 1. The Representation of Autism: its implications for the Learning of Children within the Spectrum

This chapter narrates how autism has been represented and how this may influence approaches to teaching children with ASC (autism spectrum

condition) in general and preverbal children in particular. The first section presents a brief analysis of the representation of autism during the XX Century and its social construction. The second part focuses on discussing stigma imposed on children with ASC and how this affects learning expectations, especially for the ones who, for a long time were diagnosed as having "severe autism", or "low functioning autism", a label that disappeared for the diagnosis in 2013 but continues to shape common ideas about the potential of children.

Finally, the third part posits a humanistic perspective to autism, to guide educational efforts and design learning strategies nurtured by the best ideas offered by social models of disability, the sociology of technology (Winance, 2016), the ethics of care (Kittay, 2011) and the concept of neurodiversity.

Chapter 2. Preverbal Children with Autism as Users and Participants: Mobile Devices for Literacy and Learning

The chapter explores the role of mobile devices (MD) in the learning process of children with autism. There are two approximations in the relationship between media and learning: learning with media and learning about media (Buckingham, 2008). *Learning with media* refers to the use of media as a tool for learning. *Learning about media* refers to understanding them in a cultural context, as cultural artifacts or cultural devices inserted in a context, as well as thinking about the broader and more transferable abilities that users need to manage technologies like communication and media creation devices (literacy).

In the first section, the advantages and capabilities of MD to foster learning are explained. In the second section, there is a review of studies where MD has been used to promote the learning or literacy for children with disabilities in general and autism in particular. The chapter includes a case study of MD in the home. It makes use of auto-ethnography as a method to expose how I have used an iPad for five years with my son, who has an Autism Spectrum Condition and is preverbal. Admittedly, this

experience is based on a single case, but it has the advantage of being long term and in a natural context, which is nonexistent in the literature.

The chapter proposes that children with autism, especially if they are preverbal, should receive literacy instruction. This implies establishing what children should learn about the implicated devices to ensure that devices foster agency. Finally, it offers recommendations to support learning practices based or facilitated in MD emphasizing ideas to promote active viewing, involvement, interaction and participation and collaboration without depending on oral language.

Chapter 3. Children with Autism as Fans. From their Deep Interest to connected Learning

This chapter focuses on studying the potential that fan-cultural practices of people with autism might have in their life, to posit strategies that connect fan practices to learning.

First, this discussion is based on a theoretical approach that explores the role that fan practices could have for children with autism. Since these practices have not been explored empirically in previous papers, this framework acts as a hypothesis based on fan studies theory and empirical papers; papers that relate to fan practices and their role in forming or belonging to communities, informal learning, and self-representation on affinity spaces.

Second, the main focus of the chapter presents a case study that describes the fan cultural practices of Emi concerning the Disney franchise. *Emi* is a 14-year-old teenager with autism for whom Disney is a source of worlds to explore. The case study focuses on his daily practices as well as in the role of his mother with them. The study concludes that Emi has developed transmedia literacy competencies (Scolari et al, 2018) thanks to his interests in Disney. Although "narrow interests" might be a challenge for learning, they can also have a positive effect.

Third, there is a proposal including general strategies on how parents, teachers, or caregivers could take advantage of "narrow interests", in this chapter presented as deep interests, which could foster learning through connecting interests to learning needs and objectives.

Chapter 4. Transmedia Learning for Preverbal Children with Autism. Foundations and Design

First, the chapter explores what learning paradigms might be useful to frame the learning process of children with autism in the XXI Century and consider what, how, and where they should learn. It proposes that interdisciplinary teams make a diagnosis of learning status and design learning objectives periodically. This might align strategies to the learning and therapy frames that parents, teachers, and therapists agree on for every child. However, I emphasize that frames that are externally based either in regular child development or just in training or promoting and /or reinforcing behaviors could be insufficient. I suggest that learning should be conceived as an experience, and I recommend taking advantage of frames and tools of experience design. For instance, using empathy maps to design learning experiences based on each child's needs. The proposal is based on concepts such as long-life learning, connected learning, ubiquitous learning, personalized learning, mobile learning, and microlearning. It recommends paying attention to sensory barriers and preferences.

Second, the chapter explains transmedia storytelling, transliteracy, transmedia literacy, and transmedia education background.

Third, the chapter presents the transmedia learning proposal which is based on varying the roles of children to promote involvement: spectators, readers, users, players, participants, collaborators, creators.

Finally, it postulates four strategies for transmedia learning design:

- Critical adoption of transmedia Storytelling productions to fit the learning objectives of the Child. That means selecting, adopting

and adapting critically (based on learning objectives) the materials sold by the franchise, remix and make materials for personal use. Examples of transmedia productions for children: Peppa Pig, Cleo & Cuquin, Gravity Falls, Mickey Mouse, Toy Story.

- Transmedia Learning Design based on a character and its connection to other characters, topics, toys, and real-life actors or experiences. For instance: Nemo as a character and its connection to fishes and other animals from the sea.

- Transmedia Learning Design based on Worlds and Fictional Spaces. For instance: The sea, the jungle.

- Transmedia Learning Design based on personal experiences: vacations, a visit to the zoo, going to the supermarket, and so on.

- Chapters are organized prioritizing: first, the perspective; second, exploring mobile devices as media, explaining the necessity from children with autism to learn about them and through them, and exploring mobile device use in context. Third, by focusing on media cultural practices. Fourth and last, based on previous frameworks, previous works, and two case studies included in this work, the author posits a transmedia learning design model.

While this structure is sequential, the reader could explore the transmedia model first, and then go back to deepen on the perspective and ethical bases, the technology and literacy foundations, or the cultural foundation of the model according to her interest.

Approach and Methods of the Work

We need more participatory action research to make research in autism

We need more participatory action research to make research in autism more meaningful and useful

more meaningful and useful for the autism community. Participatory research has been identified as highly meritorious, since the community it occurs in informs its very objectives, research methods, context and usefulness of output, as asserted by Fletcher-Watson et al. (2019).

These authors suggest leadership by autistic researchers, partnership with autistic people or allies as co-creators of knowledge, engagement with the community in general and consultation with relevant individuals or community organizations. Some of the tasks at hand include adapting the research environment, methodology and dissemination routes to permit the widest and most accessible engagement, and particularly engagement from specific groups (e.g. non-speaking autistic people).

This book endeavors to apply these principles by:

- The awareness of vocabulary use. Quirici (2015) explains how labels matter, especially in its relationship with expectations. In this work, I use "autism spectrum conditions" instead of "...disorders" to promote a view focused on diversity, not on impairments or deficits. I speak about "Preverbal Children" instead of "Nonverbal Children", recognizing medical contributions but avoiding seeing characteristics of autism only as impairments and deficits, and avoid a discourse that considers people with autism as "abnormal".
- The type of research questions and the tone used to posit them in every chapter.
- The focus on Preverbal Children. In the second case study, I point out the inclusiveness of Emi as an informant and identify his mother as the person who best knows his needs.
- The validation of autoethnography as a method in case studies, and the validation of an ethnographic perspective when it is useful. I am the mother of a 10 year-old preverbal child. As part of the autism community, somehow, I have been in an extended ethnography made of the experiences lived from the diagnosis of my son to the present (7 years). Since the diagnosis process, I have lived in Queretaro, Mexico, and Barcelona, Spain. I have faced diagnosis, treatment, and education challenges in both countries. I belonged to a parents association for two years in Barcelona. My son has attended one inclusive school in Barcelona, and two special education schools specialized in autism in Mexico. He was

homeschooled for a year. I have met parents with very different perspectives about autism, socioeconomic situations and needs, most of them, parents of preverbal children. As a researcher, I am conducting another research project where thirteen mothers of children within the spectrum participated in several focus groups telling their experiences and challenges raising their children. That research has informed the present work as well.

● The discussion of the model with different autism specialists, and family members.

The Contributions and Limits of this Book

I expect that one of the main contributions of this book is for readers to rethink the learning journey of children whose learning opportunities might currently be very limited. As any other child growing in the XXI Century, preverbal children with autism could learn throughout their whole life if they are immediately given the resources and strategies to take advantage of available technology.

This is not just a matter of educational technology. Currently, autism-related discourse surrounds giving therapy to remedy a deficit instead of building their life-long learning process. Without denying the importance of medical and psychological assistance, we are forgetting than preverbal children need not just therapy but learning.

They are not just autistic, they are children. They have learning styles, sensory needs and preferences, interests and strengths. Ubiquitous and informal learning can be their context, too. Innovations in learning strategies are for them, too.

> *They have learning styles, sensory needs and preferences, interests and strengths*

Extensive hours of therapy are expensive everywhere and might take time away from families, time they can use to enjoy and educate their children, get to know them better and develop strategies to cope with challenges.

This does not mean that parents should be the only ones in charge.

Children within the spectrum may benefit from spending more time in regular kid's clubs and activities than in therapy offices

Social inclusion is a societal responsibility. Children within the spectrum may benefit from spending more time in regular kid's clubs and activities than in therapy offices. It can be beneficial to think about "learning" universally, instead of exclusively in formal education in schools. We can include strategies to extend and connect learning in settings where semi-formal or informal learning are possible. If members of our society are involved and, for example, library and museum programs for children are inclusive, they can learn from new mentors. If parents have more home-based and microlearning strategies, they obtain more agency to foster learning.

In research, we usually think about findings, but we may need a pause. We should first reconsider paradigms and perspectives, reconsider places and strategies for research, be aware that learning happens not just in school or therapy offices, and involve the very community that will benefit from our research output. We should also pay attention to experiences even if they don't include a great number of participants, and have more exploratory studies from which new approaches and new research questions may emerge.

The proposal of this book will need to be complemented, critiqued, applied, and evaluated. Every chapter contains lines of research that can be adopted by researchers from different disciplines. I hope that the research community feels compelled to maintain this effort and improve the quality of life of people within the spectrum.