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BEYOND THE ‘UNTOLD’

Encountering Autism: Situated Insights On Ways To Enable Participation In Design

Alessia Cadamuro

A Doctoral Thesis submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy of Open University

March 2020

Abstract

The number of people who experience autism is constantly increasing. In 2020, the Center for Disease Control and Prevention determined that, every year, approximately 1 out of 54 children is diagnosed with the autism spectrum disorder (ASD). In the last years, the number of research and studies dedicated to children with autism has increased; however, scarce attention was paid to research on adults with autism, particularly those on the severe end of the spectrum (low-functioning autism), who have limited verbal abilities and non-normative communication. Consequences of this include issues of social inclusion, lack of services, work opportunities, social and civil rights, to mention a few, which are not yet sufficiently explored nor implemented for this specific group of people.

This thesis employs Participatory Design to explore novel ways to engage with people on the autistic spectrum, in the attempt to understand what processes and participatory dynamics become enacted in acknowledging them as equal, valuable presences in the constitution of our collective existence and society. In particular, the research looks at processes and activities that can lead to a collaboration between designers and adults with severe autism and non-normative communication abilities, and their active participation within the research process.

By theoretically drawing from traditions of Feminist Theory and Participatory Design, this thesis considers one single case study, where collaboration with the participant is achieved by means of a situated approach to design research. My standpoint and philosophical positioning here are to acknowledge that there are multiple realities through which one can make sense of the world: this research envisions that each person constructs her or his own reality through their personal experiences. Such philosophical perspective aims at emphasising and valuing subjectivity, and the consequent, intrinsic partiality that constitute our human experience. Personalised and situated research objects are also used across the thesis as methodological elements, oriented to explore the potential of triggering participation, crossing the boundaries between different communication abilities and achieving mutual understanding between designer and participant.

The contribution to knowledge provided from this research is three fold: first, it provides new insights about the creation of research objects that result from a situated and process-oriented approach to Participatory Design; second, it extends knowledge concerning design practices that involve the collaborative participation of people experiencing the severe

end of the autistic spectrum; third, it contributes to provide new narratives concerning people with non-normative communication abilities and autism.

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Acknowledgements

This PhD has been an intense journey that pushed me to explore and deepen my interests as a person and as a researcher. In this journey, I learned that kindness, resilience and a bit of recklessness enable us to overcome even the most complex adversities that life sometimes puts before us. I learned this from you, “Enea”, and only thanks to you, this thesis has been possible.

Enea is not your real name, but when I was thinking how I could identify you in the thesis, without mentioning your real identity, I understood that I could not simply call you ‘participant A’, or another generic name. One day, after being with you for few hours, I decided that I could choose a name that identify the beautiful characteristics that distinguish you from everyone else. From here came the idea to call you Enea. Virgil, in the Aeneid poem provided a beautiful description of who Enea (Aeneas in English) was in his poem. He was identified with the virtue of pietas. The meaning of this word is complex and articulated; it is a mixture of devotion, respect for gods and family, but also for other men. Enea, in the Aeneid, renounces his personal needs to carry out the task entrusted to him by a superior will; he does not forget the past, but he must always go forward, without stopping or turning back, so as not to risk losing his way. He is a hero who sacrifices himself, and in the name of collective interest he lives a life that he did not chose but that was imposed to him. This reminds me of you. You live a life that you have not chosen and every day you need to commit yourself one hundred percent to adhere and conform to a society that it is not yet ready to welcome you as you are, and like an ancient Greek hero, you sacrifice yourself. I admire you and I am honoured that I could develop this research with you. A special thank goes to your parents for letting me enter in your life and being very welcoming with me. I will never forget them, their kindness and their open minds. I thank also your therapists for being very patients with me and for letting me follow you and asking millions of questions.

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challenging for me. I know that, when I was a rebel child who absolutely hated school and especially homework, I made your lives probably not very easy. Thinking about that time, I now laugh a lot, I've always been an irreprensible "scugnizzo".

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Declaration

I hereby assert that the material presented in this doctoral thesis has not been submitted for any academic award or qualification other than that for which it is now submitted. I also declare that it is my own work and that all opinions, ideas and contributions included in the thesis that refer to the work of others have been fully acknowledged.

Name: Alessia Cadamuro

Signature:

Date: 31/03/2020

Glossary

This section addresses and clarifies the way in which terminology is used in this thesis, to avoid misinterpretation of notions and, most importantly, for ethical reasons. I am aware that people understand the meaning of words subjectively, especially when those words clinically define a medical condition. I believe it is important to clarify that none of the definitions or terms used in this manuscript have the intention of diminishing, hurting, or marginalising anybody, by any means.

Concerning terminology, the expression '*person on the autistic spectrum', 'person with autism', 'autistic person',* embeds different philosophies of thought, which are sometimes in contrast with the community of people on the autistic spectrum. Some studies show that people with autism prefer to be identified with the term *autistic persons* (Sinclair, 1999). In this thesis, I will sometimes make use of both expressions, to respect the preference of those people. Furthermore, I will refer to the same concept through the expression '*people experiencing autism',* to emphasise the lived, embodied experience that only a person with autism can inhabit. This has no discriminatory connotation, however it highlights the concept of experiencing autism as lived condition.

Furthermore, I decided not to adopt the term 'neurotypical', but instead to use 'person not on the autistic spectrum'. The word neurotypical literally means 'neurologically typical', and implies that only people within the typical range of human neurology can adhere to the dominant societal standards of 'normality'. This research utterly opposes this concept, departing from a binary understanding of the human experience (e.g. normalcy/non-normalcy, healthy/ill, etc). Instead, I consider what is widely considered not-conforming to a dominant paradigm, as a way of questioning the limits and absurdity of such definitions.

ABA Therapy: Applied Behavior Analysis (ABA) is a therapy based on the science of learning and behavior. The aim of ABA therapy is to increase behaviours that are helpful and decrease behaviours that are harmful or affect learning;

Agency: The capacity or power to act creatively and influence courses of action;

Apraxia of speech: Disorder that can interfere with a person's ability to properly say what they want;

Autism Spectrum Disorder: In 2013, the American Psychiatric Association released the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The Autism Spectrum Disorder is described as a persistent deficit in social communication and social interaction across multiple contexts, repetitive patterns of behaviours, interests, or activities. Symptoms are usually present in the early developmental period and, on the long term, can lead to significant impairment in social, occupational, or other important areas of life;

Dyspraxia: Developmental co-ordination disorder (DCD), a condition affecting physical co-ordination;

Embodiment: it is a way of considering the bodily experience, which acknowledges the value of living-through-things, as a way of accounting for the inner aspects of specific situations, and that certain experiences can only be understood when directly inhabited;

Human encounter: It refers to the flow of meaning between a person and another person. It is seen as the outcome of situated observations and meaning-making processes, from the perspective of better understanding another individual;

Inhabiting: It refers to a notion inspired by Irit Rogoff's (Rogoff 2006) feminist practice, which suggests that knowledge production could be rooted and "lived through a specific situation";

Non-normative communication: Type of communication that is not conforming to the dominant form of communication which is oral transmission and written transmission. Non-normative communication is a multimodal communication, that comprises a vast and subjective selection of elements, such as: gestures, flapping or tapping with hands, echolalia, jumps, fast and repeated movements, physical repetitive interactions with objects, instruments that create sounds or act as sensory pleasing tools;

Normative communication: Type of communication that is conforming to the dominant form of interaction, which is only constituted by verbal and written communication. This term has a narrow meaning as it excludes all other forms of communication that exist and are actively used in human as well as other-than-human forms of communication;

Normocentric: In this thesis, the term describes practices, modes of perception, methods, etc., that give importance to what falls within the characteristics of an alleged normality;

"Other": A minority of a group of people not included and/or isolated from the dominant group;

Social environment: In this thesis, it refers to the network of relations that a person has with his or her parents, family members, friends, therapists, pets, including more distant or occasional relations.

Chapter 1: Introduction

1.1. Thesis Background: Personal, cultural and ethical motivation

So you're here? Still dizzy from
another dodge, close shave, reprieve?
One hole in the net and you slipped through?
I couldn't be more shocked or speechless.
Listen, how your heart pounds inside me.

This small excerpt from the poetry of Wislawa Szymborska (Szymborska 1998) excellently encloses the essence of empathy, this unique state or ability to share someone else's feelings. A few months ago, I was on a train, thinking about random things that I was supposed to do that day, slightly worried that, by the end of it, I might have not been able to complete them all. Suddenly, my attention was captured by a man, who acted in a strange way. He was muttering something, but I couldn't understand what. The rest of those who sat in the carriage also noticed him and his unusual behaviour. While muttering, now and then, he also started to do some little screams. Suddenly, I noticed that other passengers began to react as if they were frightened by the tall man. At that point, the man stood up, and I had the clear impression that he could perceive that his behaviour drew a lot of attention. His screams became louder, and he started to walk up and down the train's corridor. A few young guys started to laugh at him and I noticed that the man became increasingly anxious and frightened, until another passenger aggressively stood up, in an attempt to stop him. Noticing this, the man screamed, run towards the door on the opposite side of the coach, and finally disappeared in the adjacent carriage. After the event, I heard a few passengers commenting on their experience: "this was really scary", "people with these problems can be really dangerous", "unbelievable", "these people should travel with someone else, that can take care of them".

This event triggered in me conflicting thoughts and emotions; I recognised that I was unable to react and approach that frightened person in a welcoming and delicate way, and above all, I could do nothing but observe the situation unfolding terribly in the front of my eyes. Re-thinking about what happened in that train, on a personal level, makes me feel deeply uncomfortable. I do not know what that man was experiencing, nor what condition he might have been affected by. However, what emerged was the huge cultural and emotional lack of

information at stake behind it. Collectively, we often lack the instruments, knowledge and empathic abilities to welcome people, situations and reactions that we cannot immediately understand.

I wonder, what would happen if we placed ourselves in that situation? Or what would happen if, in that same situation, there was another person, someone we love, for instance? How would we like people to react? It is evident that we are in great need of reconsidering what the term 'other' means to a dominant group, whether this otherness has to do with a physical condition or disability, different mental and sensory processing, chronic pain, race, gender, ethnicity, developmental conditions such as autism, and more in general any life condition that is shared by a minority of people. My position is that it is fundamental to learn about ethical ways of engaging with different bodies and abilities, and recognize them as equal and valuable presences in the constitution of our existence and society.

This thesis focuses on low-functioning autism, non-normative communication and adulthood, and there are three main reasons that pushed me towards this choice. The first is a personal motivation, that comes from my fascination for untold stories, stories that are not narrated because they are painful, difficult to tell, or simply because nobody tells them. While I was doing my BA in Architecture, in Venice, I had the opportunity to become friend with some of those who, back at that time, I considered 'others'. With a few friends, I began to work as a volunteer, providing food and human closeness to homeless people living in Venice and Mestre. I did that for a few years. That experience changed me deeply, it helped me to realise that, as first, there are no 'others', but simply different life experiences, different responses to tragic and joyful events; second, that there are no differences or hierarchical divisions among living creatures. No person is more valuable, nor one's abilities can be considered more precious than those of another, by any means. It goes without saying that those realisations deeply changed also my way of thinking about design. After that experience, I decided to concentrate on work that centralize social issues affecting, for instance, the life of homeless people, people with mental disorders, people with alcohol and drug abuse problems, people with dementia and their families, refugees and people within the autistic spectrum. I eventually started to work with people who presented limited verbal abilities and non-normative communication, caused by an advanced state of dementia or autism. Particularly, what caught my attention was the autistic condition on the severe end and adulthood, which lately became a topic of personal and work interest.

The second reason concerns my interest in design as an instrumental discipline, through which to support and encourage a positive and much desired societal change, in ways that are more ethical and inclusive. Being part of a minority, people with low-functioning autism and non-normative communication abilities, are often marginalized. Unfortunately, the inability to verbally express a thought or a story, is still perceived as accompanied by lack of intelligence, an issue that leads to cultural stigmatization (St. Pierre 2015). Important evidence proves that this thought could not be more inaccurate and divisive. In recent years, more people experiencing autism and limited verbal abilities have found ways to express their voice and agency, also using assistive technologies. Autobiography and "life narration" appeared in the 1980's and since then have been shared by those people as a way of expressing their life experiences (Rose 2008). Although this certainly opened new possibilities of communication through normative modes of expression (such as written narration, for instance), the predominant language used by those people is non-normative. Unfortunately, the value of the latter is still underestimated and not yet sufficiently accepted in several disciplines, design research being one of them. Design research is mainly based on normative communication styles, implying that direct participation of people with autism is mostly limited to specific aspects of the participatory activities. This arguably prevents those people from fully participating during the research process. For instance, complementary information is usually provided by relatives, therapists or teachers, rather than being directly narrated by the participant under question. This is particularly true for individuals who do not have extensive verbal skills, people who live on the severe end of the spectrum, often deprived of the possibility to auto-narrate their experiences using their own communicative skills. In that, non-normative expressive abilities are often deprived of their true value, limiting the narration of the autistic experience to a mere translation, made by subjects who do not know nor embody the experience of autism. This creates an ethical dichotomy, between the real abilities that a person with severe autism has and what other people (in this case, non-autistic designers) think a person with autism can or cannot do, defining arbitrary barriers that are painful to accept. This reality is well described and shared on projects like "The Loud Hands: Autistic People Speaking", a collection of essays written by and for autistic people (Bascom 2012). In the following extract from one of the essays, one author explains the pain and violation that she feels when the outside world does not accept the embodiment of autism, forcing her to bend her abilities towards the so called 'normalcy':

> *"I know I'll be an object of pity. I know that some people will still see me as less human. I know those same people will see me as broken. I know they'll try to break the person I am in order to fix the person I never was. I know they'll think I'm trapped in the shell of Autism, not the shell of normalcy they want to force me into. I know I'll be "too Autistic to understand," except when I'm "not Autistic enough." I know I'll be ignored. But I also know that nothing will change unless we make it change, and those same people won't. So I know that I have to do it. I guess I can't hide anymore." (p 191)*

With this awareness in mind, this research focuses on encouraging Participatory Design activities that respect the subjective skills of the research participant, and treasure non-normative communication as an important resource, which should always be learned and valued. The thesis wishes to encourage a shift in current design approaches towards autism, triggering the development of new projects dedicated to adulthood, autism and non-normative communication abilities. It also wishes to contribute to knowledge about non-normative communication associated with autism in relation to design, particularly in terms of inclusion and novel forms of participation and participatory dynamics.

The third reason has socio-cultural foundations. In this research, I reflect upon issues of social blindness and marginalization in relation to autism, based on a lack of information and effective social policies of inclusion. People with autism -and particularly autistic adults, are part of a minority in current societies and most of their rights are not fully respected nor protected. Our human history tells about the perpetuation of terrible, unspeakable forms of aggression and cruelty, suffered by people with disabilities and more in general, those who do not conform to the concept of normalcy. Even though important steps have been made since the end of the second world war, much can still be done for the empowerment of those on the autistic spectrum. In the current sociocultural context, the traits of autism are often not recognized nor understood. Society mostly ignores how to interact with a person that has a moment of tantrum or simply feels disoriented, an issue that often leads to abuse, accidental arrests, marginalization and social stigma. This underlines the urgency of addressing peripheral and complex subjects such as autism. In this research, I wish to encourage a greater awareness of this subject and contribute to provide a central position to people on the autistic spectrum.

1.2. Research Context

The experience of adulthood and low functioning autism is for many people complex as those individuals often find themselves at the periphery of social inclusion, social rights and work inclusion, to name a few. The design discipline also struggles to find and provide space for inclusion of adults with low functioning autism and non-normative communication abilities. There is limited research that involves adults on the autistic spectrum and when those persons are included, they are often not directly consulted. Their experiences are instead often translated and narrated by family members or therapists, a decision frequently taken to protect the participant; it is also undoubtable that the design research community still prefers a mode of communication that mostly values verbal interaction and oral transmission. I question, as a design researcher, if we are not once again risking a marginalization of adults with autism and limited verbal communication skills, by removing them from the possibility of exploiting their self-explanation and self-narration abilities? And why is non-normative communication still not fully accepted in the design field?

The politics of communication are extremely relevant in the social ordering and shaping of particular bodies. Considering how many people with non-normative speech abilities and autism are present and actively involved in current society or represented in the media, our work environment and everyday life, the number is disheartening. We, however, live in a historical period, where technology provides great support to those who are in need. In particular, the rise of assistive technologies provided people with communication impairments to reclaim some degrees of agency and discursive power, which ones seemed to be out of reach. Nonetheless, this is still not enough. Verbal abilities are part of the boundary that form the great divide between abled and disabled. The “body that does not, cannot, or chooses not to perform or approximate normal human development risks being casted out from the ever exclusionary space of the human” (McGuire 2016, 102). The limited ability to verbally present one’s flow of ideas is an important source of marginalization, and this understanding is not sufficiently nor accurately debated. Furthermore, today's creation of skill and abilities-based hierarchies seemed not questioned enough. As described by (St. Pierre 2015) “[o]ral speech has occupied a dignified position within the humanist lineage, shaping central questions of what it means to be human, imbued with the power to persuade others, serve human affairs, and articulate truth” (p. 330). Through truth- making claims, non-normative speech or the lack of speech is then pathologized and these voices are made subaltern.

Daily practices and life experiences, at some points, become words; oral transmission plays an important role in informing and expanding knowledge. The discursive practices are effective storytelling instruments that embed meanings and support the 'currently accepted' dissemination of information. Presenting the condition of autism is mostly relegated to experts in the field of neuroscience, that define deficit on the basis of cognitive abilities. Baron-Cohen's definition of "Theory of Mind" (Baron-Cohen 1997) implies that and individual should perform mind reading of the self and of others in order to make behaviour legible, to react predictably, and continue such patterns of communication (McGuire & Michalko 2011, 165). This definition introduces a medical paradigm, accepted in the scientific context, for which the binary division between normative and non-normative identifies different medical conditions and inform diagnosis. Although this is the currently dominant perspective on autism, this research departs from this reading. There is an important discussion amongst members of the autistic community, which concerns these medical paradigms and the restricted definition that constrain such vast and subjective condition to a binary perspective. This is arguably perceived as a further stigmatisation that divides people based on their capability to adhere to certain "norms" (Sanchez 2017). Different narration is then provided by the parents and more in general the relatives of people with autism. The autistic condition is always both lived and lived with. In this way, when we talk about 'living with' a dis(ability), where low-functioning autism is included, we also set to discuss how disability relates to and is constituted by a relationship with non-dis(ability).

Family bonds, unconditional love and daily caring actions, are just a few elements of entangled relationships, which can help the relatives of a person with autism to know what their loved one feels and experiences. Physical and emotional proximity provide in-depth understandings of the autistic condition, and certainly allows family members to act as good spokespersons for the 'voice' of those who experience the condition. Parental memories are a staple and a great resource, as documented, for instance, in the bestseller "Life Animated: A story of Sidekick, Heroes and Autism", written by Ron Suskind (Suskind 2016). The book recounts the real-life journey of an entire family with Owen, an autistic man, and how people learned how to communicate with him thanks to his passion for Disney movies. Families, more often in these days, share on online platforms their daily journeys as parents of children and adolescents with severe autism (Figure 1). The topic of parenthood and their efforts in advocating a better future and a more inclusive society for their kids, is extremely important. Those who usually watch these videos are often other parents who have children with autism,

interested to understand ways for dealing with moments of tantrum and everyday activities. This modern narration is now supporting a silent, but vast community, which looks forward to share untold and un-easy experiences of parenthood in relation to severe autism. This community, made by parents of people on the spectrum, is often the only voice available to spread knowledge concerning the everyday life and actions surrounding people with autism and their loved. The subjective experience of a person with autism, however, cannot be fully understood by another, even if the two share a tight, close relationship. The embodiment of the condition is personal and intimate, and for this reason it is unique: the only one who can share it is the person who lives through it, and thus fully embodies it.

Figure 1: frame from of a YouTube video, published on the channel FatheringAutism ("FatheringAutism: Autism Meltdown or Tantrum at The Fair" 2018). The picture shows the parents of an American adolescent with low-functioning autism, sharing their parenthood's journey within the spectrum.

People with high-functioning autism also often act as spokespersons for other people with autism. Here, however, it is important to emphasise that their experiences are not representative of the whole spectrum. Some traits and symptoms are shared among people that experience the

autistic condition, as described in Donna Williams's "Nobody Nowhere" (Williams 1998), the autobiography of an autistic girl. However, the personal abilities and capabilities to express themselves on a societal level are different. People with high-functioning autism can excellently explain and articulate thoughts in a normative way. As a consequence, the verbal narration of their personal experiences is vastly accepted by society at large. This implies that marginalization can be less radical if compared to the experience of those on the severe end of the spectrum, who also rely on non-normative communication abilities. With this, I am here not suggesting that experiencing high-functioning autism is easy and not challenging; on the contrary, there are still issues concerning isolation, suffering and abuse that should be addressed. Compared to people on the high-end of the spectrum, however, those who experience severe autism are still unheard and marginalized.

Recently, there have been instances of activist on the spectrum that advocate the need for a change in the common understanding of non-normative communication. Amanda Baggs (2007), for instance, is an American blogger diagnosed with low-functioning autism and limited speech abilities. Through works such as her video "In My Language" (Kinder 2007), she has been raising awareness about autism. In the video (Figure 2), she reframes her 'non-communicative' state as a constant conversation through the body and the environment, encompassing a complex combination of senses. Through contributions such as Baggs's manifesto, non-normative communication is no longer read as an isolated, out-of-this-world, unintelligible act. Baggs adds her own thoughts concerning what she feels, and her personal relation with her home environment and objects, including how her communication and thoughts take place. Her message is meaningful and asks for deep reflections concerning the acceptance and recognition of different modes of communication and expressions, which could lead to important cultural and societal changes:

> *"The way I naturally think and respond to things, looks and feels different from standard concepts, or even visualization that some people do not consider it thought at all, but it is a way of thinking in its own right. However, the thinking of people like me is only taken seriously if we learn your language, no matter how we previously thought or interacted… It is only when I type something in your language that you refer to me as having communication… I find very interesting that failure to learn your language is seen as a deficit, but failure to learn my language is seen as so natural, that people like me are officially described as mysterious and puzzling*

rather than anyone admitting that it is themselves who are confused… we are even viewed as non-communicative if we don't speak the standard language… It is meant as a strong statement on the existence and value of many different kind of thinking and interaction, in a world where how close you can appear to a specific one of them, determine whether you are seen as a real person or an adult or an intelligent person; in a world in which those determine if you have any rights… Only when many shapes of personhood are recognized will justice and human rights be possible."

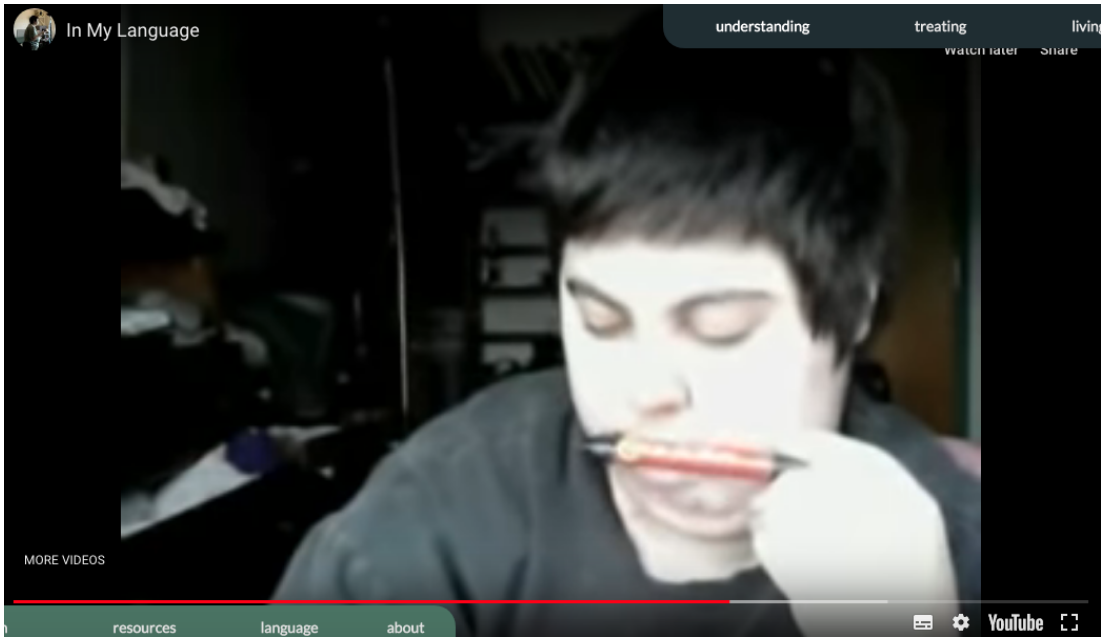


Figure 2: image extracted from the video of Amanda Baggs.

In the work of Loud Hands a self-published essay written from people with autism from the Autistic Self Advocacy Network (ASAN), the authors wrote: "We can use loud hands. To say that flapping can be communication, that autistic people have voices regardless of whether or not we speak orally. The loud hands project as a whole, serves to document and explore that. Bit by bit, piece by piece, we're rewriting the world into one where our voices are heard" (Bascom 2012). These words embed the potential to redefine and change the dominant understanding of autism, promoting the true communication abilities embodied by those who experience non-normative communication. During the last few years, several books and blogs written by people with severe autism and limited speech abilities questioned the boundaries that emerged due to on an obsolete, discriminatory understanding of normalcy. Although such

boundaries are unfortunately difficult to demolish, this thesis provides a contribution to this cause. While being aware that this will not be enough, I also acknowledge the importance that all projects, researches, books, movies, videos, conferences, debates, newspaper articles, testimonies, have in collectively triggering new reflections on the equal value of both 'normative"' and "non-normative" modes of communication.

1.3. Social Blindness towards autism: Bodily experience and marginalization

Living with autism is a process that evolves over time as the subjective sensory experience of a person gradually develops, and in tandem with the creation of responses and personal coping mechanisms. From an outside perspective, it is complex to understand this long, inner process, and how it influences and impacts the life of a person. Within the autism spectrum disorder, the dichotomy between the body that a person has and the body that a person is, and the consequent personal embodied experience, is a fundamental key to understand the living experience of a person with autism.

In "The Body Multiple", Mol introduces the concept of the "body we have" and the "body we are" (Mol 2003). To better understand this, I refer to the difference existing between the representation of our body and the experiences that we have through it. This can be applied to every human being, but in this case, I use it as a lens to explore autism. Autism is not a condition that can be associated to a precise body image; the traits of autism are detectable through behaviours such as repetitive movements, reactions to stimuli, body postures and gestures. These traits are idiosyncratic, as they are intended as a set of behaviours and actions/re-actions. Mol argues that "we do our bodies in our everyday practices" (Mol 2003), referring to the evolutionary process of coming-into-being, and the importance of the subjective bodily experience as an inevitable life path.

People at the severe end of the spectrum, use their corporeality to interact in the world. In light of this, the bodily experience is not identifiable with the limited understanding of the external expression of the bodies, but through the richness that characterizes the body we are, and the consequent experience of it. This concept enhances the physical experience as embodiment. The concept of embodiment is here correlated with the definition provided by Wilkerson where embodiment includes pleasures, pain, suffering, sensorial and sensual engagements with the world, vulnerabilities, capabilities, and constraints as they arise within specific times and places (Wilkerson 2015).

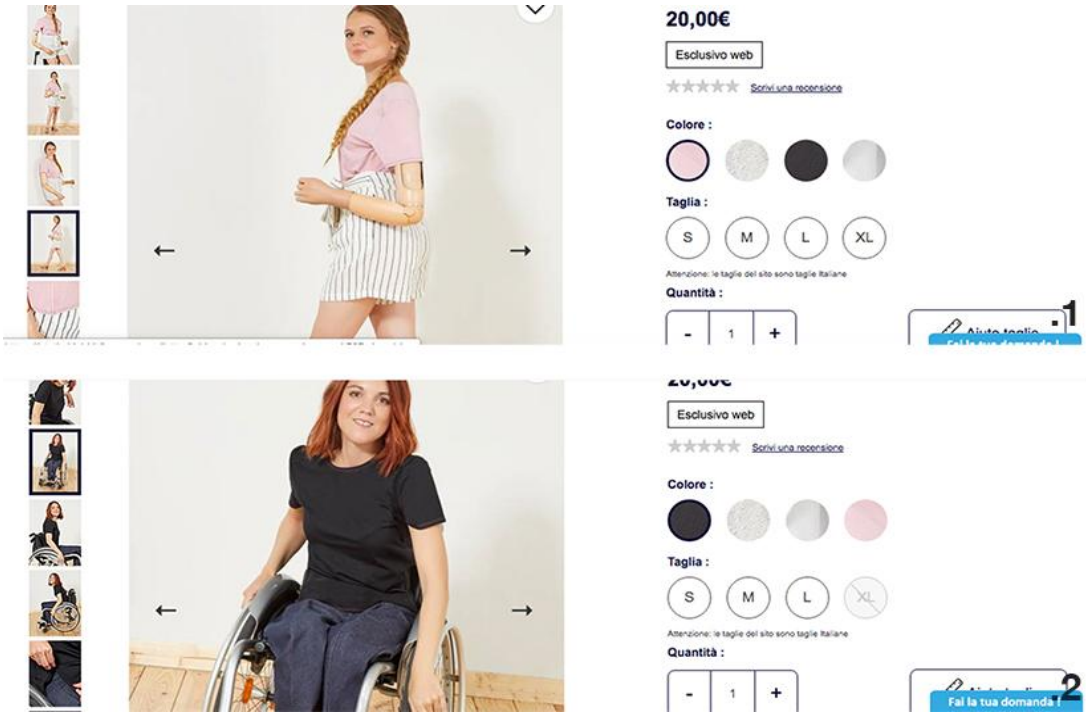
The dichotomy between the body that a person has and the body that a person is, is often misinterpreted by society at large, particularly when we consider people with severe autism. It seems that there is social blindness concerning autism, and a vast ignorance towards the traits of the spectrum. The dichotomy I refer to can be understood by reading an article

that recently appeared in the US news (Amir 2018). In July 2017, Connor Leibel, a 14 years old guy with autism and intellectual disabilities, was pinned and aggressively thrown to the ground by a police officer, who did not recognise some of the autism traits (Figure 3). The police officer explained that he believed that the boy was under the influence of drugs. Stories like this one are unfortunately reported frequently, which explains how difficult it is to judge the outward appearance of a behaviour if we are not properly informed, if we ignore what autism is and how its effects a person life.

Figure 3: moment of the arrest, in 2008, of Connor Leibel's, in Arizona

As members of society, we owe to reflect upon why, even if more people are diagnosed every year on the autistic spectrum, there still a lot of ignorance surrounding this condition. Wendell (1985) stated that: "the problems of living with dis(ability) are not private problems, separable from the rest of life and rest of society. They are problems which can and should be shared through culture as much as we share the problems of love, work and family life" (Wendell 1989, 115). This implies that there still is no common notion concerning non-normativity at large; health is a matter that is often taken for granted, as well as the ability to do whatever the average able-bodied person can do; be it not the case, we would be considered unable to participate in life (p. 111) and eventually could find ourself marginalized.

Another issue that contributes to social blindness concerning autism, in particular towards those people on the severe end of the spectrum (although not exclusively towards them; see, for instance, most of non-normative life-experiences) is the lack of societal narratives. With this term, I refer to the lack of inclusion and representation in society, particularly in popular culture, of people that have non-normative abilities. Only recently, people with physical dis(abilities) have started to be included and portrayed in publicity and the modelling industry (Figures 4.1 andFigures 4.2); these however, are still a minority of cases, not yet fully embodied nor accepted in common society.



Figures 4.1 and 4.2: two models with physical disabilities. Screenshots from a website of a clothing company

Probably, the in-depth motivation for this general avoidance and ignorance towards humans with non-normative abilities has ancient historical roots. It should not be forgotten that, until the 1980s, people with severe autism and poor verbal skills were locked up in asylums. Enormous suffering has been poured out on people that presented diverse abilities, and did not adhere or conform to the widespread notion of normality. We must not forget what happened under the ferocious political dictatorships of the twentieth century, and the tragic murders of countless numbers of people with disabilities or simply with non-normative personal or bodily traits. For example, in the 1920s many US States approved laws to compulsorily sterilize

people with intellectual disabilities, in the name of eugenics. In 1978 in Italy, the Basaglia Law (also called Law 180), generated a large reform of the psychiatric system in Italy, which was perceived as revolutionary in several parts of the western world, and started to unhinge the idea of annihilation and un-recoverability concerning non-normalcy, disabilities and mental health. However, this was not enough and nowadays, for instance in Italy, a person diagnosed with severe autism is recognised by the Italian law as autistic only until adulthood (18 years old); after that age the person is defined as an individual with mental health problems (rather than autism). With this, comes also a deprivation of important rights such as the right to vote; all of this, especially at these days, sounds like a tragic failure for a society that has been defined 'modern'. Those gaps in law and social justice are just the tip of the iceberg. In his keynote at the UN Convention on the Rights of People with Disabilities in 2017, Simon Baron-Cohen (2017) argued that "people with autism account for a significant minority of the population worldwide, yet we are failing them in so many respects" (UN News 2017), by avoiding to fulfil their basic human rights. The human rights that are still not respected are summarized in the following points: 1) People with autism are three times more likely to be victims of abuse or neglect, robbery, or assault; 2) one out of five children with autism have been excluded from school; 3) most of people with autism are denied the right to equal access to public services; 4) the right to work and employment is not yet extended to all people with autism, as only 15% of them are in full-time employment, despite many having good intelligence and talents; 6) the lack of right to protection from discrimination, and the right to a cultural life, to rest and leisure are not yet extended nor fully practiced by the autistic community; 7) the lack of right to protection of the law, and the right to a fair, impartial trial.

People on the spectrum who contend for an improved equality -such as Morénike Giwa-Onaiwu, a writer and educator who advocates for racial justice and autism, or Lydia Brown, an autistic activist, have been rising their voice, asking for equal opportunities, respect for diversity and protection of the dignity of people with dis(abilities). Arguably, the historical and present misconceptions that affect our perception of normalcy, perpetuate a lack of understanding and openness towards the diversity of abilities that belong to the human species. From the second world war to the current days, many steps forward have been made and still must be taken forward. There is, however, a great need of channelling more energy, work and resources to break down the stigma surrounding people with non-normative abilities, and such contributions are more effective if the research behind that is conducted across different areas

and disciplines. Design, I believe, is one of them, it is a discipline that can support such kind of changes, that can help to better understand and eradicate social blindness and exclusion.

1.4. Participatory Design and non-normative communication

Design and specifically Participatory Design (PD) is seen here as an approach that can be used to engage with adults on the autistic spectrum who have non-normative communication abilities, and to contribute to a more inclusive and respectful process of social transition. Similar to Akama's and Light's (Light and Akama 2012) perspectives, I interpret PD as an approach that is configured by the people, practices, places and structures with which it is entangled, rather than advocate universal standards for participation.

Participatory Design was developed during the '70s and '80s in Scandinavia (Ehn 2008; Robertson & Simonsen 2012). The initial PD projects carried out in collaboration with worker unions, focused on workplaces, and sought to bring both the knowledge of workers' practices and workers' values into the design process, as many tasks were becoming automated (Robertson & Simonsen 2012). Participatory Design can be identified as a set of methods and practices of engagement, and a commitment to a particular set of values, all enacted through design (Disalvo and Lukens 2011, 179). Nowadays, participatory design has been extended to many different contexts, from healthcare (Sjöberg & Timpka 1998) to government (Anthopoulos et al 2007). This evolution of PD over time allowed to move from the creation of a product, service and even product service system (PSS) to something more intangible but equally fundamental, such as the study and empowerment of the participants within the design process. This requires that the involved polyphony of voices and participation are equally valued, which is a fundamental principle on which this research is founded.

Currently there are only a few projects that involve adults in the autistic spectrum and with limited verbal communication abilities. In all these projects the participants do not speak for themselves, but their experience is mediated through the words of their therapists or parents. As previously stated, power is linked and belongs to whom tells the story; thus, narration can only stand by the side of the narrator, even if the intention is to be equal and inclusive.

This thesis takes the position that non-normative communication is valuable communication, and as a consequence it contains cultural values. In doing that, it departs from the conception that the disabled body represents a deviation from how bodies (and minds and senses) ought to be, considering in contrast that enormous cultural and social value comes from

the diversity of lived experiences and the diversification of people's abilities. To unlock and transform one's own knowledge, abilities and resources to carry out design tasks, it is crucial to consider the impact of material objects and processes that are used during the PD research activities (Zamenopoulos, et al, 2019). Such research materials and objects can support empowerment, providing instrumental means to explore possibilities to trigger more dynamism in terms of power relations, with the aim to incrementally achieve a more equal participation. This thesis adopts this approach to participatory design and non-normative communication, focussing on giving the research participant the freedom to use his own subjective abilities to self-narrate and articulate his participation, without any type of translation provided by other people.

A key point for this research is what Amanda Baggs expresses in her video: "… I find very interesting that failure to learn your language is seen as a deficit, but failure to learn my language is seen as so natural". Being a design researcher, and not experiencing autism or any form of non-normative communication, I approached this study with an understanding of my own limitations and respect for the 'other'. I am also aware that my understanding of non-normative communication as used by the research participant, is limited and certainly imperfect.

1.5. Research Aim, Question and Objectives

The main aim of this research is to explore situated, Participatory Design approaches that can enable an adult on the severe end of the autistic spectrum and with non-normative communication abilities to participate and co-produce knowledge in a design research. This thesis is motivated by the following research question:

How can an adult living with low functioning autism and non-normative communication abilities actively engage in a design research and how would this contribute to the field of Participatory Design?

To provide answers to this question, the thesis poses the following series of objectives:

1) *Objective 1: To understand how autism and its traits is approached from the point of view of multiple disciplines and perspectives, and critically examine how design can help explore the condition, positively contributing to the life of adults living with autism. This objective includes:*

    - exploring existing definitions of autism in neuroscience and other disciplines;
    - understanding how the autistic community defines neurotypicality and its traits;
    - critically examining how Participatory Design and disability studies are currently reflecting on the participation of people with disabilities;
    - exploring issues and opportunities surrounding the use of Participatory Design approaches to engage with people on the autistic spectrum who use non-normative ways of communication;

2) *Objective 2: to propose a new understanding of Participatory Design as a process-oriented, situated research practice that can help exploring and promoting the inclusion and empowerment of adults experiencing autism and non-normative communication abilities. This objective includes:*

- exploring how participation can work as a trigger, even when there is limited verbal mediation;
- exploring what the research participant experiences during this study;
- analysing and interpreting experiences of encounter and participation between the research participant and myself, as the researcher;

3) *Objective 3: to carry out a case study, to learn from the participatory dynamics and the research objects. This objective includes:*

- identifying novel, inclusive narrative concerning autism
- identifying key learnings experience from situated Participatory Design approaches;
- identifying potential new research objects and enabling mechanisms;

1.6. Thesis Outline

This thesis is organized into seven chapters:

1. Introduction

The Introduction describes the research subject, approach, context, and the questions and aims behind it. Disability studies and work from autistic activists inform here the definition of the research context. Moreover, my own motivations as a designer undertaking this study are included;

2. Literature Review

The literature review chapter is divided into three main sections. The first reviews the notions of Autism Spectrum disorder and Neuro-typical disorder to approach the understanding of autism from two very different viewpoints; the first one comes from a scientific comprehension about autism; the other comes from an inside perspective about autism. The second section presents Participatory Design approaches as methods that can help to critically discuss and explore participation with adult with autism and non-normative communication. The third section presents a revision of the existing projects dedicated to people that experiences the autistic spectrum;

3. Epistemological position and methodology;

The chapter presents the theoretical and epistemological underpinnings of the research and discusses in detail the methodological approach. It particularly focusses on an explanation of the case study method and key approaches adopted. Finally, the chapter discusses ethical considerations surrounding research with a person with different abilities

4. Inhabitation and Immersion

This chapter presents the preparatory and preliminary study through an immersive and situated methodological approach and accounts for the ways in which this provided body of knowledge that informed the main study.

5. Participation

This chapter provides a reflective account of the research process developed together with the participant during the main study, to understand what processes, research dynamics, modes of mutual understanding, non-normative communication, and research objects are at stake while supporting and enacting participation.

6. Discussion

In this chapter, the multiple findings of the case study, and its methods and evaluation techniques are brought together, providing an analytic account of the research outcomes. Moreover, the chapter provides insights that address the research objectives introduced in chapter 1.

7. Conclusions

The conclusion chapter brings further the insights discussed in chapter 6, addressing the contribution to knowledge provided by the thesis. Due to the explorative nature of this research, the chapter mostly gestures towards future research directions, which are summarized in a section of concluding thoughts and reflections. A section of personal reflections is also part of this concluding chapter.

Chapter 2: Literature Review

2.1. Introduction

This chapter covers three fundamental topics that are the centre of this enquiry: autism, Participatory Design, and existing design research projects designed with and for people with autism. The literature concerning autism spectrum disorder examined, takes into consideration the scientific perspective as well as the perspective of people that experience autism and who see neurotypicality as a neurological condition as well.

In this study, design plays a fundamental role and is explored as a possible trigger to active participation. The literature examined focusses on a democratic understanding of Participatory Design (PD), which see design and participation as serving social and political functions. Furthermore, this chapter includes a review of existing design work, research and projects, concerning people with autism and other non-normative abilities, and explores the way those projects have been developed, with a special interest in understanding the procedural dynamics and final results. This section serves to understand design outcomes as well as gaps in existing design research dedicated to people with autism.

2.2 The Autism Spectrum Disorder

Autism spectrum disorder (ASD) is an umbrella term used to define a spectrum of conditions causing difficulties in social communication and social interaction, restricted and repetitive behaviour, interest or activities, DSM-5 (American Psychiatric Association, 2013)
ASD is a lifelong neurodevelopmental disorder that presents different characteristics affecting people in multiple and unique ways, with variation in the way that children, young people and adults manifest different behaviours. Autistic people typically show enormous difficulties in social-communication, sensory stimulation, reduced flexibility in control of visual attention, learning disabilities, obsessions for patterns or specific high intellectual ability (Lai et al. 2011). However, it is important to understand that the autistic spectrum is extremely diversified and includes the following characterisations:

High-Functioning Autism (HFA) is a term applied to people with autism who are deemed to be cognitively "higher functioning" (with an IQ of greater than 70) than other people with autism. High-functioning autism and Asperger Syndrome are both part of the autism spectrum. The main difference between the two is thought to be in language development: people with Asperger syndrome, typically, will not have had delayed language development when younger.

Low-Functioning Autism (LFA) is a form of autism at the most severe end of the spectrum. Individuals who have it often have extensive impairments. Many have little or no language skills and many have some level of mental retardation.

Atypical Autism or Pervasive Developmental Disorder is when the person's behaviour pattern fits most but not all the criteria for typical autism.

This specific research will focus on Low-Functioning Autism (LFA); the most severe end of the spectrum.

The huge inhomogeneity of autism and the variety of symptoms that affect people’s everyday lives lead to difficulties in understanding and diagnosing ASD, as the symptoms are extremely

different (in some cases opposite) from person to person. Normally, the average delay between parents first seeking help and diagnosis is still 2–3 years (Siklos, Susan & Kerns 2007).
Currently the research is largely focused on biological and cognitive theories in order to provide an explanation of the possible causes of ASD (Gaudion et al. 2015; Dell et al. 2016). The understanding of autism has evolved in the past 70 years, from 1943 when the child psychiatrist Leo Kanner described for the first time the behaviours of 11 kids that were happy when left alone, indifferent to visiting relatives, avoiding contact with other people and showing a specific literal understanding of words. Kanner's syndrome was originally entitled "autistic disturbances of affective contact" (Kanner 1943).

In 1944, paediatrician Hans Asperger described four boys and their behaviours who were never able to become integrated into a group of playing children and exhibited certain stereotypic movements and habits. Asperger's syndrome was originally called "psychopathy in childhood" and is now part of the autism spectrum (Lai, Lombardo and Baron-Cohen 2014). From the 1940s to the early 1970s, autism was associated with schizophrenia (Grandin & Panek 2013), however since the 1970s the research in autism has grown and evolved into different theories based on neurodevelopmental and cognitive science.

Those theories are important in this research to help deepen knowledge about autism and consequently support the designer's understanding in order to facilitate interaction with a person with low functioning autism. Although existing theories involve mainly people with Asperger Syndrome and high-functioning autism (Pellicano 2014), some patterns and characteristics are identifiable across the whole umbrella spectrum. In this study it is important to underline that cognitive and neurodevelopmental theories are often focused in identifying, measuring and explaining the deficit of abilities, especially cognitive abilities (Dell et al. 2016). However, this research aims to look at scientific findings from a different perspective, focussing on how to empower people with autism instead of defining their limitations, and paying attention to the dignity of persons with autism, making sure that tasks that could be perceived unpleasant and not meaningful are carefully avoided.

According to the Theory of Mind (ToM) hypothesis (Baron-Cohen, Leslie and Frith 1985; Baron-Cohen 2001), people with autism are thought to have delay in developing ToM, that is the capacity to attribute mental states to others, and "read other people's minds," or to imagine what they are thinking or feeling. Furthermore, part of the Theory of Mind is taking in consideration empathy through the notion of "Empathy Quotient" (Grove et al. 2014). Baron-Cohen explains empathy through two main different components: *cognitive empathy*

and *affective empathy*. *Cognitive empathy* is explained as the drive to identify another person's thoughts and feelings, and vice versa, while *affective empathy* is connected to an emotional reaction, and is the drive to respond appropriately to another person's thoughts and feelings. A person without autism (neurotypical), has cognitive empathy and affective empathy (Baron-Cohen 2012), however in case of autism, cognitive empathy is absent.

With this in mind it is possible to improve our understanding of autistic people's behaviour and consequently reflect on scientific information in order to define a possible design approach. For instance, following from the above it can be argued that participatory design activities must be explained in a straightforward manner to autistic people and any workshop activities preferably should avoid exercises that involve implied meanings. Although in the ToM hypothesis cognitive empathy is considered absent, in this thesis empathy is considered as an extremely important means for establishing collaboration and participation. People with autism process information in different ways compared to people without autism; in fact, autistic people tend to notice small details and patterns that others don't notice and recognise. This particular ability can be central during inclusive design activities and will be an important aspect of the study. Like ToM, the Weak Central Coherence and The Executive Function theories, also provide informative insights into this investigation. The Weak Central Coherence (WCC) theory (Frith 1989, 2003; Shah & Frith 1993; Happé 1994; Happé and Frith 2009) suggests that people with autism focus on fragmentary information and have difficulty integrating what they perceive, as well as perceiving things in context. This difficulty is manifested at different levels, from perceiving whole objects to grasping the essence and significance of a story. WCC research has generated interest in remarkable aspects of autistic perception, and has given attention to what can be seen not just as deficits, but as cognitive capacities and advantages (Frith and Frith 2003; Happé and Frith 2009). In 2001, Mottron and Burack developed the theory of enhanced perceptual functioning, following the theory of WCC, that takes into consideration not only autistic people's excellent focus on detail, but also excellent abilities in several aspects of perception, remembering and, detecting objects and patterns (Mottron 2011).

The Executive Function (EF) theory proposes that people with autism lack control over their actions and attention, associated with activity in the frontal lobes. This would explain, for instance, problems with the inhibition of behaviour, the strong need for routines and structure, narrow interests, repetitive and stereotypic movements and thought processes, and a need for sameness (Russell et al. 1991). According to the different theories introduced above, repetitive

movements and behaviour, strong routines and narrow interests, are typical patterns of the autism spectrum disorder. However, from a designer prospective, repetitive movements and narrow interests, may mask deep enthusiasm towards something that generates curiosity, happiness, pleasure, or positive feelings (Hassenzahl et al. 2013). Conversely those behaviours could also represent a way react to physical pain or mental confusion and it is therefore extremely important to pay attention to such behaviours in this investigation.

2.2.1. Neurotypical Disorder

Existing literature uses the term neurotypical to describe a person who is within the typical range of human neurology and falls within the dominant societal standards. The theme of autism in the previous section was discussed from an external perspective; in this section the focus is placed on perspectives of people who experience autism.

Some autistic people think that being “neurologically typical” or “neurotypical” is a disorder rather than autism being the disorder. ‘A field Guide to Earthlings’ (Ford 2010) presents 62 behaviour patterns used by “neurotypical” people and states that “neurotypical” perception is restricted by their use of language and cultural symbols’ (p.16). In a description of “neurotypical” by an autistic person: Neurotypicality is a pervasive developmental condition, probably present since birth, in which the affected person sees the world in a very strange manner. It is a puzzle; an enigma that traps those so affected in a lifelong struggle for social status and recognition.

The Institute for the Study of the Neurologically Typical features the DSN-1Vlist of the various disorders that emerged in the qualitative study of the “Normal Disorders” (1998), (see appendix 1.2.). Within the impairments are mentioned: marked delusional sense of awareness of the existence or feelings of others; extreme or abnormal seeking of comfort at times of distress; constant or mindless imitation; constant or excessive social play; gross impairment in ability to make peer friendships, more specifically obsessive interest in making peer friendships with other neurotypics; marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation; inability or lack of understanding for or interest in stereotyped body movements such as, hand-flicking or twisting, spinning, head-banging The Diagnostic and Statistical Manual of Normal Disorders (1998). Those are just a few of several impairments listed that clearly present an important shift towards what is

also considered abnormal, lack of ability and non-normal. This reverse perspective concerning what can be considered impairment and normalcy, shows how much direct lived experience creates the normality in which a person is immersed. This vision is very informative and helps a person like me, that does not live through the direct experience of the autistic condition, to avoid creating boundaries based on scientific definitions, without really knowing the potential and the abilities of the research participant. What this study cares about is to avoid falling into misconceptions and stigmatization about autism. The contrary, the aim is to overcome the boundaries that are normally created by the binary division between opposites, such as autistic and non-autistic. Moreover, what within this thesis I want to do is to avoid the limitations and lack of accuracy that a single narrative, a single voice and a single perspective produce.

2.2.2 Gaps in Autism Research

Thanks to the rising understanding of ASD during the last few decades there has been increased awareness among parents, professionals and researchers. However, a recent report called 'A Future Made Together: Shaping Autism in the UK' (Pellicano, Dinsmore and Charman 2013), identified that more than half of all autism research in UK is dedicated to understanding the biology, brain and cognition of autistic people. By contrast, little research is dedicated to diagnosis, new treatments, services, and societal issues. The report highlights the following gaps in Autism Spectrum Disorder research:

- Areas that affect the day-to-day lives of autistic people;
- Public services;
- Life skills;
- Cognition and learning;
- The place of autistic people in the society;
- Research on physical and sensory based treatments.

Autistic people (Sinclair 1999), family members, practitioners and researchers all aim to prioritise research so as to:

- Improve the life skills of autistic people,
- Identify how public services can best meet the needs of autistic people,
- Understand how people with autism think and learn;

Furthermore, the majority of the research is concentrated on children with autism and little is known about adults with ASD and the quality of their lives. School activities are fundamental in order to provide correct stimuli and also help with individualization of educational and occupational planning, which is extremely important in order to support independent living and the inclusion in society. Once school finishes, the all-important and age-appropriate stimuli are missing, and this may lead to depression, apathy and the regression of acquired skills: "Transition to adulthood, which often involves loss of school support and child and adolescent mental health services, is a challenge. The end of secondary education is often accompanied by slowed improvement, probably due to reduced occupational stimulation and insufficient adult services." (Lai, Lombardo and Baron-Cohen 2014, page 899).

Moreover, individuals with autism have a mortality risk that is 2.8 higher than unaffected people of the same age and sex. This difference is mostly related to co-occurring medical conditions, such as gastrointestinal problems, rheumatoid arthritis and nerve damage and depression. Furthermore, studies showed that 58%-78% of adults with autism have poor or very poor outcomes in terms of independent living, educational attainment, employment, and peer relationships. (Lai, Lombardo and Baron-Cohen 2014) (Figure 5)

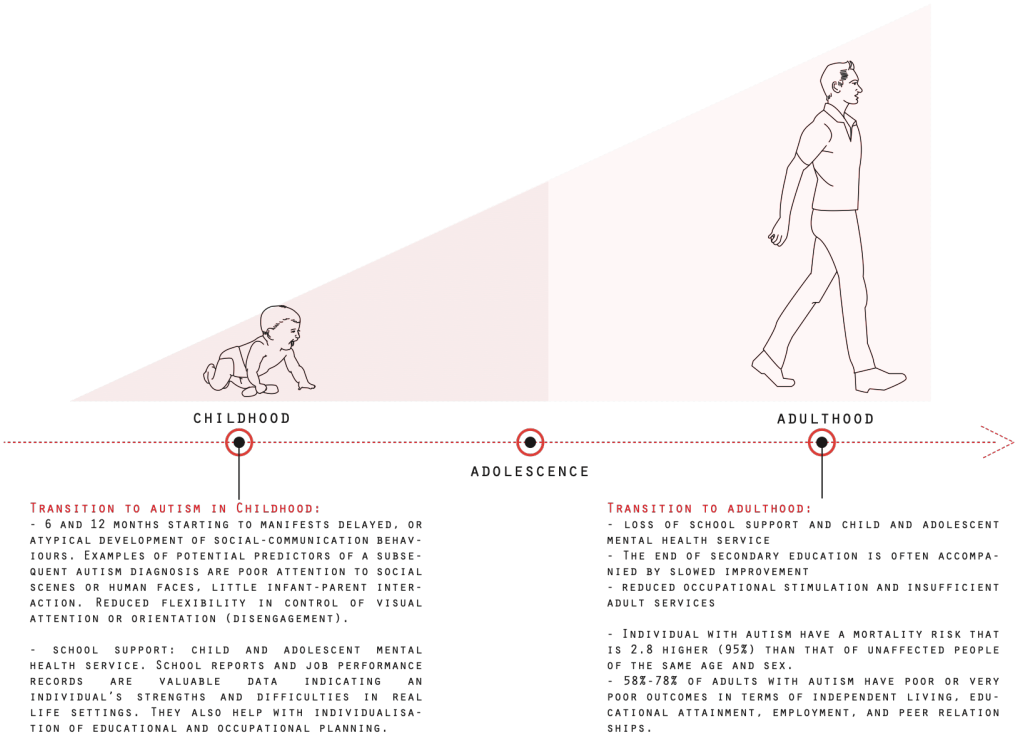


Figure 5: scheme illustrating the evolution of autism and associated services, from childhood, adolescence and adulthood

From an autistic person's perspective, and that of their family members, there is a deep dissatisfaction concerning their lack of involvement in autism-dedicated research. In *A Future Made Together* (Pellicano, Dinsmore and Charman 2013; 2014) several interviews with autistic people are reported:

"I feel like researchers are working in their own world with little direct engagement with us, isolated from the practical issues people face"
Mother of pre-schooler with autism (page 33)

"I don't think many researchers feel like they can talk to autistic people as if they matter; they're too busy studying them like specimens
Early career autism practitioner (page 33)

"It is important for research to have practical outcomes. Researchers need to be closer to those affected by autism"

Older autistic man (page 34)

"Most of the research centres on the high functioning, Asperger's type of autism. It's not relevant to my son's life"
Mother of adolescent with autism (page 34)

From people's reactions to existing autism research, it is possible to understand the urgency, and the demand for different research directions and approaches. Taking all this into consideration my research will be focussing on explorative Participatory Design approaches and tools in order to investigate and dig in neurodiversity to:" challenge cognitive normalcy and to offer alternative, positive, interpretations of autism and autistic identity" (Dell et al. 2016, 172). Furthermore, people's reactions underline the importance of increasing the involvement and inclusion of autistic people and their relatives, not only in the studies, but also in debates about scientific findings and their possible applications, such as science engagement activities and Participatory Design activities.

In a recent publication concerning what autistic people want from autism research, evidence showed that: fostering "autistic flourishing" requires that researchers focus on similarities between autistics and neurotypical people while allowing for autistic differences. Consulting autistic people helps to ensure that their personhood is acknowledged (Sosnowy et al. 2019). This further shows the direction that research dedicated to autism should undertake in the upcoming future. In this thesis, the focus is on exploring means of participation to allow the direct involvement of an adult who experiences low-functioning autism.

Another noticeable characteristic and gap in knowledge that emerged from the review of literatures concerns the language used and selection of words, especially in scientific and medical publications for people experiencing autism. Often, words such as: 'retarded', or 'severely retarded'; 'abnormal'; 'person with lack of interests' or 'lack of skills' or 'lack of abilities'; 'failure to understand other people's emotions'; are sometimes used to describe those who embody the autistic condition. Although this type of language is widespread in medical contexts, it is problematic as it supports a divisive and reductive type of narrative. Language is important because it is a construction. When a person is defined as 'retarded' or 'abnormal', a negative connotation and -consequently, a negative meaning becomes associated with that person and his or her potential. This flattens the real complexities that constitute the human experience, which is based on abilities, personal histories, subjectivities and resources capable

of generating unique patterns for each human being. This kind of language expresses a lack of careful reflection, empathy and sensibility towards how words are thought, selected and used in relation to people who experience the autism spectrum. In this thesis, this gap suggests the need for a serious reflection on the importance of humanizing and selecting with caution and sensibility what language should be used while approaching this sensitive topic.

2.3 Participatory Design and inclusion

Participatory Design (PD) emerged in 1970 in Scandinavia starting from the ideal of bringing democracy to the workplace (Robertson, & Simonsen, 2012). It was rooted in workers' movements, and provided a foundation for imagining the political stakes of co-design (Greenbaum & Kyng 1992; Robertson & Simonsen 2012).

The participatory approach was commonly classified under the label of "cooperative design", which emphasized designers and users actively working together in a process aimed at improving the quality of working life (Halskov, Kim & Brodersen Hansen 2014). Participatory design an umbrella term including different practices such as co-design (Sanders, Stappers and Ave 2008) which was developed to foster collaboration between designers and other stakeholders, and to understand how design could support collective creative efforts. These processes often generated meaningful artefacts, leading to more committed workers and more efficient work processes (Robertson & Simonsen 2012).

The participatory approaches have begun to be adapted and applied in diverse design fields such as interaction design, service design, and more recently in several contexts such as healthcare (Sjöberg & Timpka 1998) and policy making (Anthopoulos, Siozos & Tsoukalas 2007). Even if the initial politically-driven philosophy over the years has become less prominent, participatory design retains its core as democratically-oriented practice, where design practitioners and participants are directly involved in the collaborative process.

Nowadays participatory design can be identified with a set of methods, and practices of engagement, and a commitment to a particular set of *values* all enacted through design (DiSalvo & DesPortes 2017, p. 179). By the word values I refer to a set of meanings that include: *cultural values* that can be defined as the ways individuals choose to act in the world based upon their family, friends, media, and other influences to which they have been exposed (Swidler 1986). In this way, cultural values are not simply the values expressed by the community or the values of the individual themselves (DiSalvo & DesPortes 2017). Learning what is valuable, to whom and to what end, is a critical part of this work (Agrid and Chin 2019). Authors in the fields of Participatory Design, Design and Anthropology and Human Computer Interaction (HCI), highlight the intersections of people's involvement in making their own futures (Greenbaum, Joan & Kyng 1992; Robertson & Simonsen 2012) the importance of making space for complexities of collaboration across powers and differences (Light and Akama 2012; Le Dantec and Fox 2015; Eriksen et al. 2016; Agrid and Chin 2019). Participatory Design in this

study is framed by feminist and postcolonial orientations that privilege relationality, power-sharing, inquiry, and de-centring the researcher/designer as the expert (Agrid and Chin 2019). From a feminist theoretical perspective, the focus is on the value of embodied and emergent practices; this theoretical perspective on Participatory Design approach is largely discussed by authors including (Light and Akama 2012; Light 2015; Akama 2014; Karasti, Baker and Millerand 2010). These authors explore the explicit value that openness and emergence, situatedness and accountability, close listening and an investment in learning from people, and non-Western or dominant orientations to knowledge-making and understanding bring to the design processes and to all participants (Akama, Stuedahl and Zyl 2015) .

In this specific study the learning process is made possible thanks to the research participant, a person whose experience of life and knowledge are left out of the margins of this normocentric society. The differences between me and the research participant are indeed valued as salient elements capable to generate a more meaningful and ethical engagement with the process of design (Bennett and Rosner 2019).

This research aims at establishing an active collaboration with a non-designer participant to explore reflexive and performative dimensions of Participatory Design, mostly mediated by non-normative communication interactions. In this thesis Participatory Design approach and inclusive approach are tightly interconnected.

Participatory Design is understood as an act of sensitive and respectful relationality, where the role of the designer is open and flexible to adapt when is needed to meet the research participant's subjective requests and needs. Careful observation and preparation are fundamental steps of this approach, especially in light of non-normative communication. This can help achieve a deeper understanding of the research participant, understand how to improve communication, and pin down what can be modified along the way to increase good collaboration. This approach draws inspiration from Light's words who suggests that it is timely to think again about how we enact our choices and values in our practices relating to others. In doing so, we need to stop seeing the method as detached from the design practitioner (Light and Akama 2012). Light and Akama (2012) provides an accurate account of the agency of designers in terms of facilitating PD activities. Engestrom uses the term "mycorrhizae", a word borrowed from biology, to identify an entity made up of heterogeneous participants working symbiotically, thriving on mutually beneficial or also explorative partnership. This vision resonates well with the notion of infrastructuring and fluid constellation discussed by (Star 2010; Star and Ruhleder 1996). This provides an interesting perspective that

acknowledges the importance of these relations, that are considered an object of design in their own (Dindler and Iversen 2014). Another fundamental element of PD is the use of research objects, probes *and* tools as means for inspiring participation, (Gaver, Dunne, and Pacenti 1999;Sanders 2000) the designers often uses commonly found, playful, everyday objects to access, interpret, visualise, articulate and communicate implicit knowledge through facilitated conversations (Light and Akama 2012).

The research objects are powerful instruments to stimulate and open possibilities of participation but also are important as means to disclose 'tacit knowledge' that is both cognitive (Polanyi 1958) and affective (Schön 1983) and is created through the interconnections between people. Tacit knowledge is gained through personal experience and is not transmissible easily and openly nor is easily codified and neatly translated, but carries meaningful value. To disclose tacit knowledge (Polanyi, 1958) trust, and human closeness that is embedded within the relational dynamics that occur among participants, can constitute a fertile ground within Participatory Design.

2.3.1 Limitations and gaps in Participatory Design

Participatory Design is a field in constant expansion and evolution, as new knowledge, perspectives, applications, and visions are constantly being developed. Although many recent projects advance knowledge in the PD field, there are very few contributions that focus on procedural dynamics and the relational experience in Participatory Design. Dindler and Iversen (2014) also suggest that the relational perspective on design should be further articulated for the benefit of participatory design (Dindler and Iversen 2014). More specifically there is a lack of PD projects that involve people with disability and within that field there is little knowledge concerning the procedural dynamics, the difficulties, as well as the relational dynamics between participants, and more specifically between the design practitioner and the non-designer participants. Often these dynamics remain hidden and are not explicitly studied or carefully articulated. Focussing on this gap can help to advance not only our understanding of disability but also the field of Participatory Design in general. As Boys suggests "starting from disability does not lead to universal or simple design solutions but instead opens up to creative

engagement the complex, messy and often contradictory intensifications of our diverse lives with others, artefacts and material space" (Boys 2014, 4).

Another gap identified in Participatory Design research is the limited number of investigations involving adults who experience severe autism. This number becomes even smaller if we consider the active involvement of adults with autism and non-normative communication abilities in PD research. This topic is currently under-investigated, and the knowledge concerning how participatory design activities can be developed and what kind of approaches can trigger active participations among participants who use non-verbal and non-normative communication are very scarce. This observation indicates that not only is an important part of our society not yet involved in PD research activities, but also that there are important gaps concerning those who are communicating in non-normative ways. There are a lack of instruments and comprehension concerning the real abilities of those who experience the severe end of the spectrum. Consequentially there are the limitations in the language that is used to describe potential contributions of people with autism in PD research. The language used by researchers sometimes can be perceived as controversial, even lacking sensibility and adequate understanding concerning this specific group of participants. What unfolds from this gap is the missing voice and real consideration for the abilities and embodied experiences of adults with severe autism and consequently their contributions to this branch of research.

2.4 Existing Design projects for Autistic people

Design as a discipline, started to develop projects engaging with autism in the 1970s. The first project, "A Playroom for Autistic Children and its companion therapy project " was developed by Richer and Nicoll in 1971. In the same period in the Netherlands, the design of a multisensory environment called *Snoezelen* was realised (Figure 6), which allows a person with autism and other disabilities to select and receive sensory input of desirable type and amount. Since the 1970's Snoezelen has been expanding internationally, and is being used in schools, hospitals and sometimes even prisons (Kaplan, Clopton, and Kaplan 2006).

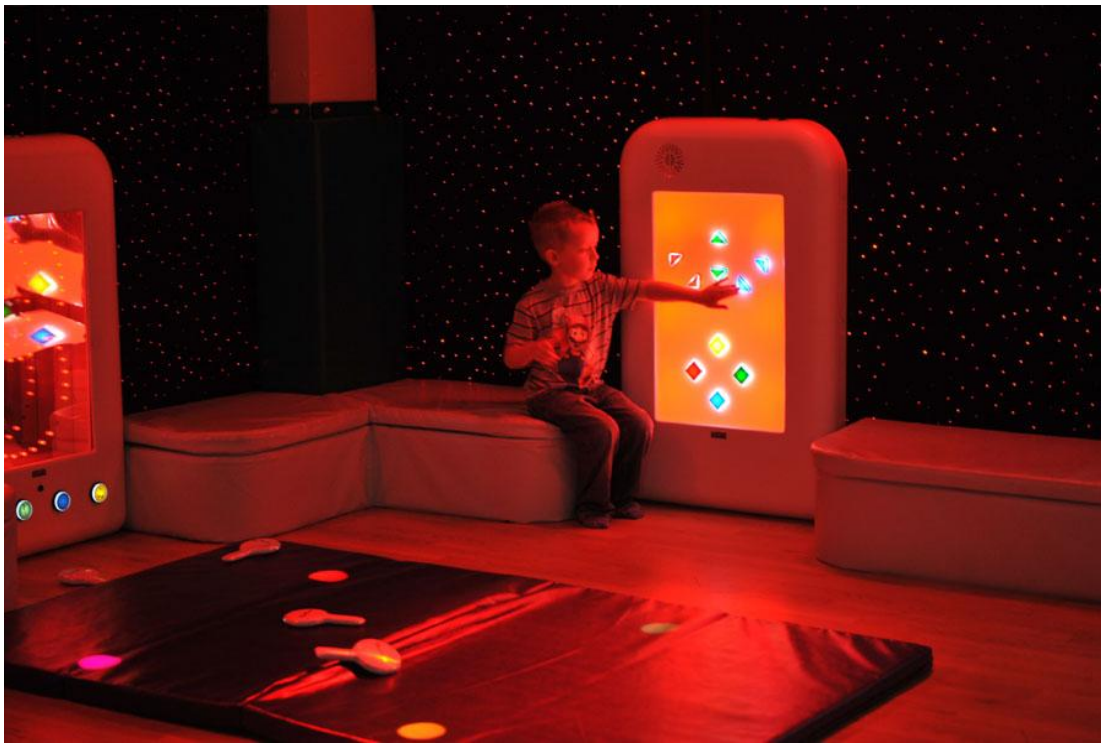


Figure 6: Snoezelen room at the Brickkiln Community Centre in Wolverhampton.

Nowadays the majority of design projects related to physical environments are dedicated to improving the design of schools and classrooms (Gumtau et al. 2005; Mcallister and Maguire 2012; Tufvesson and Tufvesson 2009; Mostafa 2008) as well as outdoor spaces such as playgrounds (Gaudion and McGinley 2012; Herbert and Herbert 2005; Hussein 2010; Menear

et al. 2013; Yuill et al. 2007). Different design interventions also use interactive technologies, assistive technologies, apps and virtual environments to help improve autistic people's skills concerned with communication, social learning and imitation skills (Garcia-Zapirain 2014).

Technology is frequently used as a valuable medium to develop diagnostic aid tools such as *Transporters,* a facial emotion-recognition training through multi-media content, which is used from Baron-Cohen in his research activities (Golan et al. 2010). Other technology implementations are designed to support children's everyday activities. For instance mobile technologies, as well as multi-touch technological applications, have been developed with the aim to enable children with autism to understand the immediacy of social interactions and facilitate the relationship with people that surround them (Farr, W. , Yuill, N. , Raffle 2010; Hourcade, Bullock-rest, and Hansen 2011; Tentori and Hayes 2010).

Recent design interventions with humanoid robots are proving to be extremely useful to support children with autism: *Kaspar,* a robot created at the University of Hertfordshire (Figure 7), is the first example of robotic interface that is purposely created for children with autism. *Kaspar* uses tactile feedback provided by a novel robotic skin, with the aim to provide cognitive mechanisms to improve human–robot interaction capabilities (Robins and Dautenhahn 2014). Before *Kaspar*, another humanoid robotic doll was developed to study the efficiency of robots in stimulating children to mirror behaviours (Robins et al. 2004).

Figure 7: Kaspar, the humanoid robot

The use of humanoid robots revealed to be relevant especially for children with autism that have verbal disabilities and social difficulties and who use the sense of touch to understand and communicate with the outside world. Through imitation and playful contact with the robot, children were shown to feel safe and comfortable during the activities, and this generated important and valuable improvement in their lives. Furthermore, the whole research, design and prototyping process provides fundamental knowledge and understanding concerning the role of personal interaction with technology for children with autism.

The direct involvement of children with autism in the research phase through inclusive design methods is a big source of inspiration for this research project. Examples of such research projects include the *IDEAS* (Interface design experience for the autism spectrum) participatory design method (Benton & Johnson, 2014; Benton, 2011) and LINXX, a language-learning toy developed by adapting context mapping techniques that could facilitate working with children with autism (van Rijn and Stappers 2008). In more detail, IDEAS is a supportive participatory design approach tailored to specific needs for children with autism and is guided by the TEACCH program. TEACCH (Mesibov and Shea 2009) covers fundamental characteristics of autism spectrum disorder based on 'evidence-based practice' and the guidelines are considered appropriate also for this research project. The characteristics are (1) difficulties with the concept of meaning; (2) greater focus on details and difficulty prioritising relevance; (3) distractibility; (4) literal thinking (limited social skills/emotional empathy); (5) issues with combining or integrating ideas; (6) problems organising and sequencing; (7) generalisation difficulties; (8) visual learning preference; (9) prompt dependence (difficulty with initiation); (10) strong impulses, and (11) excessive anxiety.

These general guidelines are common not only in children but also in adults with autism, especially low-functioning autism. As a consequence, these guidelines will be taken in consideration during this investigation to support the design and organisation of the study and the participatory design activities that will be developed together with an autistic adult.

Another project relevant for this thesis is the ECHOES - Technology-Enhanced learning project, which investigated technology as a tool for facilitate participation together with children with autism (Frauenberger et al. 2012; Frauenberger, Keay-bright, and Pain 2012; Spiel, Makhaeva, and Frauenberger 2016). My interest in ECHOES is due to the mindset and inclusive approach towards the participants (children with autism) that the researcher adopted during the investigation. Children were asked to explore their wishes and their personal interests, which has allowed a personalised approach and deeper engagement with the

participants. The researchers approached the investigation not with a concrete problem to solve but with the will to understand what a child with autism considers useful or important for his/her daily activities based on his/her personal interests.

Such approach is important especially because at the moment there is very little information concerning the wishes and personal interests that people with autism have. Unveiling untold personal interests and needs could be beneficial for people with the autistic condition, helping to prevent social isolation, and to generate activities that stimulate interests and curiosity. Aiming to understand the personal concerns and interests of people with autism, the participatory design approach showed and proved to be, in the projects highlighted above, a fundamental resource for researchers and caregivers alike. However, within the ECHOES project, Frauenberger et al. (2012), highlighted the emergence of research gaps, especially concerning the small number of participatory design projects involving autistic children and adults.

Another project of interest for this research is that of Gaudion (Gaudion 2015) who described her research experience in a charity that promotes independent living for autistic adults. Her research involved adults with autism and contains a few elements that are interesting. She created a strategy called the triangle of strength that focuses on the strengths and abilities of the research participants in order to promote participation.

Another strategy adopted by Gaudion is emulation: The researcher noticed the "destruction" that an autistic man created in his home environment: "a ruined sofa where all the leather had been picked off and a damaged wall" (p.5). When Gaudion met and interacted with the autistic man in his house she started mirroring his favourite activities and she noticed how content and relaxed the autistic man was, sitting quietly picking at the leather on his sofa. Mirroring the same gesture, the researcher described how satisfying was the action of picking the leather from the sofa and compared this gesture with popping bubble wrap. (Gaudion et al. 2016, p.5). Gaudion uncovered that what a "neurotypical" researcher might think and perceive as a disruptive behaviour in reality can be the outcome of a very pleasurable activity for a person with autism. For this PhD investigation the approach adopted by Gaudion is very interesting and inspiring. Emulation can be a valuable instrument for a research to get a better understanding of unexpected and at first incomprehensible behaviour. Furthermore, this can help to enhance empathy and human closeness.

2.4.1 Gaps in existing Design projects

Nowadays numerous technology options are available to support learning and communication for people with a wide variety of disabilities. These often include voice output communication aids (VOACs) as well as computer hardware and software applications that provide writing and/or spelling assistance (Mirenda 2001). For the most part, those projects are only partially developed using Participatory Design approaches and there is evidence to suggest that, for example, "people with Autism not only desire, but also expect, to be included in decisions affecting them, and that the risk of abandonment of assistive technologies is reduced with user-involvement in design and selection, it appears that the question is not whether this group should be directly involved in the technology design process, but *how this should be done*" (P. Francis, Balbo, and Firth 2009, 133). Although all projects listed above provided extremely important support for children with autism, few of them were developed with the direct involvement of an autistic adult. In other words, the majority of the projects dedicated to autism spectrum disorder are mainly dedicated to children, and their involvement varies from project to project.

From a broader perspective, since the 1970's, have been involved as testers in the development of new technologies for educational purposes (Druin 2002). However, their direct engagement, and the engagement of adults with autism through participatory design is still not fully adopted to this day. Some design research projects such as (Hirano et al. 2010), attempted to engage with the theme of children affected by autism. Nevertheless, the project mostly involved focus groups with caregivers, autism experts and parents, rather than children with autism. This is because the involvement of young subjects with low functioning autism in the design process was still considered highly complex.

There are practical difficulties that researchers must take into consideration when working with autistic people and the most evident is the different perception and understanding of the physical world and sensory stimulations and reactions. However, this difference can also be a fertile ground to help expand knowledge concerning autism and autistic people, if we look at the spectrum not only as a complex condition but also as a resource.

With this in mind, in this investigation the role of the participatory design approach and its possible applications will be studied together with young adults with low functioning autism and their relatives, to enrich the knowledge existing in the current academic literature.

The design interventions mentioned above are mainly focused on improving autistic people communication and social skills; however, there are several areas of the daily lives of autistic people that are not being fully explored yet. Design can play an important and new role, looking at technology from a different perspective and along with different uses, to create a dialogue across different fields and expertise. Moreover, the majority of existing design researches are concerned with children living with autism and only a few projects focus on adults (Ahrentzen et al. 2009; Brand and Gaudion 2012; Decker 2014; Gaudion and McGinley 2012; Kandalaft, Didehbani and Chapman 2012; Parsons et al. 2000).

Despite this, it is important to take into account that people living with autism will spend the majority of their lifetime living as adults, and the lack of design research focusing on such target group is of concern. Some of the consequences are the inappropriate use of childish tools that do not respect the dignity of an adult, or the individual perception of tools that do not feature adequate aesthetics and could accordingly function as vehicles for social stigmas. A direct consequence is that such tools would not be largely used or appreciated.

The focus on a general classification of autism based on someone's deficits, didn't allow to consider the heterogeneous nature of autism, the different age groups related to autism and individual strengths and interests. To face the gaps in literature is also important to mention that nowadays between 44% and 52% (NAS) of people living with autism also have a learning disability. Including them in design research is relevant, however, compared to the project dedicated to "high-functioning" autistic children, only a few works focus on adults with "low-functioning" autism (Gaudion et al. 2015).

This research builds upon the gaps described above to explore and address possible design and methodological contributions in the domain of autism research, with the scope of triggering possible life benefits to young autistic adults in the low-functioning spectrum.

Chapter 3: Epistemological Position and Methodology

3.1. Introduction

This chapter describes the theoretical and practical orientation of this research. This exploration is by its nature situated and influenced by the practice-based approach and methodology that I have been engaged in, through my design practice for almost 10 years. What will be presented here is a single case study conducted by adopting a Participatory Design approach.

I understand that there are multiple realities through which one can make sense of the world, and in this thesis the position is taken that each person constructs his/her reality from their own personal experiences. My standpoint and philosophical perspective fundamentally aims to value and respect the subjectivity and consequent partiality that underlies human experience, which is particularly salient in the case of people on the autism spectrum and with limited speech abilities. This standpoint is embedded in my approach throughout the whole thesis.

Furthermore, my research has been underlined by a commitment to preserve and protect the wellbeing of the research participant; this has been the priority and the most important concern in this PhD research. The following sections present the theoretical and epistemological underpinnings of the study and the methodological approach adopted which is founded on three key principles: immersion, situatedness and participation. In addition, this chapter contains information about data collection and the approach applied to qualitative data analysis which is based on reflective practice and co-reflection with the research participant. Finally, the chapter presents the ethical guidelines and principles adopted.

3.2. Theoretical ground for the study

While this thesis does not aim to make a novel contribution to theory, it is important to state the 'theoretical understanding of the world' that underpins this research. A brief description of its theoretical grounds is given here.

Drawing from feminist theory, disability studies and the work of Jos Boys (2014), this research builds on the position that any single experience in a minority is valuable experience, which can provide important insights into the world. Here I am interested in people with disability as a minority (Hahn 1988 and 1993) and I focus on people with autism who are themselves a minority group within a minority, especially those that have limited speech abilities and non-normative communication. As discussed in the literature review chapter little is known about those people's ideas, thoughts and self-understanding of the world (Pellicano, Dinsmore and Charman 2014). Feminist theorists, in this respect, are proposing an approach to constructing ideas of the good with full respect for and inclusion of the viewpoint of severely dis(abled) people as members of a community (Francis and Silver 2007; Silver and Francis 2013; Longino 2001). From this highly inclusive position, the feminist theory assumption adds that "only partial perspective promises objective vision" (Haraway 1988, 583), especially when the perspective comes from a person that, at this moment in time, is in a position where his or her "voice" is not being sufficiently taken into consideration. The partial perspective, in this investigation, is the perspective of a single person's life experience and the valuable knowledge that they can offer to the whole autistic community, the design community and the society at large. This position is influenced by disability studies, which acknowledge that disability is defined by the way society is organised rather than a person's impairment (Wendell 1989). Such studies are not concerned with individual deficit, or the limitations apparently imposed by disabilities. On the contrary, they are interested in empowering disabled people to define their differences in terms of personal experience and self-authorization, free from the burden of medical diagnosis and social stigma or limitations (Morris, 1991). This vision proposes a position of equality in society for those that experience disabilities (both physical or cognitive), in which their existence is not merely defined nor confined by a diagnosis.

With this in mind, this thesis values the Autism Spectrum Disorder as a condition that does not define a person in its entirety, but that is part of the life experiences "inhabited" and "embodied" from that person. This expresses an epistemological position which considers people affected by autism as the actual experts of their own life, defined by their subjective

abilities and understanding of the world. However, this perspective can be too simplistic if the social context in which the disabled embodiment take place is not taken into consideration. Loja describes that “disabled embodiment is produced and experienced within an ableist context that mobilizes the charitable gaze and the medical model to signify impaired bodies at the expense of the recognition of disabled identity” (Loja et al. 2013).

3.3. Case Study

To explore the research question, the work in this thesis focused on a single exploratory study of an autistic adult with non-normative communication abilities. According to Yin (Yin 2003), a case study is an appropriate approach when: (a) the focus of the study is to answer "how" and "why" questions; (b) you cannot manipulate the behaviour of those involved in the study; (c) you want to cover contextual conditions because you believe they are relevant to the phenomenon under study; or (d) the boundaries are not clear between the phenomenon and context. The decision to use a case study as a research strategy in this thesis is justified by the above- mentioned criteria and with Flyvbjerg's information-oriented selection of case study. The effort is to explore together with an adult on the severe autistic spectrum and with limited speech abilities, how and if it would be possible for him to take active part in a participatory research project, using his own abilities. Furthermore, it is fundamental in this research to answer and show why this type of investigation could inform design research projects dedicated to adults on the severe autistic spectrum.

The complex nature that characterizes autism spectrum disorder in its multiple forms, and the subjective nature of this condition, call for an in-depth investigation which is conducted by taking into consideration subjective experience. The use of a case study is conceived in this thesis as a powerful means to understand how to enter in the life of the research participant by fully respecting his abilities and wellbeing.

While researchers like Flyvbjerg advocates the real possibility of generalization through case studies (Flyvbjerg 2006; 2011), it is important to specify that in this thesis the possibilities for generalization are somewhat restricted due to its emphasis on subjective experience, and in contextualising this experience in a person's specific context and behaviour. As discussed, autism spectrum disorder affects each individual in a unique way, and although some common behavioural patterns and traits are shared between people on the autistic spectrum, each person experiences autism in a specific and subjective way. Dr. Lorna Wing for example states "Once you've met one person with autism, you've met one person with autism" to indicate the diversities that determine each condition and consequently the inapplicability of generalization as a general principle. Furthermore, the life experience of each person on the autistic spectrum presents substantial differences due to the context where they grew up, the stimuli and the therapies they did undertake, the social and cultural context that

surrounds each person, constitute a unique pattern. The arguments above aim to justify the decision to adopt a case study approach, however there are multiple types of case study, which is useful to clarify here.

A descriptive case study describes an intervention or phenomenon in the real-life context in which it occurred (Yin 2003). According to Stake, an intrinsic case study is a type of study used when the aim is to better understand a case or a specific situation. It is undertaken primarily because in all its particularity and ordinariness, the case itself is of interest (Stake 2005). This is the approach adopted in this thesis. The thesis describes a case study with one participant exploring his subjective life experience with ASD. The context-dependent knowledge that a case study research approach produces, it has an aspect of primary importance in this thesis. Flyvbjerg highlights that context-dependent knowledge contributes to an important learning process necessary to allow people to develop from rule-based beginners to virtuoso experts (Flyvbjerg, 2011).

A comparative study would have been ineffective not only because the condition manifests differently in different people, but also because of the difficulty to control external parameters affecting different people's condition and behaviour such as their social, cultural and personal environment and their current and past treatment. Additionally, as autism is associated with a difficulty in navigating the social world, it was considered that group work might generate or become a source of restlessness and potential risk for them, as each individual reacts differently to similar stimulation. Furthermore, when moments of tantrum for people on the severe end of the spectrum arise, they can possibly lead to episodes of self-inflicted or inflicted violence. As a consequence, special care was taken to avoid the occurrence of this type of episodes. The unpredictability of what can trigger negative emotions and agitation calls for a thoughtful consideration concerning how to approach the entire research strategy. Therefore, this research focuses on one participant, and his subjective life experience with ASD. In particular, the aim is to explore the possibilities of communication with the participant through participatory action research, i.e. working with the participant and in his own context, in order to develop ways of communicating and understanding that are responsive to the participant's needs and wants.

An alternative approach that was considered for this research was to work with a group of participants, instead of just one. Furthermore, multiple case studies were also considered, however, after a careful considered, both alternatives were excluded, mainly to prioritize the well-being of the participants. It is important to acknowledge that even a small number of

participants with severe autism can have very different responses to similar stimuli, and for this reason a group session could potentially trigger unwanted emotions and reactions. More specifically, some of the participants might find the research activity funny or interesting, while for others the same activity might be perceived as it annoying or even painful. This could not only generate potential difficulties in facilitating participatory design sessions, but also make it difficult and uncomfortable for the participant to take active part to the research process. To avoid these difficulties, a thorough understanding of the research participants, and what makes them vulnerable was considered fundamental. Moreover, this research wishes to follow an in-depth iterative and exploratory investigation path, which requires extensive availability of time, to achieve an appropriate understanding of the participant's abilities, interests and communication modalities. Considering the available time within an AHRC funded studentship, as well as the concentration and expertise necessary to work with one participant, this research followed the route of the single case study, with the intent to explore one person's unique abilities, experience of the autistic spectrum and potential personal mode of communication.

3.3.1. Recruiting a research participant

The decision to pursue a single case study with a unique research participant, was taken early on in this investigation. The following considerations guided the recruitment and selection process:

- The first requirement was to approach people that are on the severe end of the autistic spectrum and with non-normative communication abilities;
- The second requirement was to recruit adults who are older that 21 years of age;
- The third requirement was to find a person with enough time to dedicate for a few months to this research;
- The fourth requirement was to find a person that could use assisted writing or other assistive technology to communicate his thoughts in the final phase of the research;

These characteristics determined a very specific starting point that made the research and selection of the participant quite complex. The considerations listed above, refer to a person who is living an adult life, outside of schooling and possibly with an occupation such as work activity or alternative forms of daily activities. Support for adult people on the autistic spectrum in considered extremely poor and inefficient (Lai, Lombardo & Baron-Cohen, 2014) as all the support provided via school or other child support services end when a person turns 18 years old. To recruit participants in the early phases of the research the National Autistic Society and various other organizations dedicated to autism spectrum disorder were contacted, including a school for autistic children in East London (Phoenix School). These first few steps did not provide concrete opportunities to establish the aimed collaboration.

Through further research I came across a social enterprise based in Italy that supports interesting projects dedicated to people experiencing autism, and through them I identified the research participant. The recruitment of the participant was made via email. I contacted an Italian social enterprise and quite rapidly our collaboration positively unfolded and provided the possibility to develop this study together with the son of the owner of the social enterprise. After few exchanges of emails with them and a phone conversation, we organized a meeting in Italy inside their social enterprise. During the meeting, it has been discussed the aim of this investigation, the time schedule and the possible involvement of Enea the son of the owner and to which extend he could possibly be involved. During the same meeting, I met for the first time Enea, which became the research participant, and in the same day I met one of his ABA therapist.

3.3.2. Research Participant

The research participant is a twenty-five years old young men. Enea has been diagnosed with severe autism and atypical autistic traits when he was two and a half years old. He lives in Italy with his family, where he works for a social enterprise, together with his parents. A few years ago, he graduated from high school and since then he is in contact with some of his classmates. Enea has limited verbal abilities, however, his non-normative mode of communication is rich and eloquent. He can write through assisted writing, he loves to paint and does sports.

3.4. Methodological instruments and stages of the research

The following section leads into the key methodological instruments and principles of the research: immersion and inhabitation, situatedness and participation. In line with this the three instruments are also defining three different stages of the study, where the immersion and inhabitation is the preliminary and explorative study, developed in close contact with the research participant and his therapists and family members. This stage leads to gain fundamental information concerning autism, through official and unofficial training and to establish the first personal human encounter with Enea in this study.

The second stage is situated: key instrument used to gain information about the daily routine of the participant and to establish rapport and a way of working with him. This stage was important in the first part of the research, which included small design activities, situated in the participants' context and routine. These two important research steps laid the foundation for the implementation of the third stage. The third stage is the participatory action research where I worked together with the participant to explore enabling participatory activities and objects.

3.4.1. Immersion and Inhabitation

For someone who is not personally experiencing the autistic condition this can be a difficult human experience to even grasp, let alone understand deeply. The notions and theories concerning the autistic spectrum have helped to shape a general understanding of what is a complex, highly subjective and severe condition. But an in-depth understanding of an individual adult's subjective experience required an immersive approach. This included exploring the structures of his daily life and the daily activities, his rituals, training and therapy sessions, his behaviours and reactions to different occasions, and his communication skills, and abilities. At the same time it was also important to observe how people that are part of the research participant's life, such as his parents and therapists, communicate with him, their tone of voice, the type of words they use, which kind of behaviour they perform in moments of distress if and when they arise, etc. In this immersive phase the use of diaries was adopted to record detailed descriptions of events and insights into their meaning. Observations were done in natural settings, such as the home of the research participant, his work environment, the art therapist's studio, grocery shops, etc. This approach supported a respectful and slow immersion in the life of the research participant, with observations happening three/four days a week over the duration of three months. This allowed the research participant to know me and understand if he could trust and accept my presence in his life, before starting our collaboration.

From my perspective, this approach facilitated a deep immersion into the participant's life. immersion was achieved through a "lived through" type of approach, and this is rooted in the concept of inhabiting. The concept of inhabiting is inspired by (Rogoff 2006) feminist practice, and her reflection on how knowledge production could be different if it was rooted and "lived through a specific situation". Rogoff calls "embodied criticality", the practice of inhabiting, that is only possible when we live through things and this experience can provide critical understanding towards the inside aspects of specific situations. The subjective inhabitation of Enea's life experience with autism is impossible for me to comprehend because it is not possible for me to directly experience autism. This is due to the subjective nature of the autistic spectrum and the unique strategies that each person adopts when living with the condition. However, even facing the limitation of not being able to thoroughly live through what exactly the research participant experiences, emulation was adopted as a practical

approach to understand the possible meanings behind Enea's behaviours and rituals. As discussed in section 2.3, mirroring his behaviour and trying to immerse myself in his rituals supported a deeper level of understanding, reinforcing a non-verbal understanding with the research participant. This approach required a process that involve:

- *TIME AND RELATIONAL ABILITIES*: Dedication of time to establish a connection with the parents of the research participant, to allow them to clearly understand the purpose of the research and its time frame, to negotiate my access, and to discuss all the activities that are developed with their son. The dedication of time to cultivate a positive relationship with the participant's parents included my reliability in answering questions and possible doubts. This was a valuable path to create mutual trust, also with all the subjects that are actively present in the life of the participant.
- OFFICIAL *AND UNOFFICIAL TRAINING*: Learn how to enter and be present in the life of an autistic adult. I undertook certified official training within the National Autistic Society and unofficial training with the research participant's therapists, to understand how to positively interact with him without being in conflict with the therapeutic orientation followed by the research participant for years.
- *FLEXIBILITY*: The dialogue with Enea's parents was intentionally kept flexible to negotiate the time for the activities, spaces and the content of the activities themselves, as he already had a tight daily schedule and therapeutic path to follow.
- *SENSITIVITY*: In this investigation, the entire observation and immersion was approached with delicacy and sensitivity, looking at any situations and subjects involved without preconception or judgement.

Following this immersion into the research participant's life, a deeper understanding of what the research participant feels, and the reason behind some behaviours was achieved.

3.4.2. Situated approach

Driven by the need to root this investigation in the life of the research participant, the research approach required to construct this investigation upon the unique individual circumstances that are embedded in the participant life experiences and abilities. This led to a tailored situated approach. The notion of situated knowledge questions the foundational understanding of traditional objectivity which envision the subject as a simple, singular point of empirical knowledge-gathering, where the object of inquiry is identified as passive and stable. Through situated knowledge, subjects become complex contraptions made of biological vision and personal will. From this prospective situated design is a process that takes place in a particular situation and is carried out from embedded positions (Haraway 1988; Simonsen et al. 2012). This approach emphasizes situated contexts that are dealing with the complex relation between the context, the design situation. Simonsen draws on a situated understanding of the world to put forward a particular approach to design, through situated design. This implies from his prospective that design is always carried out with partiality and from a specific embedded position. The situated nature of this specific research is constructed in the actual experience of research participant and my personal experience being embedded in this study.

This investigation is situated, as first, within the autistic condition that the research participant experiences, which differs from all other people that live with autism; second, in the strategies that he applies to cope with his condition, these are personal; third, is the social environment that surrounds the participant, where social relations shape and impact on his life. The term 'social environment' is meant the relations that he has with his parents, family members, friends, therapists, pets, including more distant relations such as the occasional ones (e.g. meeting strangers in public spaces); fourth, situated is the physical environment where the research participant lives and grew up, including his family house, the schools, the work environment, etc.; last, situated is the therapeutic path he undertook since he was a child.

Consequently, also my approach in this thesis is situated. The design interventions involve ad hoc research objects, created to investigates possibilities for stimulating mutual understanding, relational bonds and reciprocity with the research participant. The design of the research activities and research objects is strongly interconnected with the knowledge and situated information concerning the research participant. The research objects have also the aim to protect and enhance the abilities of the participant. Therefore, has been designed and

created research activities that highlight non-normative communication, and the use of objects and gestures specifically appreciated by the participant.

3.4.3. Participatory Action Research

This research follows the principles of participatory action research with an iterative and incremental approach. The concept of action research was introduced by Lewin in 1946 in the context of social psychology and is described as: “It is a Type of action-research, a comparative research on the conditions and effects of various forms of social action, and research leading to social action. Research that produces nothing, but books will not succeed.” (Lewin 1946, 35). Participatory Action Research (PAR) is a methodological approach that emerged from social science. This approach considers that any development process undertaken is biased if it does not incorporate the beneficiaries of this process as the protagonist of this. (Guzman et al. 2015)

The nature of PAR is specific to its context, as it is situated, and it helps to make sense of the world through collective efforts to transform it. Its fundamental premise is that all participants gain knowledge through a communal process of mutual understanding. For PAR practitioners, there is no ‘I’ without there being a ‘we’ (Wakeford and Sanchez Rodriguez 2018, 24)

Practice-based design extensively uses Participatory Action Research as methodology (Crotty, 1998, p. 5), especially in participatory type of approaches. Due to the collaborative and practical nature of researching with people that have different capabilities and skills, such as, people with autism, case study and participatory action research are chosen approaches for this PhD. More specifically this stage of the research consists of the collaboration between me, the researcher, and the participant to explore problem and skills within the research context, learning from real people daily experiences (Creswell 2007).

According to Lewin action research is research that proceeds in a spiral of steps each of which is composed of a circle of planning, action, and fact-finding about the result of the action (Lewin 1946, 38). An important element of the Participatory Action Research is this iterative sequence of intervention on work practice and the possibility to learn from this through critical reflection (Avison, Baskerville, and Myers 2001). For this PhD, a closed loop of planning-action-reflection cycles was followed to address the research objectives and progressively evaluate and refine the approach. In more detail, this process was highly dependent on the research participant’s reactions, which are difficult to predict. For this reason, each activity with the research participant was followed by a reflection to evaluate whether the activity can be considered adequate or must be replaced with another activity or research object.

The different phases of the research are explained in the following scheme (Figure 8) and described in detail below.

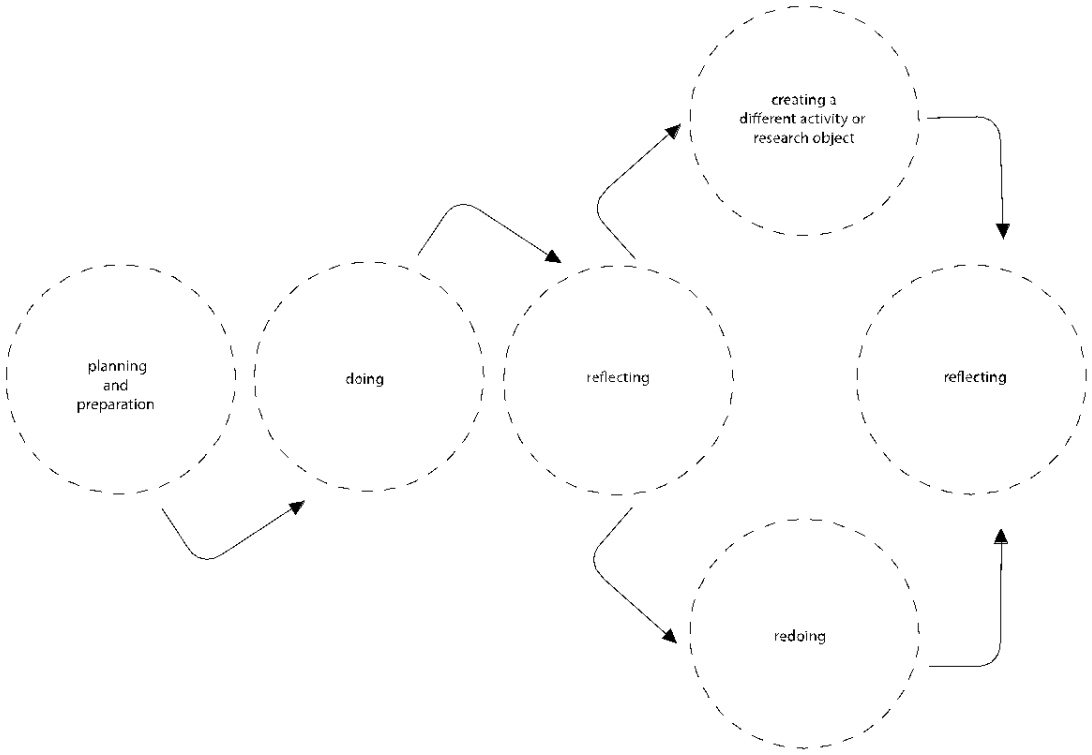


Figure 8: scheme that illustrates the phases of action and reflection linked to the Participatory Action Research process

- *Planning and Preparation:* This phase includes all preparatory work supporting the participatory action research, such as training, planning and preparing the activities and the materials used, defining the time frame and specific time structure of the activities including planning the brakes, preparing myself for the work with the research participant. The act of becoming ready and readiness is informed by Akama and Light work (Akama and Light 2018).
- *Doing*: This phase is associated with the actual activities carried out with the research participant, including the exploration of the research materials and the research objects, and their suitability and effectiveness in supporting active collaboration and participation with the research participant.

- *Reflecting:* This phase is associated with critical reflection at the end of each participatory activity with the research participant. This reflective practice is undertaken in order to understand what is the most appropriate next step.
- *Redoing or creating a different research activity and research object:* This phase consists in revising actions based on the outcomes of reflection. The unpredictability of the participant's response is approached through two strategies. In the case the participant's response results in positive and active collaboration, the activity is re-proposed and or continued. If an activity does not trigger participation, or even if it triggers negative reactions, then the activity is changed and re-designed based on what I learned from the interaction with the research participant. However, the negotiation with the research participant is constant and extremely valued and other strategies, such as improvisation are used too.

In this specific project, the participant is considered as the real expert on autism, due to his life experience as a young man on the autistic spectrum. The thesis takes great care in considering the power relations that inevitably emerge between myself (the designer) and the participant, who is in a vulnerable position. For example, I have initiated this research, I have a certain type of control over this study as a designer, I have abilities that are largely accepted by the current society and I communicate in a normative way. As a consequence, undoubtedly my position is privileged in comparison to the position of the research participant. However, starting from this awareness and conscious consideration of the potential problems that this can create, the enabling activities created for the research participant are thoughtfully designed to create the right conditions for the participant to act in his own terms.

This thesis built upon the historical approach to PD and the idea of democracy to facilitate and to establish the conditions for equal participation. In order to engage participants in participatory design projects, designers and researchers have been using physical artefacts, tools and probes. Such objects/processes encourage multi-modal communication within and across different social worlds through activities such as making, enacting and telling (Sanders and Stappers 2014, 12). Although tools and cultural probes have helped supported the engagement of participants in design projects, it is important to underline that in these existing approaches participants are generally thought to have the speech abilities or capabilities to express themselves verbally, or actively interact with the probes and tasks that designers are creating for them. Little consideration has been given in the current literature on how to engage

participants who do not have the capability to take a picture or actively build or modify a mock-up or keep a visual or a written diary, tell a story or even verbally describe their experience or thoughts. People on the severe end of the autistic spectrum are the type of participants that are too often left out from participatory research.

3.5. Ethical Considerations

In the section the data collection and data analysis processes and methods are discussed and extensively explained. Furthermore, the ethical guidelines that have been followed are presented in this section.

3.5.1. Data Collection

Data collection in this study was driven by the access I was able to negotiate with Enea's parents. The data collected during, the inhabitation, immersion and situated phase of the research includes diaries with, ethnographic notes, sketches, and pictures that did only involve objects or activities; direct pictures of the research participant in this phase were excluded.

During the participatory action research activities data collection started to include video, audio recording and pictures of the research participant, and the research objects and materials that were produced and used. Research objects and artefacts were developed to support participation and to facilitate non-verbal communication during the investigation. Over one hundred and sixty pictures have been collected, thirty-two hours of video recording, eleven hours of audio recording, and fifty-three documents and artefacts produced by the research participant during the research activities, such as drawings, collages, etc. The data was collected over a period of nine months, and the data are stored in a hard disk specifically dedicated to this research. Following anonymisation protocols, Data such as video recording of the work sessions were not shown in this thesis, and any pictures published do not directly show his face. As discussed, the pseudonym Enea is given to refer to the participant throughout the thesis to respect anonymity.

3.5.2. Data Reflection and Co-Reflection

In this study the final reflection is aligned to an interpretivist paradigm, which Robson (Robson 2002) describes as a flexible type of research that should be adopted when no clear information

is available before pursuing the research, but the focus of the investigation evolves through a reflective, interactive and experiential process. The results, generally presented in the form of narrative, are generated through an inductive process of data clustering and categorisation in themes and description, leading to the development of a theory (Strauss and Corbin 1990). However, this PhD doesn't aim to generate a theory, but discuss possible implementation about participation and research dynamics in design research with adults experiencing the severe end of the spectrum and non-normative communication abilities. This research use a qualitative approach to data analysis and it follows the participatory design belief system that reject the traditional positivistic framework and on a contrary take inspiration from field such ad Design Research and Action Research (Frauenberger and Good 2014).

This type of approach is largely adopted in PD projects with the aim to pursuit rigor and structure a critical reflection with a meta-analysis and the coherence of the findings as describe in ECHOES project, where it has been created a tool to guide PD practitioners in a process of critical reflection and coherence to provide a robust and flexible means of assessing internal rigor and accountability (Frauenberger and Good 2014; Bødker and Iversen 2002). In this thesis the data analysis involved three type of critical reflections that have been developed at different times during the study (Figure 1):

1. The observation was made during the research activity, the data collected were unstructured and followed the flow of events and participant reactions;
2. Self-reflection was made at the end of each research activity, in this phase the data were structured and re-analyzed carefully;
3. Co-reflection developed together with the research participant, once we completed our investigation. Furthermore, the data analysis included the reflection concerning the research objects and the collaborative dynamics that arises during the collaboration;

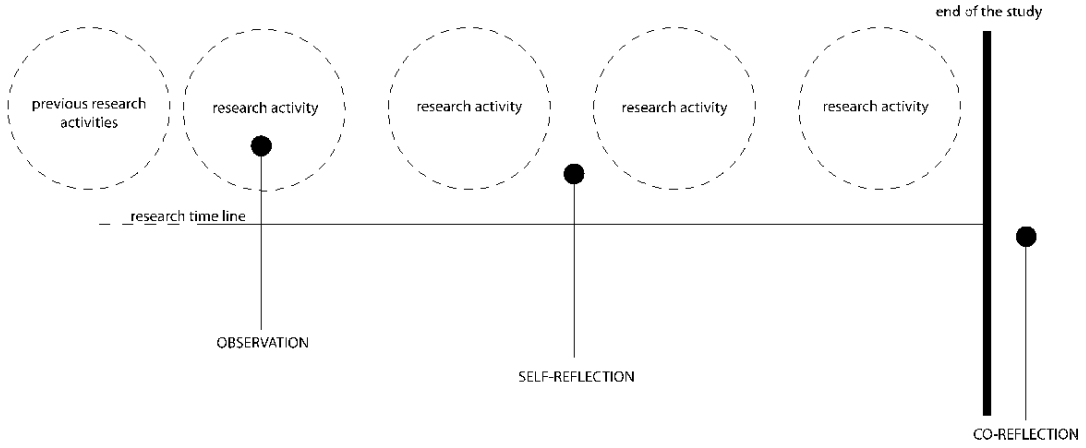


Figure 9: scheme that illustrates the research timeline, its activities and modes critical reflection (observation, self-reflection, co-reflection)

The process of evaluating the design outputs together with Enea needed to be conducted with empathy, caution and sensitivity, as introducing new activities could impact the research participant life and routine, and this could trigger a sense of stress and anxiety. The approach adopted towards the thesis relay on a practice-based approach that generated a range of observational activities mediated by the research objects and participatory design activities explored together with the participant. Semi-structure interview was conducted with the research participant using his ability to write with assistive technology. These interviews were used also remotely to help the personal schedule of Enea, allowing him to write with his how time and speed without causing him stress. What has been analysed is engagement and response to the research objects and activities and the level of interest and interaction performed by him.

The analysis that follows draws on empirical observations, self-reflections and co-reflection together with the participant concerning the participatory design activities. The intention was not to generate generalizable knowledge about participatory design, but to start constructing a phenomenological and practice-based understanding based on observations of the effects of the research objects and the research process/dynamics that have been adopted.

Furthermore, Enea agreed to interact in a normative way using assisting writing in order to let me get a more articulated understanding of his thoughts. The data analysis is articulated in the following way:

Observations: This approach to data analysis have an anthropological perspective that allowed to achieve an in depth understanding concerning the research context and the research participant. Anthropology means studying 'with' and learning 'from' people, closing the gap between observation and understanding, 'knowing from the inside' and reconstructing knowledge on the outside (Ingold 2013). Observations have been tracked when I was in close contact with the research participant in diaries, sketches, pictures and forms. The forms have been created ad hoc to track the behaviour and well-being of the research participant and understand the impact that this research had on him after each participatory activity. The forms have been filled in after each research activity by myself and by Enea's parents. This reflective practice (Schön 1983) was critical for this PhD as it enabled to form meaning from the plethora of design approaches, thoughts and experiences that culminated during the design process. Reflection helped me to refocus my thinking from existing knowledge to generate new knowledge and ideas, which influenced the modification of the methods and my actions along the way based on the responds of the research participant. This observation is linked with reflexivity in time (Akama and Light 2018) as the data have been studied in the simultaneity or immediately after the events. In *The Reflective Practitioner* (1983), Schön's book he describes how reflective practice enables the practitioner to understand and make it explicit how the knowledge of the design practitioner changes as they interact, observe and make things with others, through this *reflection-in-action* (1983);

Self-reflections: In this phase of the data analysis I focused on the research dynamics occurred between me and the research participant. I self-reflect about my actions, the way I structured the activities, the way I could implement them, the way I enabled the research participant to actively participate, and what I could correct and change towards the study to trigger participation. I observed and re-watched videos and pictures taken during each research activity and I developed a critical analysis concerning whether, in which way and to what extend participation was trigger and what could be done differently, to improve and learn from each activity developed with the participant. The systematic method used to select key sections in the data to examine in closer detail have been used is a selective and interpretative method. With a large data corpus, I transcribed all interactions and interviews and used to systematically

organise all the data. To retrieve key episodes to re-visit and inspect in detail the research objects and the activities explored together with Enea;

Co-reflections: In this phase the involvement of Enea have been fundamental. Together we co-reflected upon the entire study. Together with the participant we analysed videos, pictures and artefacts developed during the investigation. This approach is refereeing to concept of collaboration and reflexivity, meaning doing research 'with' – rather than 'for' or 'about' – participants is key within anthropology, through inter-subjective enquiry and empathy (Ingold 2008; Pink 2013). The communication between us have been through assisted communication. To facilitate this process semi-structured interviews (Kvale 1996) where conducted with the research participant. Also the co-reflection developed with Enea have been systematically transcribed and the data have been systematically organized and elaborated.

3.5.3. Ethical Guidelines

The PhD was conducted in compliance with the code of practice for research ethics and guidance provided by the Open University Human Research Ethics Committee, see appendix 2.1. The consent to participate was obtained following an explanation of the research aim and approach. The parents of the research participant and his therapists received the consent form by email in advance and I was available to provide further explanations in case this was needed. The consent form for the research participant was signed by his parents, however the form was read to the research participant and an oral consent was asked of him. Furthermore, the first time we could communicate using assisted writing I asked him again for his consent to work together, and he expressed an interest and will to do so. The information that I received during the research study is anonymized and carefully stored to guarantee a correct utilization of the data and confidentiality. Throughout the PhD the designer worked closely with the research participant's parents and therapists, to ensure the design process was appropriate and ethically conducted. Before the design of the research objects and participatory activities were first discussed and approved by Enea's family members. To ensure that the autistic participant' best interests were central to the research, the project exercised a principle of benevolence and I used the golden rule 'one should treat others as one would like others to treat oneself' as an important reference point. Furthermore, the wellbeing of the research participant was always a

priority for me, and I conducted the study with a deep respect, empathy and sensitivity for Enea, his family members and his therapists.

3.6 Summary

This chapter has described the theoretical and epistemological grounds of this research. The study adopts a standpoint informed by feminist theory, disability studies and perspectives that value the situated and embodied perspective of life experiences. The developed methodological approach took into consideration all the complexities that the research topic presented. Such complexities concerned:

- The situated type of investigation and its exploratory nature;
- The high subjectivity of the experience of ASD that each person has;
- The different triggers that can affect the well-being of a person with severe ASD;

These factors were considered important and influenced the orientation of this research towards the development of one single case study, with one single research participant. The chapter presented also the methodological instruments that are applied in this study, that is: inhabitation and immersion; situated; and participation. The chapter also described details of the data collection and analysis as well as the ethical guidelines adopted.

Chapter 4: Immersion and Inhabitation

4.1. Introduction

This chapter provides detailed information about the process that I followed to understand the research context and the context of the participant, as well as to approach and create the conditions for working *with* the participant. The chapter first describes the actions that I took to prepare myself for this research, including an official training with the National Autistic Society in UK, and unofficial and more situated trainings with the research participant's behavioural therapists, and speech and art therapists. During this time, I began to immerse myself in the participant's life using an anthropological approach, which consisted in following his daily activities, observing his reactions and his subjective abilities, and interviewing his family members and therapists. The second part of the chapter presents my reflection and analysis of the information and data collected during this immersion phase. The reflection helped to identify significant limitations and assumptions along the way, creating an accumulated body of knowledge on what worked and what did not work during specific daily activities. At the end of this chapter, I describe how I arrived to develop my own research approach, based on Enea's abilities, interests and personal characteristics.

4.2. Immersion

The preparatory phase of the study comprises two separate training events. The first involved certified training with the National Autistic Society. The second training session was led by Enea's therapists, to gain a specific and situated understanding of him. In a similar way to other participatory design projects that I developed in past years (Cadamuro 2013), this investigation required me to expand my knowledge and gain practical experience in this specialised subject. The training helped me to widen the theoretical knowledge obtained through academic readings and informed me about possible ways of facilitating positive interaction and communication with the participant. The relationships that were developed during the training sessions with the therapists supported the creation of a network that provided me support when I was confronted by doubts, uncertainties and lack of understanding of Enea's behaviours.

4.3. First Training

The National Autistic Society training focused on understanding stress and anxiety in autism and their impact on behaviour. This training is specifically targeted to professionals who work closely with children or adults with severe autism. During the training, we discussed the sources that cause stress and anxiety, together with tools to detect their possible triggers, and methods to restore a calmer behaviour. Stress and anxiety are constant presences in the life of a person on the spectrum; and while stress is defined as a reaction to a specific event, anxiety is understood as a reaction that mostly refers to fear, the nature of which cannot always be known.

The daily level of anxiety of a person with autism is considered to be higher in comparison to people without autism. Such anxiety is produced as a response to social situations; exposure to environments or activities that lack structure and detailed organization; or exposure to sounds, smells, tastes and physical contacts that trigger sensory sensitivity. Each person on the spectrum can react differently towards their anxiety and find a personal way for self-controlling and calming. For example, repetitive behaviours could be understood also as a mode of self-calming and self-caring. However, it is not always possible to control the level of anxiety, and this can culminate to self-injury, violent reactions and aggressive behaviour, until the point of a painful meltdown. 'Meltdown' was defined during the training as a highly stressful situation that is characterised by an outburst of emotions. Normally, consequential to moments of meltdown, follow moments of 'shut down', which arise after stressful peaks, where the person becomes completely calm, uncommunicative and with low responsive energy left.

Most of the time, professionals and non-professionals who work in close contact with people on the autistic spectrum can become themselves involuntary sources of distress and anxiety. This can be caused by: wearing smells and perfumes that could be perceived as strong and repulsive; wearing makeup that could transfigure the face of a person, making it unrecognisable; constantly changing hair styles; wearing clothes with colourful patterns that could be perceived extremely tiring for their eyes; using a tone of voice can also be perceived as irritating or repulsive. Consequently, careful attention should be paid on these triggers, to help to prepare for working with a person on the severe end of the spectrum and with limited abilities, and to help them naming and verbally explaining their discomfort. Moments of meltdown and distressing behaviour could be limited or even avoided through the application

of Positive Behavioural Support (PBS), and examined using the ABC chart (National Autistic Society, 2016) see appendix 4.2. The PBS approach is based on five key elements: Structure, Positive, Empathy, Low Arousal and Links.

- Structure: Adopting a structured approach, which involve consistency, repetitions of activities, strict daily structures, a structured way of working and the avoidance of unpredictable activities. Successful structured approaches are built upon an in-depth understanding of the person we work with. This includes familiarization with the history of the person, understanding his or her personality, knowing and talking with his or her family and friends.
- Positive: Using a non-judgemental approach, which involves the ability to manage our own emotions in front of a person with autism and his possible moments of tantrum or anxiety, and always use positive language to support positive communication. Additionally, the approach necessitates focusing on the improvement of the life quality of the person that we work with, building on positive experiences and activities, and tracking and understanding what are the positive and the negative experiences that those people go through, and how the ABC chart can be used to record behavioural output.
- Empathy: The Theory of Mind (ToM) considers that people living with autism have affective empathy, which is the ability to perform an appropriate response per what is perceived. For example, when a person with autism sees somebody suffering, he can 'understand' that the person suffers. However, the ToM affirms that empathy needs also another element to be complete, that is, cognitive empathy, which is the ability to place ourselves in other people's shoes. The ToM suggests that cognitive empathy is something that is lacking in people experiencing autism. This, however, doesn't mean that people on the spectrum aren't empathic. Most of people on the spectrum have different ways of showing empathy towards those around them, and it is important to be aware of this. Their way of showing empathy could be unusual or could be a response that comes in late in comparison to what you would expect from other people. For that reason, it is important to understand and welcome people with autism and accept their unique ways of expressing their feelings. Furthermore, working with a person on the spectrum requires also to learn stepping into their shoes and understanding their unique prospective.

- Low-Arousal: The low-arousal principle suggests the need to take steps not to encourage or trigger any type of disruptive response from a person with autism. For that reason, it is important to be non-confrontational, especially when a person appears to be distressed.
- Links: Working in a group or having some experts to talk with is extremely important when we work with a person with severe autism. It is always important to share with other professionals our own experience and share also the complex emotions and difficulties that could arise.

In the unfortunate case of meltdown or high distress, the suggestion is to reduce verbal communication and, if possible, also reduce any physical contact with the autistic person. Vice versa, it is correct to perform slow movements, use gentle and reinsuring gestures and voice tones, and making sure to leave a safe space between the person and possible harmful objects and obstacles. Those moments could become emotionally difficult also for the people that are simply trying to help the autistic person that is having the meltdown. In case that happens, it is important to try as much as possible to hide those emotions and give the impression of being calm. During the training, it was considered fundamental to try anticipating and possibly avoiding the insurgence of a meltdown, and to apply all the strategies that were explained and listed above. The wellbeing of a person on the spectrum is in strong resonance with the behaviour and preparation of the people that surrounds them. A thoughtful preparation could prevent to stumble into errors that could be avoided. Furthermore, having a good understanding of the person we work with can make easier the path towards a positive interaction, supporting an appropriate emotional engagement for both subjects, the person on the autistic spectrum and the person that works in close contact with him/her. At the end of this training, I received the official certification of my attendance (see appendix 4.1).

4.3.1 Training and impact on my preparation

This first training had an important impact in my preparation and shaping the mind-set that accompanied the entire research. I applied the Positive Behavioural Support (PBS) suggested by the National Autistic Society, trying to understand it thoroughly and practice it as a ritual within my daily preparation and the activities developed with Enea. My personal daily routine progressively changed by introducing simple and practical elements such as: providing an exterior image always recognizable in the eyes of Enea, having always the same haircut, plain clothes and simple makeup, avoiding shampoos, shower gels and creams with a scent (see infographic 1). Being aware that I could possibly become a source of distress for the research participant, these small precautions were followed until I was able to get a deeper understanding of his subjective sensory preferences and sensitivities. Part of the PBS approach was also a source of inspiration concerning the implementation of a tool that supported the observation of Enea's behaviour in different times of the day. The designed observational tool (Figure 10) is inspired by the ABC chart presented in appendix 4.3. The ABC chart is normally used to record behavioural concerns, based on a description of antecedents, behaviours and consequences.

· **'A' stands for antecedents**, that is, what happens immediately before the behavioural outburst; this can include any triggers, signs of distress or environmental information;

· **'B' refers to the behaviour** itself; it is a description of what actually happened during the outburst or what the behaviour 'looked' like;

· **'C' refers to the consequences** of the behaviour, or what happened immediately after the behaviour; it can include information about other people's responses to the behaviour and the eventual outcome for the person.

The observational tool was not only created with the aim of taking notes of moments of meltdown or distress, but more in general to help observing holistically the behaviour of Enea. It presents a few substantial differences from the ABC chart, as was specially designed as an aid to collect visual data (Figure 11). This tool was designed to be simple to use and was shared

with Enea's parents and therapists. Together, we recorded our impressions on how Enea reacted to my presence in his life; his reaction to the activities; any source of disruption or agitation as well as his daily mood and behaviour. The process of data-gathering provided important information concerning Enea's behavioural pattern as along the process it also was possible to identify the times of the day when he was usually calmer and capable of concentrating. It also helped identifying the type of activities that Enea enjoyed the most and comprehending the triggers that easily lead to increased agitation and disruption. During this research, Enea never had a meltdown nor he had highly stressful moments. What was possible to observe were a few moments of agitation, with triggers that were easily identified and did not result from the research activities.

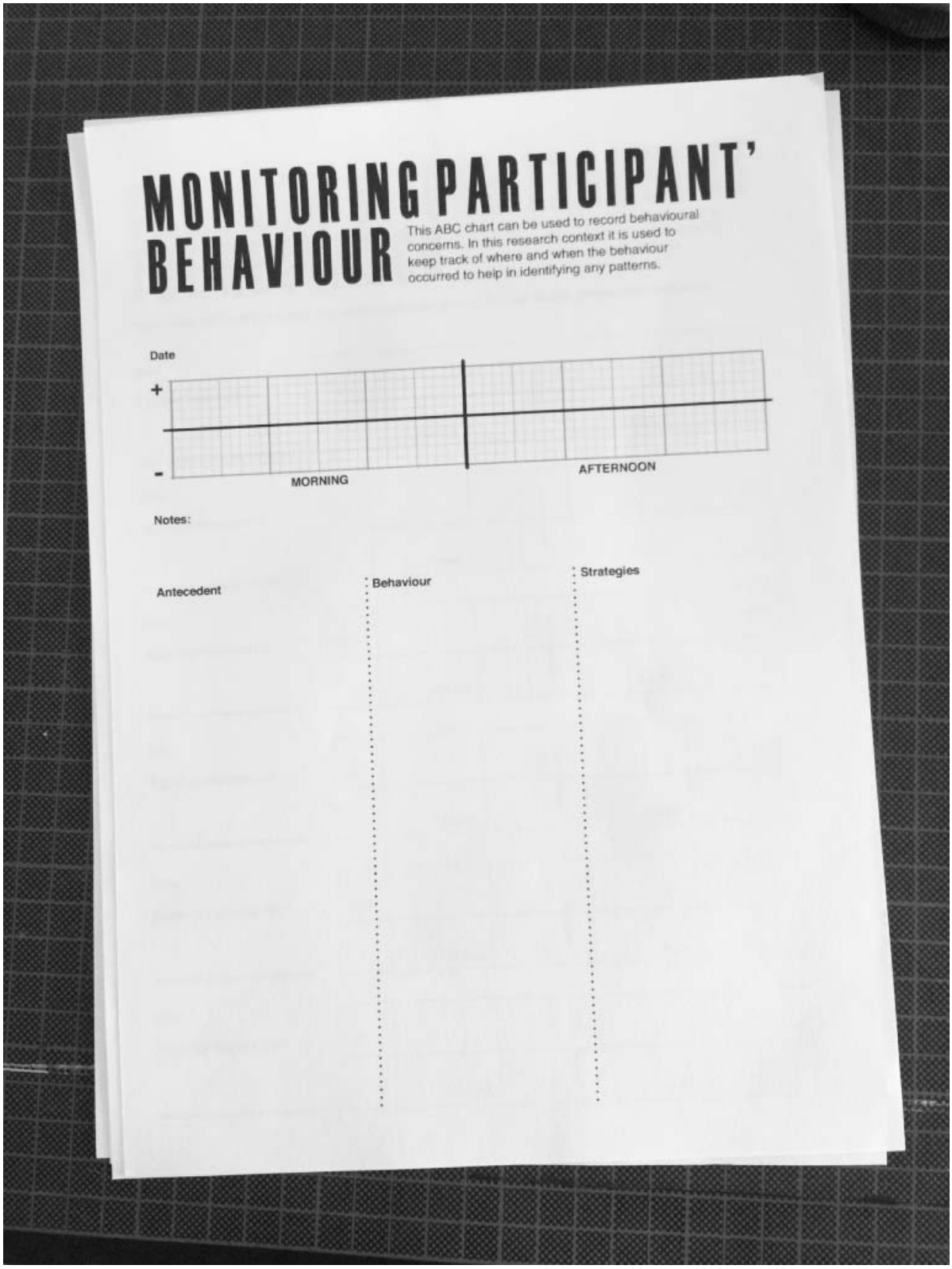


Figure 10: modified ABA form, purposively designed to be shared with Enea and his parents

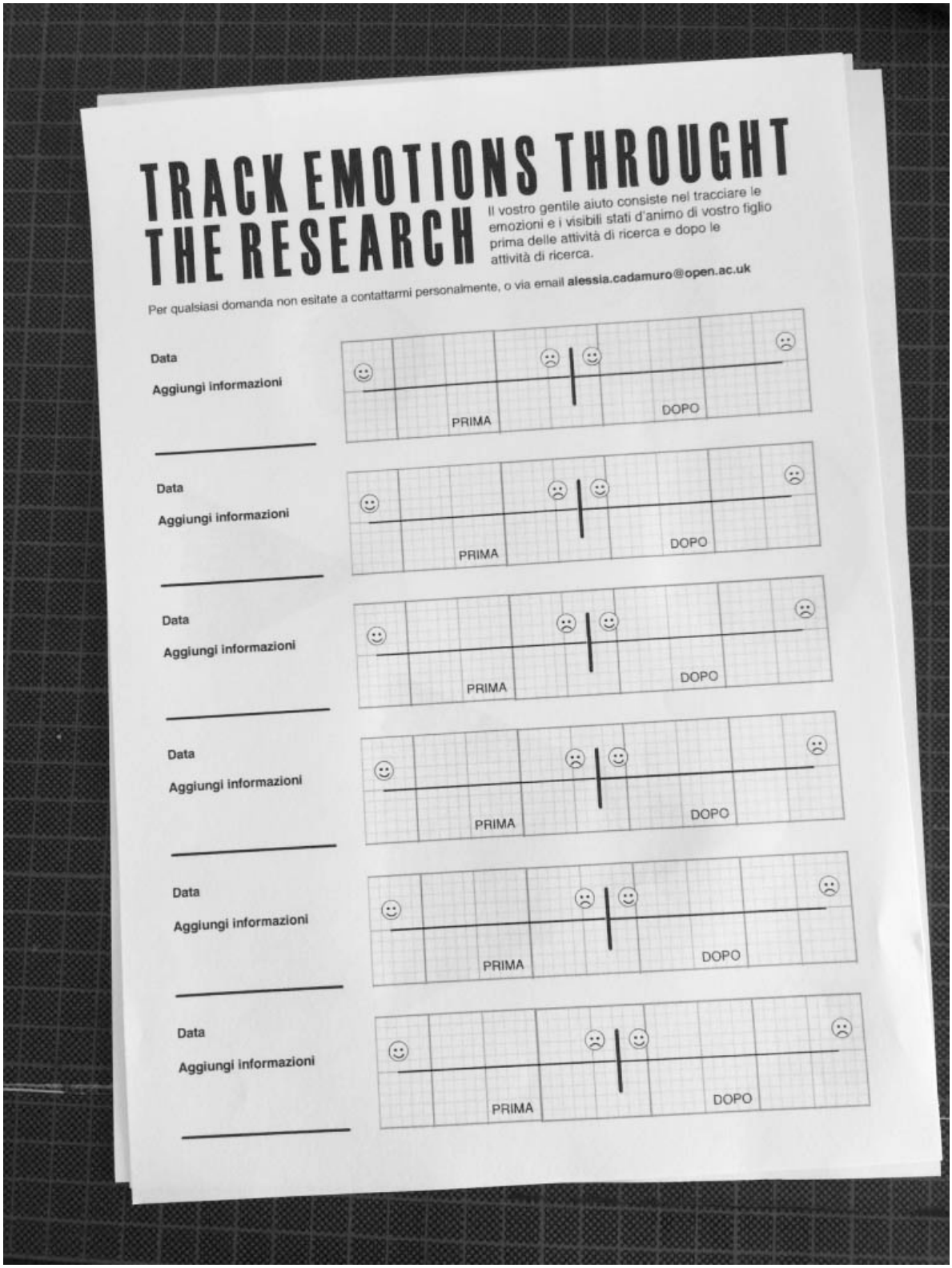


Figure 11: Tracking Enea's emotion from the beginning til the end of the research activities. Each graph reports about one activity.

4.4. Second Training

The second training was organized in collaboration with the mother of the research participant who arranged to meet with each of Enea's therapists. The training lasted for two months, where I followed the morning and afternoon activities organized by the participant's ABA therapists, speech therapist and art therapist, three to four days each week. This training was mainly based on learning in practice, where the participant's therapists showed concretely what the behavioural therapy consisted in, and the level of interaction it involved with the participant in his everyday life. This was helpful to grasp important information concerning the research participant's abilities and personal characteristics, including how to interact with him based on the examples given by his therapists. Moreover, the therapists introduced me to Enea during their activities and supported a positive entry phase for me in his life. This stage was critical to the entire research project, as it allowed me to be accepted by the participant.

This training was an intense learning process for me as researcher, where I learned how to avoid creating or doing anything that conflicted with the therapeutic path of Enea. For example, through the ABA approach, the therapists guided Enea to alter antisocial behaviours, or behaviours that could be perceived harmful or unacceptable in our society. Enea loves to touch and press with his hands the belly of people, even those that he does not know. For him, this gesture is spontaneous, and he explained this as a way of getting to better know a person. However, Enea is not capable to effectively control his strength; he is a tall, strong young man; thus, his touch can be painful or even perceived as an aggressive gesture, especially on sensitive parts of the body. Indeed, in the past, Enea and his parents experienced some issues with strangers who -not knowing the Enea's condition, did not welcome his behaviour. During the research, he tried to touch my stomach without my permission, and this was repeated on a daily basis, a few times a day. Sometimes he did this successfully, because he was very fast and I couldn't stop him; other times, instead, I managed to redirect his behaviour. Whenever I could, I had to gently move aside and remind him that he should not do that, or at least that he should try to ask my permission, as suggested by the therapists. Personally, I did not know the participant's reaction to objects such as cameras. Therefore, I recorded my learning path, observations and consecutive thoughts in diaries (Figure 12).

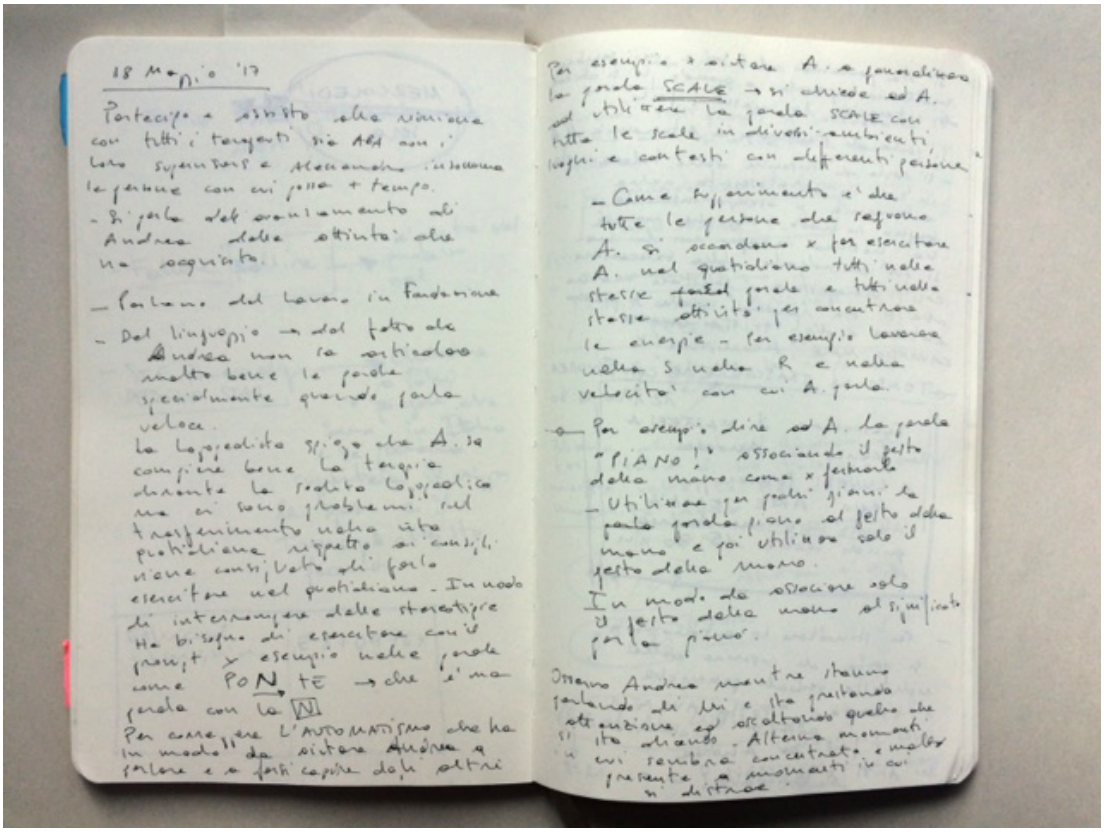


Figure 12: one of the research diaries, where written annotations were recorded during the research activities

This choice was also taken to help build trust with Enea and his family and therapists who did not know me well. I was concerned that using a camera or audio recording prematurely in the study could prevent the participants and his therapists from acting naturally and feeling relaxed in my presence. Moreover, they could have objected the study, jeopardizing the core of this research. The selected photographs that I took concerned the objects that Enea used during the ABA activities. These photographs were taken with the permission of Enea's therapists, and exclusively when Enea was not in the room.

4.4.1. Immersion into Enea's daily structure

The training usually started at 9:00 a.m. in a private office, owned by Enea's parents, situated next to Enea's house. Usually, Enea arrived with one of his two ABA therapists, after they had

breakfast together. Usually, the breakfast is prepared by Enea, under the guidance of his ABA therapist, who also helps him with his daily hygiene routine and dressing. One of the missions of behavioural therapy is to build his independence and help Enea to learn how to engage with his daily activities. From 8:00 until 12:30 a.m., Enea and his ABA therapist usually work together. The morning activities are divided in two separate sessions, following a strict routine. In the first session, from 9:00 until 11:00, Enea usually follows two activities, selected from the following list: grocery shopping, speech therapy exercises, exercises with photos or flash cards to name places and facial expressions (Figure 13), crosswords, photographic learning cards (Figure 14), short q&a time.

Figure 13: system of pictures used by Enea's therapists to help him recognizing face the meaning of different face expressions

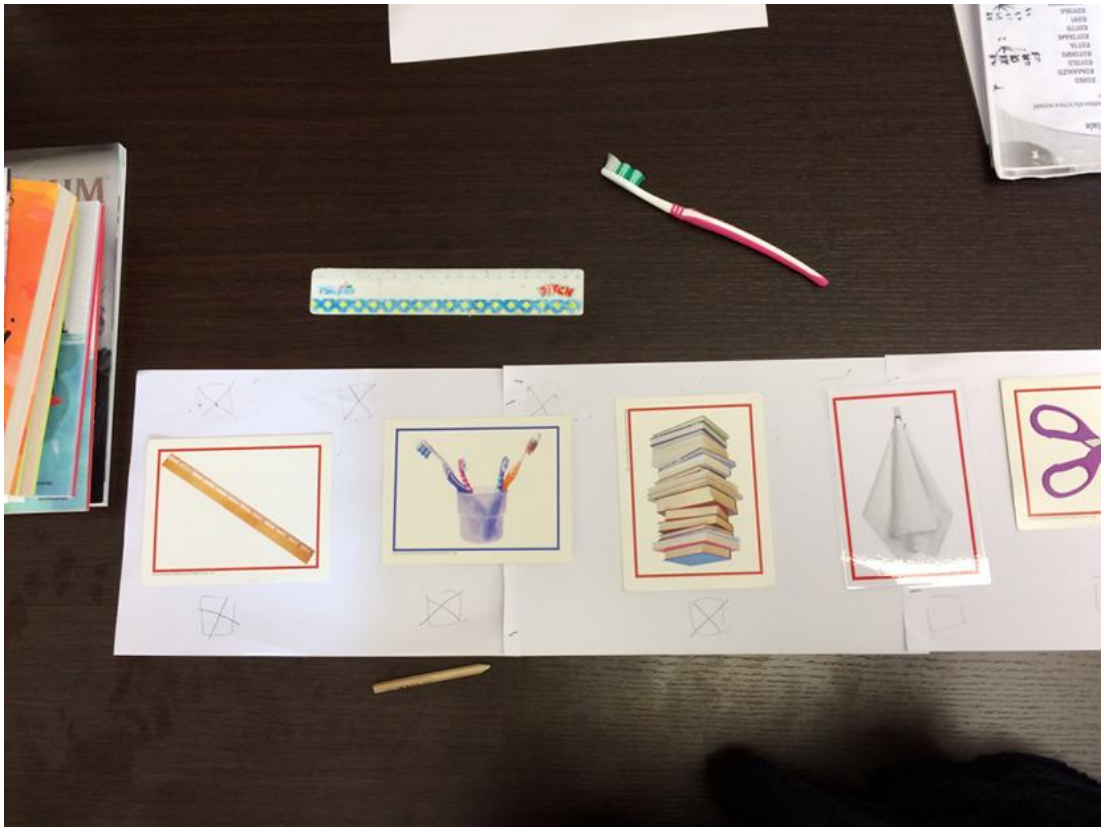


Figure 14: a game used by Enea's therapists to teach him the meaning and use of daily-life objects.

To motivate Enea, the ABA therapist usually starts the activities by asking him what kind of rewards he wants to work for. Enea's frequent choice is to go to sit outside the office, play with his phone, or go to the close-by cafeteria for a dessert. The reward system used by his ABA therapists is based on the Token economy (Figure 15). The token economy is a form of behavioural modification, designed to increase desirable behaviour and decrease undesirable behaviour with the use of tokens. In the case of Enea, an A4 laminated cardboard contains the tokens, which can be added or removed, based on the behaviour that Enea performs, and his ability to complete the required activity. When the activity is successfully completed, Enea receives his reward. Normally, the activities do not last very long; each usually lasts between fifteen to twenty minutes and is followed by a five-minutes break, where Enea consumes his reward. Often, during Enea's breaks, I had the opportunity to talk to the ABA therapist, asking them questions and receiving some guidance.

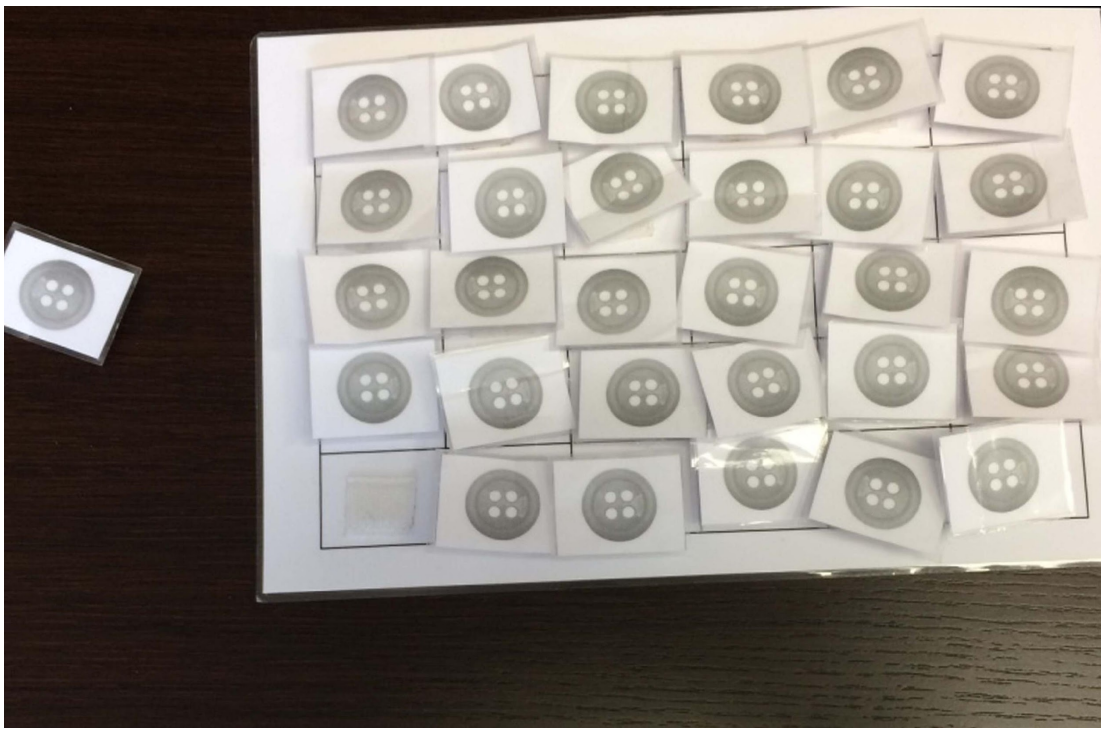


Figure 15: the token economy reward system, used from the ABA therapists during their activities with Enea. When the chart is complete, Enea can have a reward (e.g. a break from the activity)

4.4.2. First Morning Activity - Grocery Shopping

One of Enea's favourite morning activities is grocery shopping. Normally, his parents inform the ABA therapists about the day-to-day items that they might need at home, ranging from one to five grocery items. The shopping list of Enea is a visual list (Figure 16), where exchange is the main mode of communication; in fact, although Enea can read and write, he can only do that in precise circumstances and with at least two people, including his psychologist and/or his mother or father, and only by means of a tablet. For that, his grocery list is visual. The ABA therapists create this visual list by using pictures of the items that Enea usually needs to purchase.

Figure 16: visual grocery shopping list

The grocery list is made on a A3 white laminated paper, where pictures can be attached and easily detached with a Velcro system. Under each picture, the therapist drew a white box, which Enea can cross when a correct item is purchased. This activity supports him in the process of becoming more independent and learn to remember what the right steps are and how to perform them at the right time. During grocery shopping, his therapist and I waited for Enea near the checkout lines. It is important for him to do this activity alone, so that only in case of difficulties he knows that he can easily reach his therapist.

Enea seems to enjoy this activity, as he likes to be around other people, although the therapist usually choses a small supermarket, where just a few people shop in the morning. The therapist explained that, for Enea, every single daily activity contains obstacles that he must learn to overcome in order to become self-sufficient. The repetition of actions that we consider logical or trivial are not that easy for Enea. Through his behavioural therapy, Enea learns how to do things step-by-step. For grocery shopping, for example, he must remember the right sequence of actions: first, when entering the shop, he must remember to take a cart or a basket to carry his products; second, he must look at the list and search for the right item; third, once

he founds the item, he must remove the product from the list, crossing the box; fourth, he must re-check the list and search for the following item; fifth, once all the items are taken, Enea must to approach the checkout lines; sixth, when his turn comes to pay, he must take a bag; seventh, he must remember to take his wallet and the prepaid card; eighth, he must remember his pin code; ninth, he must remember to press OK after typing his pin code; tenth, he must remember to put his prepaid card back in his wallet; eleventh, he must remember to place all products into the bag. These are eleven actions, which were taught to Enea from his therapists, step by step. The ABA approach involves an in-depth analysing and disassembling of the activities that the person cannot do properly. Breaking each task into a series of small actions and repeating them over and over, often in association with a reward system, eventually lead to a full learning of the activity.

During the two months of my training, I saw how the ABA approach was applied with Enea. The Therapist told me that a few months before Enea used to go into shops, steal randomly one or two products and then run away without paying them. During my training, I saw Enea's rapid improvements in grocery shopping, and when he forgot some action his therapist helped him to remember. For example, the moment of the checkout is the most difficult for Enea, and his agitation is clearly visible. In this moment, his therapist usually moves close to him, gently taking his arm and suggesting the action of taking one bag; this type of action is intended to activate the 'muscle memory' of Enea. The muscle memory supports a form of procedural memory that involves consolidating a specific motor task into memory through repetition; this means that making Enea always repeating the same movement -such as taking one shopping bag, or his wallet when he must pay, helps him to memorize an action and automatically repeat it by himself. After shopping with Enea on several occasions, I could observe that he used to forget a few actions, for instance, showing his items before payment, not collecting all the products on the list, or confusing them with other items, however, he never forgot his pin code. His therapist explained that Enea memorised the pin code of his card in a matter of minutes, and -since then, never failed to remember it. This is explained by the high specialization of people on the autistic spectrum and how their mind operates. However, it is difficult even for Enea's therapist to understand how he can memorize well certain tasks, including quite complex actions, and, on the contrary, he has difficulties with others. Furthermore, the therapists explained that it is complex to understand why and how those preferences are applied and selected.

From observing these morning activities, I had the opportunity to understand how behavioural therapy is concretely applied in the participant's daily life. The routine, the repetition of actions and the rigid structure that therapists apply daily with Enea suggests that a consistent and coherent type of approach helped him to concentrate and successfully complete the activities that he does. The ABA therapists encouraged me to understand that a rigid and coherent approach helped Enea to manage his anxiety and made him experience small and important successes on a daily basis. I was also suggested to use this approach while working with him; for instance, I should always start activities at the same time of the day, in the same location, giving him simple instructions or explanations about it. I was suggested to divide the activities in small sub-activities for Enea's to comprehend the purpose of our work together. Furthermore, it was suggested to structure our workshops into 15-20 minutes sessions, and then take a break.

4.4.3. Second morning activity - office work

In the second part of the morning, between 10:30 and 11:00, we moved to a second location, in a different part of the town. This second location is the social enterprise created by Enea's parents. Every day Enea does office work for two hours. His therapists explained that he enjoys this type of occupation and he is extremely committed to do it. This is something I also noticed. He enjoys it so much that most of the time he prefers to continue working rather than stopping for a break. Enea's office activities are framed by his behavioural therapists, who applies ABA approach in combination with the token economy reward system. His job involves physically making the monthly brochures to be distributed to the people or companies that support the social enterprise and raise awareness about autism. Part of his work involves burning CDs, assembling them in the right order, as well as making the pages for the accompanying brochure and binding them all together (Figure 17).

Figure 17: Enea's daily work, which involves burning a CD, journal and brochure

Again, for this activity, Enea's therapists use a similar approach to the shopping list mentioned above, to suggest the order in which the activities should be done. On A4 white paper, they display the pictures of three activities that Enea needs to complete. Under each picture there is a box that he must mark every time he completes the activity shown in the photo. Enea's work is very repetitive, however, Enea enjoys repetitive movements and, in that environment, feels very comfortable. For the first time, I could see that he felt sure and confident about himself, performing actions with precision, and being keen to properly complete each task. The therapists explained that every repetitive activity is well welcomed by Enea, and this is quite common for people on the autistic spectrum. In a conversation with his therapists, we agreed that when he accomplishes something and finishes his work properly, his satisfaction is visible.

4.4.4. First afternoon Activity - Speech Therapy

Speech therapy is very important to Enea as he is affected by verbal dyspraxia, which is the difficulty in making and co-ordinating the movements needed to perform a clear speech with the mouth. The methods used by the speech therapist is the Restructuring Oral Muscular Phonetic Targets, also known as PROMPT. The technique is a tactile kinaesthetic approach that uses touch cues to a patient's articulators (jaw, tongue, lips) to manually guide them through a word or a sentence. During the speech therapy, the effort and intense concentration he makes in order to pronounce some words correctly become visible. This therapy is the most difficult for Enea, as it requires much effort and tires him. The speech therapy exercises are organised in a similar way to the behavioural therapy, and again a token economy is used in combination with a break every ten minutes. Normally, during the breaks, he lies down on a mattress and seems tired and sometimes even agitated. To contribute to the therapy, all those who surround him are asked to help Enea, particularly when he uses or pronounces a word wrongly. Furthermore, Enea needs to be helped to transfer what he does during speech therapy into his daily life, in order to be able to generalize what he learns. The therapist helps Enea to spell correctly words (Figure 18) that contain S, N, M, R and F, which are the words that Enea feels less comfortable with.

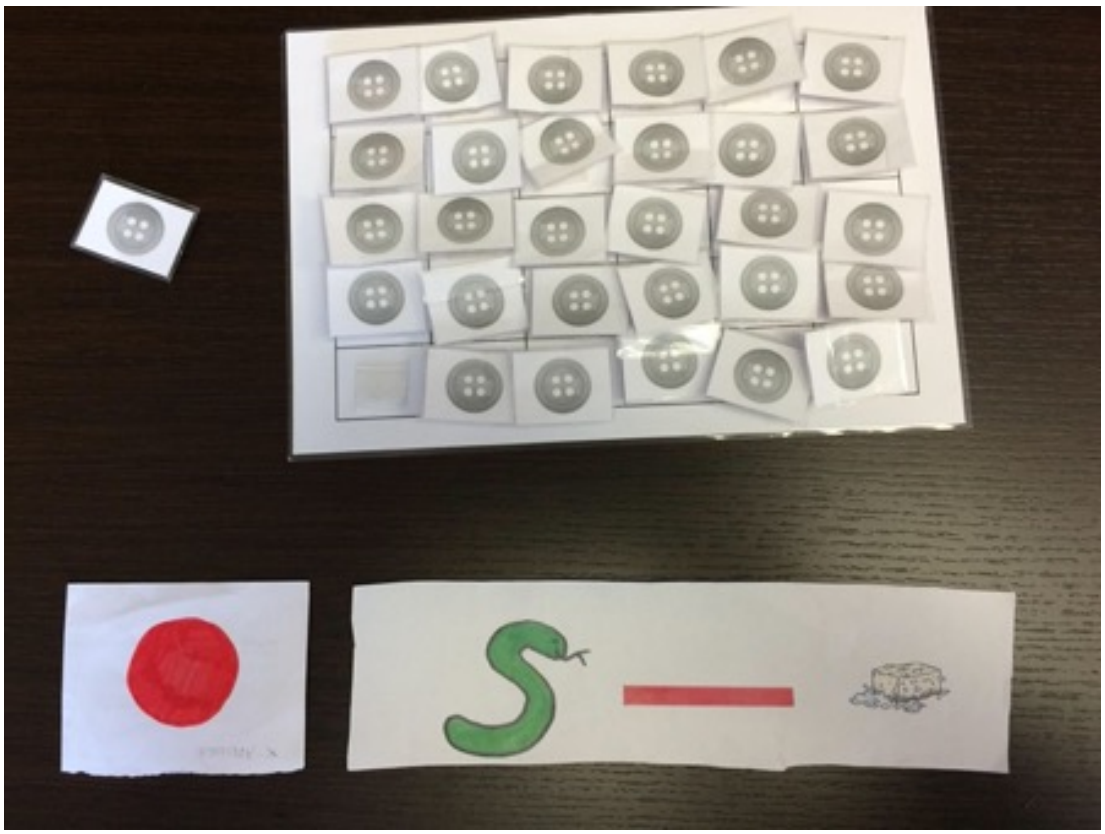


Figure 18: Spelling exercise activity, one of the practices conducted in speech therapy

For example, he called me 'Aletia', while my name is 'Alessia'; hence, I was suggested to repeat him my name slowly and ask him to do the same, so that he could pay attention to the pronunciation and sound of the double S. Another peculiarity of Enea is that he uses words out of context, giving them a different meaning. For instance; instead of saying *firma* that means signature he says *fiori* that means flowers. This makes it difficult to understand what really Enea wants to say. To not interfere with the speech therapy, I was told not to support Enea when he misspelt a word, but it was suggested to gently remind him of the correct pronunciation. The speech therapist explained that Enea uses a sort of personal verbal code, made of very few words that are not articulated together in a sentence. Those words are not used with a shared meaning but are used by the personal meaning that Enea attributes to them. For that, it was important to spend time with him, to memorize and understand his personal use of words and the meaning he attributes to them in different contexts.

4.4.4.1. Speech abilities and communication with Enea

Enea has limited speech abilities and usually repeats the same word several times; this uncontrolled behaviour is defined as echolalia. At first, I paid a lot of attention to him, while he did that, as I tried to understand the meaning of his words. However, my behaviour was very distracting for him, because he kept repeating the same word for a longer than usual period of time. The therapists explained that, through my behaviour, I was indirectly suggesting him to repeat the same word over and over; thus, inadvertently, I was reinforcing his behaviour. They showed that a good way to help Enea stopping this pattern was to verbally reassure him that I understood what he wanted to say and then, without making eye contact with him, focus on another activity. This was very effective, as I noticed that it helped Enea preventing echolalia, letting him concentrate on the next activity. The therapists suggested also to accompany words with gestures, in case I noticed that Enea not understanding something. For example, stop should be accompanied by the gesture of an open hand in front him, as well communicating a pause or to wait.

4.4.5. Second Afternoon Activity - Art Therapy

Another important afternoon activity for Enea is Art Therapy. He has been receiving art therapy once a week, since he was 10 years old. This is one of the first therapies that Enea undertook. art therapy is not framed like behavioural therapy, and the art therapist does not use the token reward system. Unlike the ABA therapy and speech therapy, during art therapy he is given more freedom to manage his time. Observing this different approach, it was possible to see how much the behaviour of Enea changed. During ABA therapy, he appears to be more disciplined, performs what he is told to do with precision and concentration but, in this context, he seems to be more relaxed and curious about the environment around him. The art therapist explained that this type of therapy helps mitigating symptoms, as well as also channelling

autistic behaviours into an expressive, creative way. It promotes communication, emotional growth and pleasurable sensory integration into an enjoyable activity. This therapeutic path has taken place over a long period of time and has not always been easy for him. At the beginning, Enea used to paint only with black all of the paper surface, and his body as well. However, with time, he started to make promising progress and it was possible to observe him becoming quieter through this activity, even if he had had moments of tantrum or a difficult day. This beneficial activity was approached in different ways and using different materials. Enea's past art activities have included figurative painting, collages and working with clay, however in the last few years he refused to do any figurative painting, and he has been refusing to use any other materials than acrylic paint (Figure 19). In fact, I was shown that nowadays he only paints abstract paintings in acrylic. Enea seems to be expressing his own preference in what he does and how he chooses to express himself.

Figure 19: setup for one of Enea's Art Therapy sessions

When we entered the therapist's art studio, he already knew what to do and he was given the opportunity to self-organise under the careful supervision and help, if necessary, of his art therapist. During the therapy, he is usually very relaxed (Figure 20.2), and from time to time he interacts with his therapists and with me. What was possible to observe during the art therapy sessions is how Enea uses his hands to paint (Figure 20.1) and at the same time to perceive the colours on his fingers (Figure 20.3). He always paints using his thumb, index and middle fingers.

Figure 20.1, 20.2, 20.3: Different moments of one of Enea's Art Therapy sessions

The abstract paintings created by Enea are extremely colourful, with unusual and beautiful colour combinations and patterns (Figure 21). The repetitive movements of Enea's fingers on the paint surface create straight lines next to each other, all with the same length and width. The art therapist explained that this repetition of movements is extremely calming for Enea and at the same time is a tool for his self-expression, through the implementation of his own talents and abilities. The compositions of the paintings, including the colour selection, it's the result of Enea's autonomous decisions, and during the activity his enjoyment and freedom become visible. This allowed me to comprehend some sides to his character that did not emerged during other therapies.

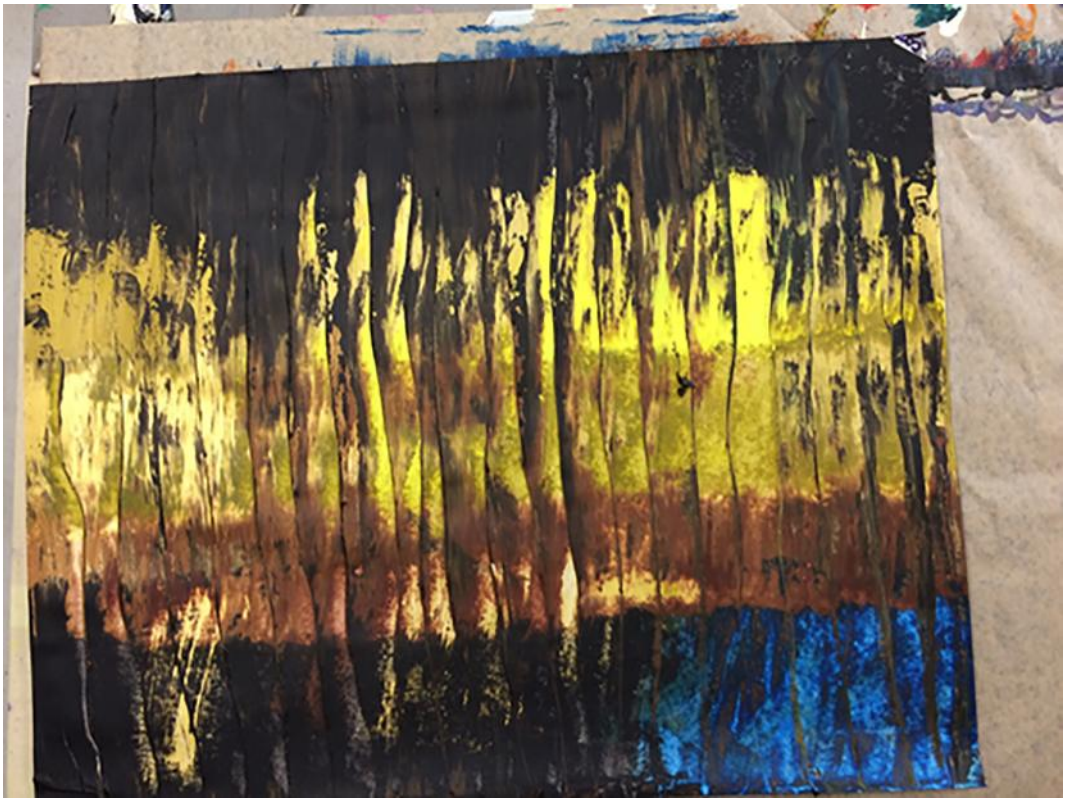


Figure 21: one of Enea's abstract paintings

4.4.6. What I have learned from the preparatory training

The two trainings in preparation for this project, provided different in-depth approaches and knowledge to be able to work in close contact with a person that is experiencing the autistic spectrum and specifically with Enea. On one hand, the Autistic Society's training provided a factual introduction concerning how to work in close contact with people on the spectrum, and how the collaboration should be framed to avoid the onset of painful emotions or moments of tantrum. This type of training did enable me to structure and programme my entrance in the participant's everyday life. Although the information presented at the training was a generalised understanding of people on the severe end of the autistic spectrum, the training opened-up the opportunity for me to self-analyse and correct my mode of thinking in the prospect of working

concretely with the participant. This led to an operational plan that was followed during the whole investigation, including the creation of a data collection tool inspired by the ABC Chart.

A different approach and a situated understanding towards the research participant's subjective experience of autism, was provided through the second training. During this training, I was guided by the therapists of the research participant, to understand and know the therapeutic path that Enea has been following for several years. This training helped me to understand how to respect Enea's therapeutic path without interfering in his daily routine, as well as understand Enea's personality, personal abilities, communication abilities, daily schedule and his subjective experience with the autistic condition. Furthermore, this training provided important understanding concerning the behaviours, activities and anxiety triggers that were best to avoid in preparation and during the applied work with the participant. This training has been useful not only for the valuable information shared concerning the situated experience of Enea, but also for the creation of a fruitful collaboration with the participant's therapists, that supported me during the entire investigation. This training represented an important starting point from which the entire research was built and made possible.

4.5. A situated approach

The training with Enea's therapists provided an important starting point to begin an ethnographic and anthropological informed observation (Simonsen et al. 2012) that has extended beyond the training. The training sessions with Enea's therapists and observations lasted almost three months. During this time, I increased my expertise concerning Enea's subjective and situated abilities and his experience as a person living on the autistic spectrum. During the immersion period, it was possible to follow Enea in his daily routine in a natural setting. In this period, I was able to spend seven hours a day for four days a week with him. From this observational activity, some characteristics and abilities of Enea became important data for the research. Furthermore, this observation was approached with the aim to understand the symbolic world of Enea, in an attempt to discern his point of view and understand the meaning that Enea gives to the world around him. Such direct observation, helped to identify the rules and meanings that govern relationships, actions and abilities in Enea's daily life. The observation was also supported by semi-structured interviews and informal questions asked to different subjects who play an active part in his life.

During the situated phase I spent most of the time with Enea and his parents, and slowly I decreased the time that I spent with his therapists. This decision was carefully made as I started to be concerned that Enea could start to associate me with his therapists and his therapeutic path. The daily schedule during this period did start in the morning with the ABA training, but after the training I usually shared lunch with Enea including his family members and subsequently, I followed Enea during his afternoon activities. The afternoon activities involved: weekly art therapy usually on Mondays; weekly writing session with his psychologist and his father or mother on Tuesdays; and speech therapy on Wednesdays. During the rest of the week Enea has free time that he usually spends either at home; walking in the park; doing a sports activity or with his friends. In the Appendix there are detailed descriptions of Enea's afternoon activities however, in the following section two activities that better synthesize and properly inform this investigation are described.

4.5.1. Enea's writing activity

This activity is infrequent in Enea's weekly schedule, sometimes he doesn't write for months due to work meetings or other activities in which he is involved in at his parents' social enterprise. The approach that is used during the writing activities is called assisted writing, and Enea does this together with his psychologist and his mother or father. In this activity, Enea showed to be quite independent, and his psychologist read aloud every letter and every word typed by Enea. This helps Enea to hear the word and correct himself in case he types the wrong letter and in order to check the content of the whole sentence.

In this activity, he usually uses an iPad (Figure 22.1 and 22.2) and I noticed that he is extremely comfortable using technological items and very often he corrects and helps his father and psychologist when they don't understand how to use it. This is not the first activity that demonstrates his ability to use technological items such as smartphone, tablet and computers. This ability and propensity to use the tablet supports Enea in this writing activity, which requires a lot of effort and concentration. The first time I attended a writing session, I didn't have a clear idea about how the writing sessions were structured and the effort that this activity required of him. The day I attended the first session in his psychologist's studio, I arrived a few minutes late, and Enea had already started the writing activity with his psychologist. Enea was concentrated in typing and replying to a question that his therapist asked him. I noticed that after a few seconds Enea's started to become anxious, he suddenly stopped to write and he stood up from the chair. This situation lasted for a few seconds until his psychologist asked him to sit down next to her. He immediately followed the suggestion and he started again to write. I was concerned about making any noise and I sat down in a small armchair next to his mother. Enea was sitting just in front us but we could see only his shoulders. When he finished writing the answer, I was invited to sit next to him by his psychologist. Observing the writing activity, I noticed that the psychologist wrote the text in capital letters, while Enea replied using lowercase.

The psychologist typed a question for Enea, asking if he had something to tell me. Enea's answer was very surprising for me, and completely unexpected. He wrote: *"aren't you tired of seeing me"*, I was very surprised by his question and I replied: *"No absolutely not, is it fine for you if we work together?"* and Enea wrote: *"I want to help"*.

In the circumstances, I was allowed to ask another question, as Enea wasn't tired. I typed one question that I considered quite important in order to understand Enea's personal perspective and experience better. The first version of the question was considered too difficult by the psychologist and she helped me to reframe the sentence in an easier way for Enea to understand. My question was: *"I would like to know how is your life, tell me about your world without interference from the outside*". Enea replied:*" Powerful question. I live in two different realities… I break my reality in order to be like you all. I am immersed in a rainbow of different sensations, sweet and painful emotions, I walk with the tips of my feet. I am not very capable to live like all of you".* This reply encapsulated Enea's experience and it was impressive to observe him replying to this difficult question. His writing style is quite poetic and his use of metaphors to invite the reader to understand his personal world perspective is remarkable.

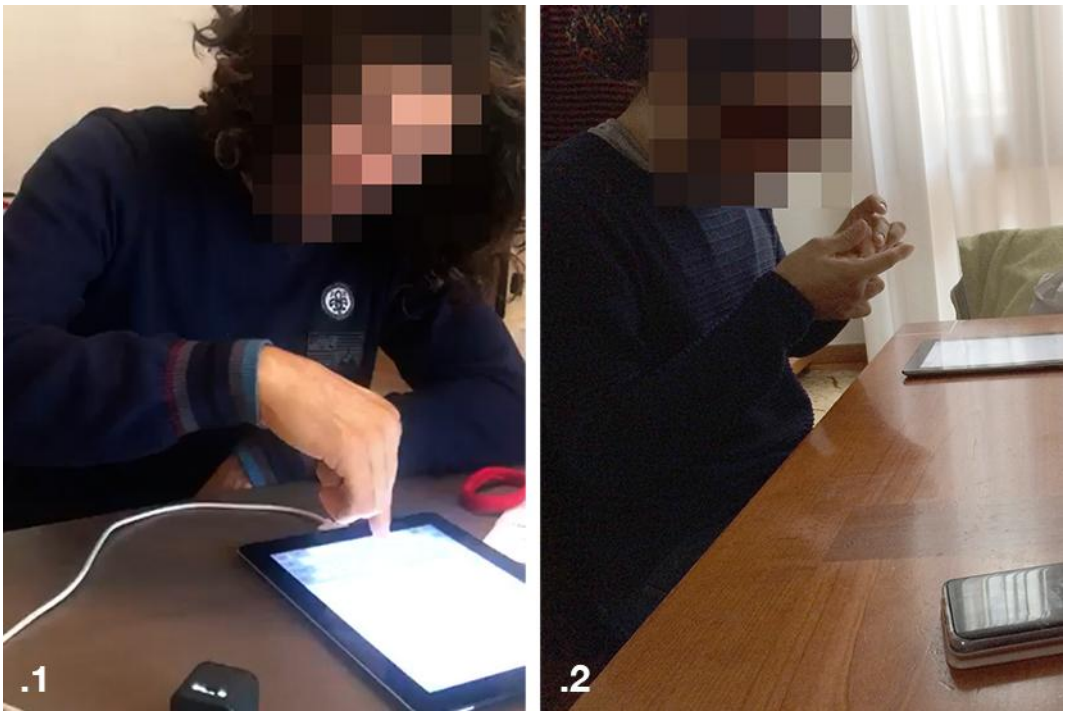


Figure 22.1 and 22.2: Enea, using a tablet, during one of our writing sessions

During the writing activity Enea needs to use all his concentration, and it is visible how demanding this activity is for him. The determination it takes to type a proper letter and difficulties to control his body movements, are obstacles that Enea overcomes with immense effort. From Enea's answer it is possible to notice that he has a clear distinction in mind between himself as a person on the autistic spectrum and the rest of society. He feels that he

needs to try to live in two different realities: the reality created by his condition, which is his own reality, and the reality proposed by the other people, or better to say, the reality in which people that don't experience the autistic condition live. The eloquence of the words and type of answer were extremely promising information indicating that Enea can express his own voice inside this PhD investigation.

4.5.2. Enea's relationships: family members, friends and researcher

Another observation that provides important data for this investigation is based on Enea's relationships with all the subjects that are actively present in his life. In the increasing time I spent with Enea and his families, I was able to observe how he lived his personal relationships and his behaviour in a more private sphere of his everyday life. This revealed important information concerning Enea's relationship with different people that are important and play an active part in his life. I saw that with his mother at home Enea's behaviour is very different compared to his behaviour in presence of his therapists. More specifically, in the company of his mother and in his own house, he is very spontaneous and relaxed. However, at the same time, under these circumstances I began to notice that he can be difficult to interact with, as he seems not to be listening or paying much attention to the people that surround him. The relationship that Enea has with his mother is very peaceful, relaxed, affectionate and supportive, nonetheless, he is not listening much to his mother and somehow, he does not place importance to her authority. Very often I have been invited to have lunch with Enea and his mother, and before lunch I had the opportunity to observe Enea going grocery shopping with his mother. In this situation, I noticed that Enea's behaviour was very different from the grocery shopping that he usually does with his ABA therapist. Inside the shop with his mother, Enea started running around frenetically, replacing products on the shelves randomly and taking sheets of paper and tearing it into many small pieces. On many occasions his mother did try to intervene, but without great results. Enea seemed very amused by this uncontrolled activity and wasn't open to listen to his mother requests to help her or behave differently. At home his behaviour was again different, for example before lunch time he got calmer and more open to listen to his mother's suggestions. In other moments during lunch, he showed delicacy and

affection to his mother; hugging her or helping her to unload the dishwasher. Observing him with his mother, I began to understand who Enea is in a context where he feels completely accepted and loved. Together with her and inside his house, he is free to be who he really is and do what he really wants.

With his father Enea is again different; he has a beautiful relationship also with his father. They are very affectionate and furthermore, Enea recognizes his father's authority and he respects it. In the company of his father Enea's behaviour is controlled and calm, very respectful towards what his father tells him. On a few occasions, I observed Enea's behaviour in the presence of one of his friends. The experience was again different as he was visibly very happy and enthusiastic to spend time with her. In this situation, Enea was so excited that he started running without stopping. He entered several shops taking items and then running away. Once he entered an art shop and immersed his hands inside a container of coloured pigments. The shop owner, thinking that Enea was a vandal, started to scream and approached Enea with aggressiveness. Fortunately, Enea's friend intervened and explained Enea's condition to the shop owner, and at the end everything was fine. Again, I noticed that with his friend Enea feels accepted, and his actions were not redirected or controlled, but welcome and sometimes even triggered or encouraged. For example, when Enea's friend laughed, running and chasing him, he ran even faster and it was very difficult to follow him. These unpredictable situations and behaviours were observed often in the presence of Enea's friends. In presence of his peer "co-conspirators", his happiness and desire to spend time with them is clear. After his friend left, his attitude and behaviour completely changed, he became calmer and his face became sad. I noticed in those moments he also tends to isolate himself.

Another important person in Enea's life is his younger brother. When Enea is close to his brother, he is always smiling although very often he is playful towards his brother. At home Enea very often enters his brother's bedroom without asking his permission. Most of the time he likes to take random objects and items from his brother's room. This behaviour is not taken very well by his brother and several times he expressed his disappointment towards Enea, complaining that his own personal spaces are constantly violated. Despite this, Enea seems not interested in the disappointed reactions of his brother. But there are not only conflicts in their relationship, they also have a very positive connection. In several moments I observed them spending time and laughing together. The relationship that I had the opportunity to create with Enea during this period did grow, over a long period of time, helping to achieve mutual understanding. From the beginning of the research I have been positively accepted by him.

Over time, Enea started to show more curiosity towards me, especially as he started to express interest in spending more time in my presence. Every morning when I entered his office before the beginning of his daily ABA therapy, he exhibited happiness and appreciation of my presence there. Big smiles and the oral repetition of my name several times, were the first few cues that allowed me to understand his positive acceptance.

He also started to ask for my presence during the reward time. In those cases we sat down together outside his office and most of the time we didn't speak to each other, even though in an initial phase I tried to initiate conversations with him, but without receiving any answer. We usually spent the time smiling at each other, sometimes sharing a small snack. After a few weeks from the beginning of the observation, Enea started to call me a friend, asking me to spend more time together, listen music on the radio or walk around the city to have an ice cream, with the sole purpose to spend time together as friends. I felt extremely encouraged by Enea's behaviour and the amount of time that we spent together during the training and the immersive observation did allow us to know each other well. A relationship based on mutual trust was built thanks to the openness that Enea showed during the entire research period. In this circumstance we had the opportunity to build a strong human encounter, that enriched our personal lives, and at the same time created an important base for our collaboration in this research project.

The approach that I considered fundamental for this investigation, and more generally, in all investigations that involve the participation and collaboration with people and especially those that are living with a vulnerable condition, such as severe autism, should involve deep respect, not only for the dignity of the participant but also, for the time and the confidence that a person decides to share with the researcher. An empathic approach was considered furthermore fundamental. This included waiting for the participant to feel confident in approaching me and at the same time allowing the participant, and the different subjects around him, to understand if they can trust me. With these principles decided upfront, I decided to approach the encounter with Enea, through sensibility and delicacy, and to respect Enea's personal timing, personal abilities, including the ability to accept my presence in his life and his personal interest to take part or not in this investigation.

From a researcher perspective there was a full understanding and acceptance that there were possibilities that Enea could not show any curiosity towards my presence or further interest in taking part in this research. Also with this realistic possibility of not "succeeding" in the creation of a positive collaboration, this approach was considered the most respectful for

the wellbeing of Enea, and as a consequence the best approach for this study. Initially I worried that Enea could associate me with his therapists, especially the ABA therapists as I attended his trainings. However, Enea showed a very different and unique behaviour in my presence, very different from the behaviour and attitude he had with his therapists. I observed that he never run away from me, even when we spent some time together without the close presence of his therapists or parents. During this investigation I had my own physical problems that did not allow me for example to run or walk fast and he perfectly understood this, without the necessity to explain to him the nature of my physical problems. In several moments Enea showed the impressive ability to read and perfectly understand the context and people that surround him, and consequently modify his behaviour. He showed also particular interest towards the research diaries that I sued to write quick notes and observations. From this observation it was clear that Enea can entertain several relationships with different people, creating a very unique and personal connection with each individual. This allows us to understand Enea's self-determination, through his ability to build his interpersonal relationships, deciding from time to time how to interact with each person.

4.5.3. Non-normative interaction with the research participant

The subjective nature of the symptoms caused by autism, and the unique strategies that each person living with the condition adopts, demanded an intense context immersion. This included the investigation of ways to unlock tacit knowledge to inform an on-going process of transformation and learning (Akama, Pink and Sumartojo 2018). Even facing the limitation of not being able to live through what exactly the research participant experienced in his daily life, I adopted emulation as a strategy to unlock hidden knowledge and to initiate a process of understanding concerning the untold reality of Enea. Between all the observed rituals and repetitive behaviour, some activities to emulate were identified, as activities that the participant was constantly doing in different situations and in presence of different people.

One of the activities that I emulated was the gesture of ripping off paper, leaves and small branches; the research participant particularly enjoyed those activities. The paper can be a flyer or a newspaper that he collects from the street, or spear pieces of paper and cardboard

that he has at home. Enea likes to use scissors to cut the paper in strips five centimeters high, keeping the length of the paper or cardboard and then ripping off little rectangles. However, if he does not have scissors, he folds the paper and rips off the desired measurement. All the ripped off pieces of paper have the same measurement. Sometimes together with the participant and sometimes by myself, I started to copy and emulate this activity. In doing so I could experience and feel that the sound of ripping the paper can be very relaxing and satisfying. Moreover, the faster I could rip off the paper the more satisfying the tactile sensation was becoming; almost addictive. Another activity loved by Enea concerned me, emulating is his own way of drawing and using the pen (Figure 23).

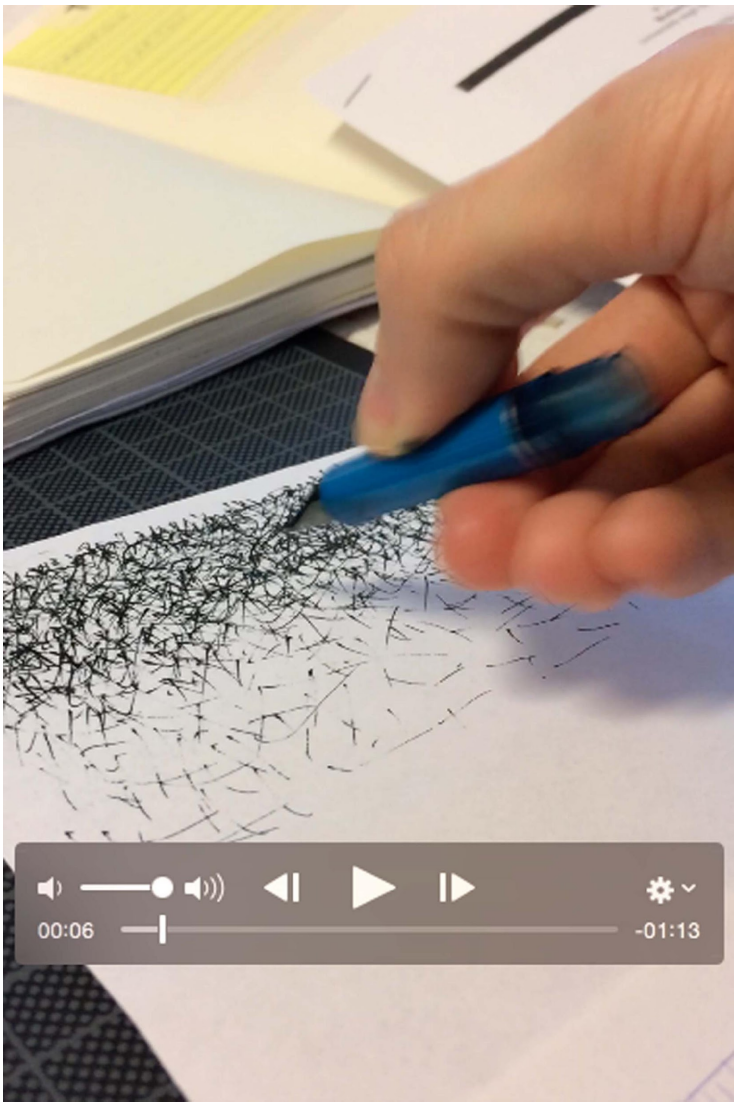


Figure 23: Emulation tests of activities that seemed to please Enea

I noticed that he particularly enjoyed moving the pen extremely fast, tracing small marks on the sheet. I did emulate this activity and once again the tactile feeling and the satisfaction that I was feeling, let me think about why Enea was enjoying that activity. In an attempt to co-inhabit and live through the experience, I could relate with my own feelings and thoughts possibly what the research participant was feeling and experiencing. This embodied type of experience supported a deeper level of understanding and capability to empathise with Enea, reinforcing a non-verbal understanding of the research participant.

4.5.4. What I learned about Enea's personality

Enea's parents and his therapists told me that he has a strong personality and he likes to "test" or provoke the people that surround him. Most of the time he does this for fun, and absolutely with good intention, but if a person is not prepared or doesn't know Enea well then, in that case it can be difficult to understand the reason behind some behaviours. Somehow, they tried to warn me that Enea could try to test me in his own way. For example, his father told me that the first few days with one of his behavioural therapists, Enea suddenly ran away, disappearing for two hours. Or suddenly he can scream "No, No, No!" as if he is in pain or disappointed and shortly after bursts out laughing. In case he tried to escape it was suggested not to run after him, but just patiently wait in the room. Furthermore, I was assured that Enea knows the town where he lives very well, his family have trusted him to walk alone for several years now, and as a consequence, I should not worry about him.

The therapists explained that if we didn't engage with this type of behaviour easily then Enea will realize sooner, by himself that this is not a funny game and quite soon he will come back. In my experience working with Enea this type of episode never happened, although quite often he repeated aloud "No, No, No!" with a smiling face and most of the time in a funny situation. In that case I always smiled with him, and I appreciated his sense of humour. He has a nice and funny personality and he likes to smile and laugh.

4.6. What I learned from the situated immersion in Enea's life

The observations provided evidence of the subjective and situated type of knowledge and abilities that Enea performs only in certain contexts with specific tools and with specific people around him. One example is Enea's capability to read and write, which is performed only when he can use an IPad or a tablet, and only in the presence of his psychologist, together with his mother or his father. In different circumstances and with different media and people next to him, this ability is not shown, even if he is stimulated or asked to perform his skills.

Similar to writing, the ability to draw and paint for Enea is situated and specific in the way he performs and applies it. On several occasions I observed that the setting of the room and the table must follow and imitate the settings that he usually encounters during art therapy. This includes the same type of art materials such as colors and instruments used by him during the therapy sessions. During an experiment with Enea's art therapist he was asked to draw my face or an abstract painting for his living room with a pen; his first action was to disassemble the pen and tear the paper in front of him into small rectangular strips. In light of this reaction I had the impression that it was difficult for Enea to understand what the task was. In an informal conversation with his art therapist she explained that the difficulty for Enea is to generalise and apply his skills in unusual or unfamiliar contexts. Perhaps also the level of agitation increases when he is asked to perform outside his routine and in unfamiliar conditions.

In an initial phase of the observation I found it quite confusing to understand what conditions allowed Enea to perform his talents and skills in a comfortable way. However, with the deepening of the observation and the understanding of the personal life history of Enea, it was possible to understand how much of his daily routine is a fundamental reference point for his life. Each specific daily activity is linked with a specific context and environment and with specific people. This is very reassuring for Enea, because he knows exactly what to do in every activity. When the environment, settings and people change in front of him, he needs to deal with his anxiety and the insecurity of not understanding what to do. Another example is Enea's subjective perception and concept of time. Time is a social construct shared by the majority of the world's population; associated with time as humans we experience pressure for a deadline or nostalgia/memories for a person that we don't see for a long time. However, in several circumstances Enea showed that he has a personal understanding and perception of the passing

of time, where short or long time have a subjective meaning for Enea. A concrete example is Enea's reaction towards a two-month long detachment from his mother and family during a learning trip. At the moment they met after two months apart, Enea reacted as if he had just seen his mother the day before. The lack of sharing of cultural and society constructs is a common characteristic of people living with tautism. In this thesis, this is accepted as a fact, and is respected as the subjective perception of Enea, even when there are no explanations that can support a further understanding. From an initial observation difficult to deeply understand the subjectivity with which the research participant internalizes emotions, abilities and the events that punctuate his daily life. However, during the observation of his interpersonal relationships, the self-determination of Enea became evident. This immersive approach rooted within the aim to know Enea and deeply respect his dignity, will and abilities, supported me whilst I was immersed in different aspects of the participant's life. Furthermore, this approach supported the creation of a tight relationship with the research context and all the people that are a fundamental part of it. From these experiences and observations, I started to map and categorize the activities (Figure 24) where Enea expresses his own appreciation, through gestures and behaviours. This first mapping served to identify possible elements for the design of the first research objects to use in the participatory activities with Enea.

However, it was difficult to clearly identify and understand what type of activities and behaviours were genuinely appreciated by the research participant, from the activities and behaviours that were influenced by his autistic condition. The blurred line between the excitement for what is perceived as interesting and what instead satisfies a sensorial request stimulated by the autistic condition is tiny and difficult to detect from an outside perspective. For this reason, the following map (Figure 24) draws attention to a grey area, where all activities and areas of interests observed with the research participant are highlighted and considered as an opportunity for developing further research activities and objects that could trigger the interest of Enea, despite what motivated his interest at first place. The situated elements in Enea's life that could be used in this research were:

- the constant use of gestures and hands as exploratory elements of the reality that surrounds him;
- the visible preference of Enea towards art, painting and drawing activities;
- Enea's interest on certain types of textures and materials;
- the predilection of Enea to tear bits of paper;
- Enea's predilection for green coloured food;

- Enea’s predilection for sports and long walks;

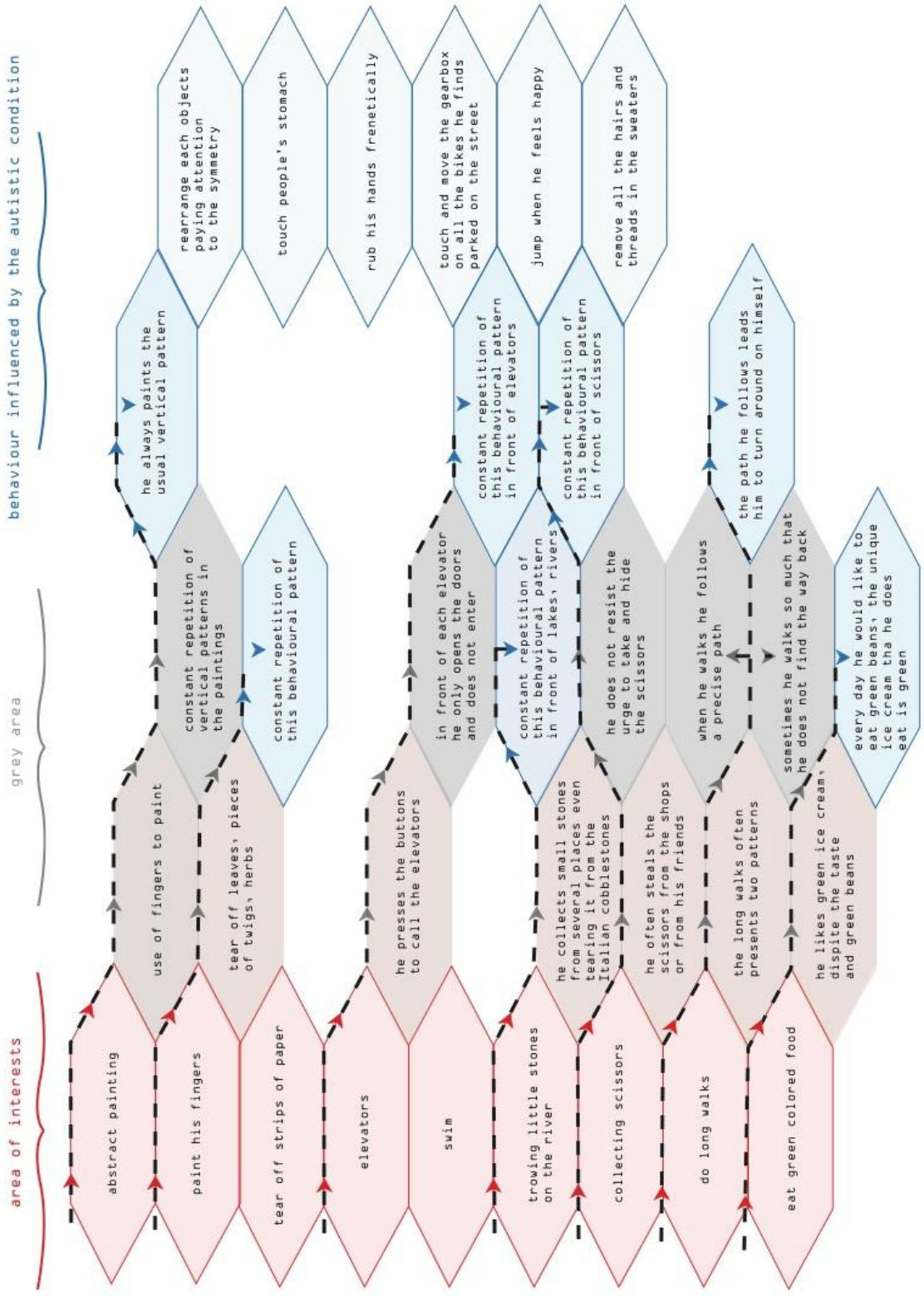


Figure 24: The diagram summarizes Enea's areas of interest and divides them by type

4.7. Summary

This chapter presented two methodological approaches -Immersion and Inhabitation, and situated, which were applied in preparation of the research activities developed with Enea. During the Immersive phase I followed two types of trainings; one training with the National Autistic Society UK, and another one informal with Enea's therapists. Both trainings were in-depth formative and learning experiences where I could slowly build my expertise concerning how to work in close contact with people experiencing severe autism. In this immersive phase, I could follow Enea with his therapists in their daily activities, and from this first approach I started entering his life. Subsequently once the training with his therapists finished, I started to adopt a more situated approach and I could spend more time with Enea and his family members. This new observation phase allowed me to know more in depth the research participant, and his situated life context, abilities, preferences. Through this approach I entered in contact with important information and data that I mapped with the scope to design the research objects and Participatory Design activities based on Enea's abilities and preferences.

Chapter 5: Participation

5.1. Introduction

"Don't walk in front of me… I may not follow
Don't walk behind me… I may not lead
Walk beside me… just be my friend"
(unknown author)

The origin of this sentence is not certain. Many attribute it to Albert Camus, others to a Jewish song. These few sentences poetically represent the research dynamics of working with Enea. Paraphrasing the text and using the metaphor of walking, it is possible to say that we walked a long journey together. At the beginning we didn't know how to do it. Sometimes I walked in front of Enea and other times, Enea walked in front of me. However, only when we understood how to walk side by side, did we succeed in enhancing our collaboration as well as our human encounter. This journey is described in detail in the following section. This chapter presents the Case Study. As discussed, the purpose of this study is to explore a type of approach and research processes that can help generate insights about how and if the research participant, a young adult with autism and limited speech abilities, could take active part in a participatory design research. This chapter is strongly informed by the observations undertaken during the immersive phase and preliminary study, which applied an anthropological type of approach. The case study was framed together with Enea the research participant, embracing the vision of Ingold who asserts in his lecture on why anthropology is not ethnography that: "It is not a study of people, but is a study with" (2007).

The approach plays a central role in this investigation where the aim is to uncover what central meaning Enea derives from his unique life experience and how he makes sense of this collaboration with me. This approach values Enea's personal perspective, with the aim to invite him to be the expert of his own life experience and actively participate in this investigation. As the researcher, I furthermore question the power relations that are intertwined in the research process and how the relational dynamics impacted on the entire investigation. This specific study sought to explore who Enea is, without any preconceived ideas and generalization about his possible expertise, needs and abilities. Instead of approaching this investigation by applying fixed methods and predetermined ideas and goals, this research used a flexible and evolving process, where the research objects emerged through the practice and Enea's responses in situations as they naturally unfolded. This study took place in Enea's everyday environment,

to maintain stability, and avoid the creation of too many changes in his daily life. Together with Enea in this case study we explored possibilities for participation and reciprocal understanding that are not supported entirely by verbal communication.

The case study is divided in *five stages* and in each stage of the research key elements that allowed the concrete evolution of the study are described. In the different stages it is possible to understand the type of activity designed and proposed to Enea, his reactions, the dynamics of participation, and at last my self-reflection towards the entire experience. Reflexivity and self-reflection is adopted as the key method of revealing the knowledge and findings of each participatory design activity immediately after being developed with the research participant. The concept of reflexivity is important in the context of critical reflection in that the term promotes the idea of our individual ability to recognise that all aspects of ourselves and the context in which we live can act as variables in influencing the way we reason and view the world. As Fook suggest, reflexivity is one way of being critically reflective (Fook and Gardner 2007). Furthermore, the reflection upon the progression of the case study and the dynamics of collaboration with Enea, respected a narrow temporality from the events. This perspective forms an important part of the PhD.

5.2. Design Stages

The study is divided in the following five stages, which are closely interconnected: *Stage one*: Preparation phase; *Stage two*: Exploration through the first participatory research activities; *Stage three*: Exploration of new means of participation; *Stage four*: Situated participatory research activities and research objects; *Stage five*: Approaching the end of the case study. In this chapter those stages help to disarticulate and better narrate the research dynamics and participatory processes that unfolded between me and Enea. The first stage covers my preparation and the different steps adopted to initiate the study, while the second, third and fourth stages focus on describing and analysing the active dynamics of collaboration with Enea, his responses and how the whole participatory process and research objects were built based on his non-verbal feedback and reactions. The fifth stage covers the important phase of separation and the end of the study, which involved the return of Enea's everyday life after an intense collaboration in a PD research project. The strategies adopted in order to turn this delicate and potentially painful moment, into a positive transformative moment are discussed.

The materials used in this phase of the study are diverse and were integrated into activities appreciated by the research participant. Each research activity was video and audio recorded and several pictures were taken during the investigation. However sometimes Enea appeared to be uncomfortable and distressed by the presence of the video camera and quite often he grabbed and turned off the video camera by himself (Figure 25). In light of this behaviour I thought it was appropriate to always ask permission before the beginning of our activities to video record our work session and to stop recording if he showed signs of distress.

Figure 25: Enea turning OFF the video camera, during one of our sessions

5.3. Stage One: Preparation Phase

The immersive and situated approaches and my training activities were fundamental building blocks in preparation for the actuation of the participatory research. However, this period was highly mediated by Enea's parents and therapists. This new phase of the research opened a new space for encounter, which directly involved Enea and myself. A new type of relation was going to be shaped by us, as I was no longer the person that followed his training and daily activities, and I was going to develop with him our own research activities, and our way of communicating to each other. This first stage of the participatory action research was marked by excitement as well as uncertainty about all the uncontrollable and unpredictable factors that could surface. I was conscious of possible obstacles and risks that this research could encounter such as: possible difficulties in communication, possible lack of acceptance by Enea of some of my personal characteristics, for example, my voice or my personality; or his insufficient interest to continue to participate in this research. However, the high degree of uncertainty was accepted as an intrinsic element of this specific study.

The act of becoming ready to step into the research is a subject that is well explained by (Akama and Light 2018). Given this contingency, however, the act of becoming ready and the preparation are fundamental research elements to disclose, as they have the power to deeply influence the wellbeing of the research participant. Furthermore, the accurate and conscious preparation allowed me to adhere to the ethical principles that protect the research participant, and at the same time laid the foundations for a greater personal and professional awareness during the entire study. The acts of becoming ready in this research are manifold, some are embedded within my own professional and personal knowledge and ability to put them in practice; others are instrumental and strongly connected with the research context, such as scheduling the research activities, the preparation of the research activities and the materials to be used (Cadamuro et al. 2013; Cadamuro 2013). Becoming ready required the synthesis of learned knowledge and inner personal knowledge. To better explain, by learned knowledge, I refer to all the information that I have learned following the training activities the observation and time spent with Enea and his family, the literature review; the informal talks with Enea's parents and therapists; the observation of Enea in his daily life; my previous research work developed with elderly suffering from severe forms of dementia and limited speech abilities; and the previous work developed with people experiencing autism.

5.3.1 Communicative acts

In this phase of the study I began to explore simple activities together with the research participant. The activities proposed did have the scope to discover Enea's abilities, and additionally explore methods to establish efficient communication and understanding with Enea. In this phase the verbal and non-verbal communication and understanding between Enea and me, was not constantly mediated by other people, such as Enea's parents, and did not always rely on spoken communication. Laughter, smiling and facial expressions, together with body postures, vocalisations and signals of discomfort or agitation, were important actions that supported a qualitative observational study, aiming to interpret and understand the actions of the research participant. Gestures were also important communicative actions. For example, repetitive touching of certain parts of the body such as the head, hands or legs, disclosed body pain. Over time, what was taking place was the negotiation of meaning to arrive at some form of understanding in the interactions between Enea and me. As described also by Luck (2014), through social interaction, and the continuous observation with the aim at understanding the participant, can be better described as an ongoing process of looking, making one step, looking at his reaction and making a next step to increase my understanding.

This moment-by-moment of interpreting someone's action such as the gestural movements is extensively described by (Luck 2014; Goodwin 1995; Garfinkel, n.d.). With the increasing of the non-verbal understanding it has been possible to experience what Hinde describes as the influence of cultural context on non-verbal communication. More specifically he explains that the human verbal performance takes place within a matrix of verbal competence, so also his non-verbal performance takes place within a wider matrix of cultural competence or cultural convention (Hinde 1975, 315). Reading the actions and gestures of Enea under the light of the cultural conventions and competences this supported an initial understanding of his needs, feelings and emotions.

5.3.2. Research context related preparation

The second type of preparatory acts were strongly connected with the research context. In this study the transition of activities that occurred, from the preliminary study where I followed Enea's daily routine and his therapeutic paths, to finding an appropriate time for our research activities, has required an important mediation with Enea parents and therapists to patiently re-schedule different activities. The daily routine of Enea is usually planned months in advance. This tight schedule helps Enea to have a well-structured and organized life, and therefore, his parents too can schedule their work activities, personal activities and the free time to spend with Enea. Inserting a new activity within his already busy life required delicate negotiation, for Enea, his parents and therapists, to understand where the research activities could best be assigned. Moreover, the schedule of Enea, although is quite well organized in advance, it can be modified based on the working trips that he does with his father.

Enea covers a fundamental role in the communication activities for his social enterprise. Together with his father, he travels quite often, in different regions of the country to raise awareness about the Autistic spectrum. Although the research activities were scheduled months in advance, some trips or events were scheduled last minute from the social enterprise, and this demanded flexibility and fast rearrangement of the research schedule. The research activities took place in Enea's personal office or home and his parents were attending the activities, sometimes in the same room while they were working or doing other activities and sometimes in adjacent rooms. This was my specific request in order to make Enea feel safe in a known environment and surrounded by people that he trusts and loves.

5.3.3. Preparation of research activities and materials

The preparation of the research activities was based on the information gathered during the preliminary study. In particular I focussed on all the activities in which Enea showed great

interest and where his personal skills and abilities were highlighted. Enea's favourite activities include: painting, tearing small pieces of paper, whistling, throwing stones and leaves in the river, walking around the city, eating green colored food. However, it was difficult to understand to which extent Enea likes these activities and why. I discussed about this with his therapists and parents but also for them it was difficult to find an answer. Enea and his inner world seem a mystery also even to those people closest to him. This peculiar element of the study created a sort of blurry territory on which to build the research activities. In this context it became difficult to understand what are Enea's personal abilities and favourite activities and when those are entangled with consolidated behavioural patterns and attitudes influenced by the autistic condition. Communication between people involves the interpretation of the meaning. When I was communicating with Enea this interpretation was further complicated by the fact that we do not attribute sometimes the same meaning to situations, behaviours, tools, objects and their utilization.

I therefore decided to involve the act of painting in the research activities as well as the act of tearing small pieces of paper. However, it was not clear what type of subjects Enea liked to paint and if he was willing to paint in a different context that didn't involve art therapy. I was also concerned by Enea's strong attachment towards his daily routine, as well as the training that he is undertaking, that are strongly shaping and influencing his life. I had occasion to comprehend that it is not an easy task for Enea to generalize activities, places, contexts, and adapt to new stimuli. The image of a blurry territory is well representative of the uncertainty that I experienced in the encounter with Enea. I could grasp something about him, little fragments of his personality and abilities, but all the information was incomplete and difficult to trust. Which activities was better to introduce to Enea?; How to explain them to him?; Which materials to use?; Is Enea going to accept to use the materials such as pens and colours?; or Will he encounter problems to generalize their use?; Is Enea going to refuse to participate?; Is Enea going to be stimulated incorrectly by the research activities?; Can I be a source of distress for Enea? I didn't have answers to all my questions, for this reason the research activities were kept flexible and open. It is difficult to predict Enea's responses. The *unknown* embedded within this study needed to be taken into consideration. Therefore, each research activity was proposed to Enea, and based on his response, the next activity was designed and modified. In this first phase the research activities were designed with the only purpose of investigating Enea's possible mode of participation. No other aim or scope were taken into consideration in this phase.

5.4. Stage Two: Exploration through the first participatory research activities

The specific objective of the first participatory activities was to understand how to encourage Enea to explore ways to express his original ideas and thoughts, allowing him to take distance from the passive type of response that he applies during behavioural therapy and sometimes with his family members too, and apply his proactivity and self-determination. The lack of experience in making autonomous decisions and his strong dependence in following other people's choices, are the key difficulties that we needed to confront and understand how to overcome, in this first stage. More specifically, I aimed to stimulate a genuine and personal response from Enea, letting him understand that there was not a right or wrong answer during the research activities. Furthermore, I paid attention to carefully avoid influencing his decisions or actions.

5.4.1. Research activities time frame

This stage started at the end of May and lasted until the middle of July 2017. During this stage I met with the research participant twelve times; however, on two occasions we needed to suspend the activity due to Enea's health problems. The activities usually took place in the afternoon between 14:00 pm and 17:00 pm, however the length of the activities was variable and strongly dependent on Enea's concentration and will. During each activity, Enea did two-three breaks, where he could relax, taking some time off from the research. The research activities were recorded in video, pictures and audio materials.

5.4.2. First participatory research activities introduction

In the following paragraph, I describe and discuss the most relevant activities that were done with Enea during the months of June and July 2017. The activities are described in detail and are followed by short reflections, that were elaborated during the activities as an act of reflexivity in time, accepting the mutual and in-becoming elements embedded in this exploration. The final aim is to map the path that was followed together with the research participant during our activities, to support a critical understanding of participation in this situated context.

5.4.3. First activities

- Location of the activities: Enea's personal office
- Time of the day: Afternoon
- Materials: Pens and blank white paper sheets, pencils, pens, colours
- Environmental information: Enea seemed in a good mood, and when I entered the room he was there, waiting for me together with his father. I was slightly nervous but very excited and interested in starting our first research activities.

During the first activity it was important to understand if drawing could become a good communication channel to adopt with the Enea, and if he could translate his thoughts by sketching them on paper. After the setup of the cameras to record the activity, I then explained with simple words the activities and carefully waited for a positive answer from Enea. Together then, we started to prepare the materials for the activities, which consisted of two A3-size paper sheets, pencils, pens and colours. The first task was to draw our favourite hot drink for breakfast. Enea, in front of this request, slowly changed his behaviour as he started to become visibly tense, probably intimidated by the request. Noticing this, I decided not to repeat the request and give him some time to think about it; meanwhile I started to sketch a cup of tea on my paper. Enea reacted to my drawing, and he took a black pen and wrote in block letters his

name and surname. Moreover, Enea, during the activities, was visibly distracted and distressed by the presence of the cameras. He touched and moved them several times, until I took the decision to put them away inside my backpack. The second task was to draw geometrical figures such as triangles, squares, rectangles or circles. Again, the research participant looked confused and intimidated and his response was once again to write his name and surname in block letters. Noticing the uncertainty and difficulties expressed by Enea's face expression and body gestures, I decided to suspend the activity.

5.4.3.1. My observations

From this first attempt, I had the clear impression that a complete miscommunication occurred between me and Enea, which brought a generalized sense of frustration and failure. Intimately, I felt disarmed by this first experience, and I wondered a lot about my role and my abilities in establishing a valuable contact with Enea. Even though I prepared myself for any type of response from him, I think that it is important to share my personal insecurities in the process. Those are part of this delicate and silent balance in the active collaboration with Enea, especially in this initial phase, which is strongly informed by the preliminary study, but still fragile in terms of personal encounter and mutual understanding with Enea and all that follows. Despite all the problems that this first activity brought to the surface, it is also important to observe that although Enea appeared agitated and uncomfortable, he decided to remain seated and he collaborated during the activities by writing his name. Enea, during the activities, had other options such as that of refusing to do the task, or run away from our meeting, but he decided to dedicate his time to me and the research. This attitude was very encouraging, and I appreciated his kindness and respect for our work. During the reflection and analysis of both activities, I questioned the way in which I explained and structured the activities.

From this first analysis, I could understand that probably for Enea the two tasks that I presented were completely new experiences for him. Furthermore, those tasks could be very different from the daily activities that he usually does. The difficulties experienced by Enea to approach this new request and tasks, were probably increased by the unclear understanding towards what I wanted from him. Enea looked confused also about the type of role that I was covering during the activity itself. For him it was a new experience not to be guided to learn something. Moreover, I didn't help him or guide him to complete the activity, and I think this

has contributed to increasing his bewilderment. There was no predetermination of what was right and what was wrong during the activity, but I needed to take into consideration that Enea is not familiar with this type of activities and approach. The novelty of the proposed activity combined with the novelty of the role given to Enea did generate agitation and confusion for him. Certainly, this wasn't the aim and the goal of this activity. What is important in this phase is to find an appropriate way to work and communicate together with him. I wondered: what kind of activity could be understood and appreciated by Enea? How can I explain it? Should I try to explain the activity with gestures?

Given the failure of this first proposed research activity, I decided to simplify and change the task. However, the materials to be used were the same, and involve the use of blank papers and pens. This was because, it was important to understand if Enea can use those materials outside the specific context of art therapy or the specific ability to write his signature. During the preliminary study, I noticed that Enea was particularly aware of the presence of the camera; he likes being photographed and in front of a camera Enea usually does a very big smile, but at the same time it seems irresistible for him not to touch the camera by pressing randomly all the buttons. The camera was undoubtedly a big source of distraction for him during the development of research task and decided to explore a different set up for the cameras.

5.4.4. Second activity

- Location of the activity: Enea's personal office
- Time of the day: Afternoon
- Materials: Pens, crayons, scissors and blank white paper sheets
- Environmental information: Enea seemed quiet, he just finished the ABA activity with one of his therapists. I felt calm and focused, furthermore I tried to avoid the creation of any kind of expectation for this second activity.

During the second meeting, the task was simplified and the complexity of the explanation was reduced. The activity consisted in two small tasks. The first was to ask Enea to draw the outline of his hands with a coloured pen on a blank white paper sheet. The second task was to cut the outline of the drawing that he did during the first task. This activity can be considered simple

for Enea's abilities and quite common, probably Enea has already done it in the past, during art therapy or at school. The specific aim of this activity was to let Enea to understand the request well and allow him to feel comfortable to complete the task without expecting my guidance. Unlike the first activity, Enea showed to understand well the explanation and the activity. He grabbed a pen and he started to draw the outline of his hand (Figure 26). During this activity it was possible to observe Enea's difficulties to control the pen and the movement of his arm, especially the arm that was moving the pen. His face expression was visibly communicating concentration and other times during the activity he smiled with excitement. In this occasion Enea painted and repainted several times his hand over the same paper. His enjoyment was visible, and I considered that this activity was successfully concluded, and I started to introduce a new activity.

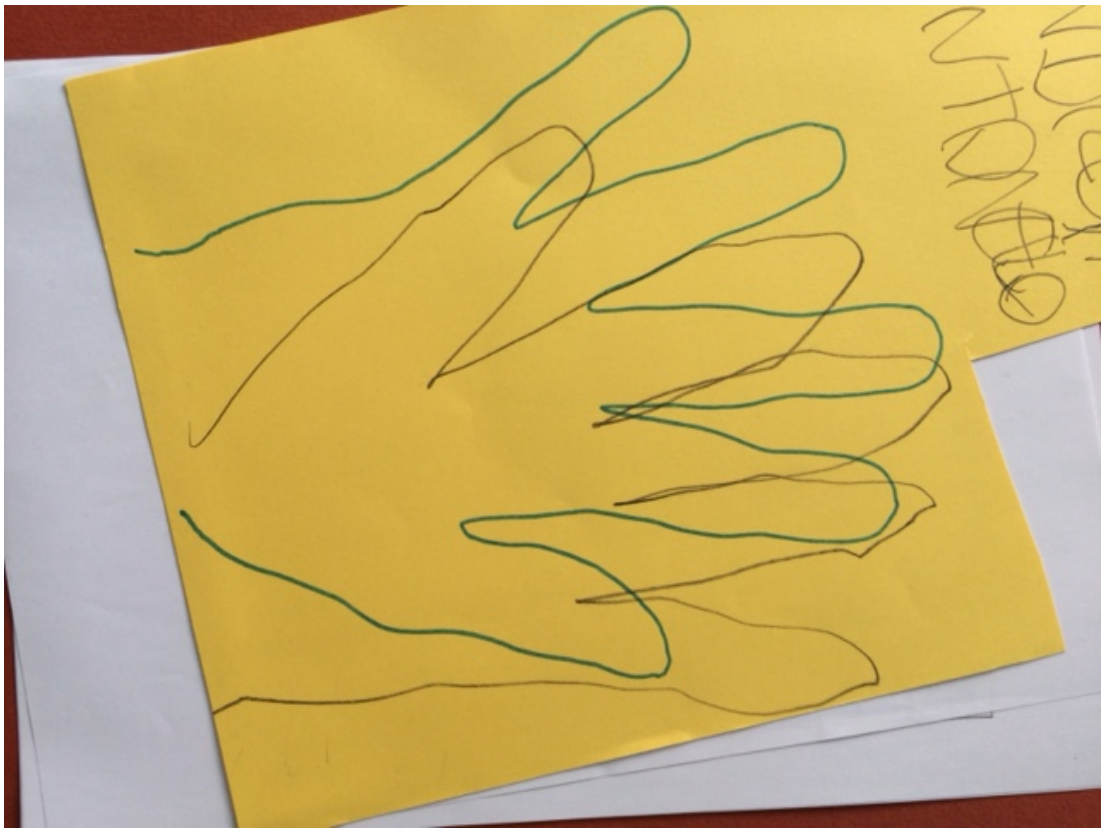


Figure 26: result of Enea's activity, illustrating multiple outlines of his hand

When I tried to change the activity, explaining a different and slightly more complex task, Enea appeared uninterested. While I was still trying to explain the second task of the day, he grabbed a new A4 paper and he drew again the outline of his hand. While he was drawing the outline

of his hand, he stopped a few times and after being motionless staring into a void space for a few seconds he grabbed three pens and he disassembled them, staining his hands and clothes with ink. This happened several times, until I decided to suspend the activity and let Enea to rest.

5.4.4.1. My observations

This second activity did show a positive outcome. The enjoyment expressed by Enea was a positive outcome of this activity, together with the improved confidence in himself. However, it is important also to reflect upon the difficulties emerged in this activity. First of all the lack of availability to change the activity, and Enea's difficulty to switch his attention from one task to a different one. I understood that the simplification of the task together with the simplification of the explanation, facilitated the comprehension of the request, encouraging Enea to show his abilities. However, miscommunication and misunderstanding were still predominant elements of this second activity. The partial achievement of the aim of the activity and the important limitations occurred during the communication with Enea, did raise doubts and concerns concerning the type of activities proposed, and how I designed and presented them. Furthermore, the repetitive behaviour of Enea raised some concern, and I started to reflect upon the possibility of a repetition of a behavioural pattern. However, it was difficult to understand if this behavioural pattern was related to the enjoyment of Enea towards the activity itself, or because he felt safe and in control of the activity and his ability to accomplish the task. With the intent to understand Enea a little more, I decided to re-propose at our next meeting the activity that wasn't completed.

5.4.5 Third activity

- Location of the activities: Enea's personal office
- Time of the day: Afternoon
- Materials: scissors and previous drawings developed by Enea

- Environmental information: Enea seemed very happy to see me, and when I entered in the office he gave me a strong hug. I also had the impression that he was agitated as he checked his office with insistence, walking around and rearranging his books and office materials, he also disassembled one office chair by detaching two separate parts of the structure of the chair. Enea's father, noticing the behaviour of his son, decided to intervene and quite firmly and impatiently ask Enea to re-assemble the chair. Obediently Enea tried to put back together the structure of the chair, however he started to become very agitated, probably because he felt the attention of his father and mine on his actions, and this was very uncomfortable experience for Enea. His face was red and his actions very uncertain. In noticing the difficulties experienced by Enea, I decided to step aside and prepare the material for the activity. I hoped that this way he could feel less at the centre of attention. Enea was very agitated and as a consequence he didn't succeed to repair the chair until his father decided to help him. I was quite concerned about this difficult beginning, especially because Enea seemed very unhappy. Before starting of our activity, I decided that it was probably important to give him some free time to play with his phone and re-balance his emotional state. Enea welcomed my suggestion positively and a for half-hour he played with his phone seated outside the office, while I waited for him inside.

In the third activity the task that Enea refused to complete during the second research meeting was re-proposed. The activity asked Enea to cut the outline of the hand previously drawn using rounded edge scissors. Enea initially showed interest in the explanation of this new activity, however, quite rapidly he changed his behaviour and he started to avoid eye contact. The meeting unfolded with a gradual closure of Enea towards any form of communication with me. Consequently, he began to perform the same behaviour carried out during the second activity. Visibly excited and with a smiling face he grabbed a blank A4 sheet and he started to draw again the outline of his hand. I tried to attract his attention by re-establishing eye contact and calmly repeating his name, however he ignored my attempts to communicate with him and he continued undaunted in his activity. Understanding and respecting the barrier posed by Enea with his unspoken behaviour, I decided not to hinder his plan and I began to observe his frenetic and compulsive actions. During this activity, he seemed very happy and amused. Intermittently he started to vocalize by emitting acute and joyful sounds as well as laughing out loud.

At the end of this activity Enea drew the outline of his hands in twenty-two A4 sheets of paper (Figure 27). When he autonomously decided to end the task, only one blank sheet remained left. The blank sheet was all crumpled and most likely for this reason Enea decided not to use it.

Figure 27: Result of one design activity. Again, multiple drawings of Enea's hand

Once the activity was completed, Enea started to observe his work with apparent satisfaction and at the same time he tried to intercept my eyes to establish a visual contact. I had the impression that he wanted to show me the result of his work, as he displayed it on the table, and he kept looking at me insistently. I was wondering if he was somehow expecting my approval. I had only a few seconds to think about what could be an appropriate response to let Enea understand that in our research activities he doesn't need to gain my approval. I quickly decided to maintain a neutral face expression, looking at Enea's eyes firmly without smiling, to not strengthen his request for approval. Then I asked him to help me to collect all the papers and once we finished tidying up his office, I thanked him for his availability and I explained him that in the next meeting we needed to do other types of activities. Furthermore, I explained

that I understood that he is capable to draw very well the outline of his hands, but at the moment we had already many drawings and we were not in need of more of them. Enea didn't answer.

5.4.5.1. My observations

This activity took place after a moment of frustration for Enea. He was unhappy, very uncomfortable and agitated. I comprehended the emotional difficulties experienced by Enea and I was concerned about how this could influence our activity. For this reason, I took the decision to postpone the beginning of our activities and instead improvised a break, to establish an appropriate time for Enea to cope with his emotions and relax. Despite the good intentions, the break didn't succeed completely, as Enea appeared to be closed in himself and not communicative. Partially this rough beginning probably played a negative role in influencing Enea's behavior, as he created an important distance and barrier towards me, avoiding eye contact and apparently ignoring my presence in the room until he decided that the activity was over. The distance created by Enea was respected and once Enea did not respond to my attempts to get his attention, I decided to not interfere in the way the activity unfolded.

Indeed, Enea took over the entire activity performing a behavioural pattern shown also during our previous research activity. His way to participate in this research activity has demanded a quick type of response from me. This response needed to adapt from time to time to Enea's behaviour and will, which is changeable and unpredictable. In this delicate contingency, my big concern was to avoid to arouse negative emotions to Enea, and at the same time allow him to express himself freely. I did experience uncertainty at the time I had to decide how to position myself towards his behaviour. I quickly asked myself if I should have stopped him, and in which way I should have done it. After careful thought, I considered it important not to stop him. Enea took for the first time an initiative and this is a welcomed action for this research, even if he didn't take into consideration the planned activities designed for this third meeting. The communication with Enea presented important gaps, and this was a relevant element that emerged during this third activity, as was the behavioural pattern that Enea performed insistently for the second time from the beginning of the study.

When Enea decided to interact again with me after the exhaustion of his repetitive behaviour, he has changed completely his attitude and he started to acknowledge again my presence in the

room. His behaviour and the way in which he was making eye contact, did let me think that probably he was demanding for my approval. Even if this is what I perceived from his behaviour, it is important to specify that it is very difficult without verbal confirmation to understand in depth his real intentions.

In those circumstances, I carefully reflected about what to do, and what facial expressions and behaviours could be adopted in order not to strengthen Enea's possible requests to receive approval. In this delicate moment, and aware of the communicative power of facial expressions, I decided not to smile with my eyes and face, nor to show any sign of disappointment. Enea in front of my reaction stopped to demand my attention and rapidly changed the object of his interest. In this phase of the study I am an observer, that is trying to know better Enea and to understand and learn how to establish a mutual communication and comprehension with him. Enea is showing his availability to take part to our research activities and I appreciate what he is doing and the effort he is making. After these three research experiences the materials used were changed, as a consequence will avoid paper and pens and will use a modelling paste instead. The aim is to stimulate Enea through another artistic and creative approach, with the attempt to avoid the onset of the usual behavioural pattern.

5.4.6 Fourth activity

- Location of the activities: Enea’s personal office
- Time of the day: Afternoon
- Materials: Initially it was planned the use modelling paste, but then other materials were used such as small branches, leaves and small stones
- Environmental information: Enea was already in his office together with his mother and he seemed very happy to see me, and in a very good mood. I was calm and glad to see Enea so joyful and relaxed.

The fourth activity took place on a very warm and sunny day. When I arrived in the office Enea was already inside together with his mother.

Before the research activity with Enea, I did spend a few minutes with his mother, to informally talk about the research. While his mother and I were talking, Enea took a sheet of paper and started to draw the outline of his hand. In noticing this, I asked Enea’s mother if he performed

the same activity also when I was not there. His mother replied that this was the first time that she saw him do this activity. When I approached Enea to start our research activity, I asked if he enjoyed drawing the outline of his hands, and he happily replied 'yes'.

When I asked what he liked about this activity, he answered 'yes', again. In the meantime, Enea took another paper from his office and he started to draw the outline of his hands once again. Noticing the constant repetition of this pattern I improvised a new type of activity. To avoid the use of materials such as papers and coloured pens and pencils, and taking advantage of the sunny day, I proposed to experience the garden and collect materials useful for a future activity with him. I asked the permission of Enea's mother to use the garden, and the proposal was positively welcomed from both she and Enea, who happily accepted the suggestion. In the garden, Enea started immediately to run, he was fascinated by a tree with fruits on the branches. Once I arrived in front of the tree and near Enea, I started to explain the reason we were in the garden and what kind of materials we needed to collect. Leaves with different colours and small branches were the materials that we needed to look for.

Enea listened to the explanation of the task, however he looked also extremely interested in eating the fruits off the tree. I then decided to start collecting the leaves from a bush, and Enea followed me and he collected a few leaves from the same bush as me. However, after a few minutes he run towards the same tree again and he started to jump in order to grab some fruit. I decided to get closer to Enea with the excuse to show him all the leaves that I collected. As a reaction Enea started to collect from the ground little branches of the tree and I did the same. Once we collected enough materials Enea started to rip off in small pieces the branches that he had on his hands. This gesture performed by Enea reminded me one of his beloved activity, which consist in rip off small pieces of papers. Indeed, he used the same gestures, the same speed and the length of the ripped pieces was the same. Furthermore, Enea also collected a few little stones, all with similar size and colour. At the end of this activity, we examined the collected material (Figures 28.1) and divided the leaves from the twigs and from the small stones (Figures 28.2, 28.3, 28.4). The different materials were subsequently placed in different containers (Figures 28.5, 28.6) and brought into Enea's office. Inside his office Enea went to sit on his desk and again grabbed another blank sheet of paper, and began drawing the outline of his hands.

Figures 28.1, 28.2, 28.3, 28.4, 28.5, 28.6: sequence of outcomes from the fourth, improvised, research activity.

5.4.6.1. My observations

The research activities conducted during this meeting with Enea demonstrated the value of improvisation as a necessary approach to the advancement of the research and our mutual understanding. In front of Enea's behaviour I took the decision to avoid to work inside his office and I improvised a new activity. I considered the improvisation a necessary research act to encourage Enea to put aside the mechanical repetition of the behavioural pattern that was echoing our previous meetings. More specifically, the planned research activity was rapidly re-thought and changed, once I noticed Enea's behaviour. It is difficult to describe and capture in words the thoughts and emotions that arose in me when I improvised the new activity to re-direct his attention. The main action that I did, was creatively wander in search of inspirations and ideas.

I wandered to find possible activities that could trigger a change to the situation that once again had arisen. To do so, I looked around me, to quickly find a source of inspiration

from the environment, objects, people that surrounded us. While I was doing so, I felt also agitated as I couldn't predict Enea's reaction. He positively welcomed the improvised tasks, participating and collecting the materials that I asked him to gather in his garden. Although during the activity Enea did participate and contributed a lot with his positive attitude, once we finished the activity in the garden and we returned inside the office, he once again grabbed a piece of paper and with a pen he drew the outline of his hand. In noticing this I begun to be very concerned about the repetition of this specific behavioural pattern. Furthermore, in a short conversation with Enea's mother I received the confirmation that he is performing this specific behaviour only in my presence. This information made me apprehensive, as I started to comprehend the tight connection between our research activities and the beginning of his specific behavioural pattern.

I decided to ask support and suggestions from the therapists. During two informal meetings with Enea's therapists, I did explain all the difficulties that emerged during the activities and the consequent response of Enea. The therapists did suggest a few practical actions to be adopted. One of the suggestions was not to let Enea make free use of blank sheets of papers, if he wanted a new paper, he needed to kindly ask for it. The second suggestion was to avoid the reinforcement of the behavioural pattern performed by the participant; and to do so, I was suggested to intervene when he started to perform the pattern, redirecting his attention towards the new task. Another suggestion was to design and propose several propaedeutic types of activities. In these activities, the task needed to be fragmented in smaller tasks, in this way the participant can be properly guided step by step towards the entire activity.

5.5. Stage Three: exploring means of participation

The new activities were designed by taking into consideration all the suggestions received by Enea's therapists. Inspired by their explanations, I designed several propaedeutic activities that were proposed in five different meetings with the research participant. This third stage took place in the month of July 2017. In the following sections the evolution of the participatory research activities and the beginning of new phase of this study are described.

5.5.1. First activity

Location of the activities: Enea's social enterprise office
Time of the day: Morning
Materials: Blank white paper sheets, pens and markers
Environmental information: Enea was already in his office together with his father and together with all the people who work for the social enterprise. In front of his father Enea was behaving with seriousness, however once his father went in a different office Enea ran out of the office and started to activate all the elevator buttons in the corridor. To start the activity, I went to Enea in the corridor and I kindly asked him if he wanted to work with me. Once he gave me an affirmative answer, I then asked him to follow me inside the office. Enea seemed very amused by his own behaviour, and I didn't know if it would be difficult for him to concentrate and shift the object of his attention. I was calm and open to know more about Enea, I was also open to re-adapt or change our propaedeutic activity in case of necessity.

This activity is divided into two different tasks. I prepared a geometric pattern using small triangles, rectangles and circles. The pattern was printed into two A4 sheets. The two A4 blank sheets were used for two slightly different activities designed for Enea. His first task was to colour only the inside of the geometric figures with a unique colour. The activity was presented

using simple words and mimicking the activity. Enea did understand quickly his first task and immediately started to colour inside the geometric figures. During this task it was possible to observe that in the first few minutes Enea did colour inside the geometric shapes, however with the passage of time, he seemed to become more distracted as he started to draw also outside the geometrical shapes. When I recalled his attention to the original task, Enea did remember what to do, and immediately started to colour inside the geometric figures. Approaching the end of this first task, Enea showed another moment of distraction when he stopped the activity and he started to disassemble his coloured marker consequently smearing his hands and clothes with ink. Once again, I did recall the attention of Enea as suggested by his therapists, and I proposed a small break to allow Enea to go to the restroom to wash his hands. Enea accepted this suggestion and he washed his hands. Coming back from the short break Enea walked following his usual personal path, which involved walking near the wall and turn on himself when in front of a column, however he also stopped a few times in front of a few objects displayed above the office furniture.

Noticing this I recalled the attention of Enea to complete the task. He accepted once again my suggestion and without further interruptions he finished his task. After a short break where Enea decided to eat a small snack and play with his phone, the second part of the propaedeutic activity began. The task consisted: to colour only inside of each geometric figure using different colours. Triangles, circles and rectangles were subdivided by three different colours (Figure 29.1, 29.2, 29.3, 29.4). Also, for this activity the oral explanation was simple and I mimed the task in front of Enea. He understood effortlessly the task and grabbing a colour he started to fill in a triangle. Similarly, to the previous activity, after a few minutes he showed a lack of concentration and started to colour beyond the edge of the geometric figures. In addition to this, he started to use the same colour for the different figures and noticing this I decided to intervene by repeating the roles of the task to him. This intervention helped Enea to complete the task with an excellent result. I thanked him for the good work that he has done, and Enea responded with a joyful face expression. At the end of the activity when I was collecting all the research materials, Enea started to repeat the usual behavioural pattern, and he started to draw the outline of his hand, above the paper where he completed his second task. I decided to intervene and stop Enea's intention, by kindly explaining to him that the task was completed and there was no need or request to draw the outlines of his hands. After this explanation Enea stopped his behavioural pattern and handed the paper he was using to me.

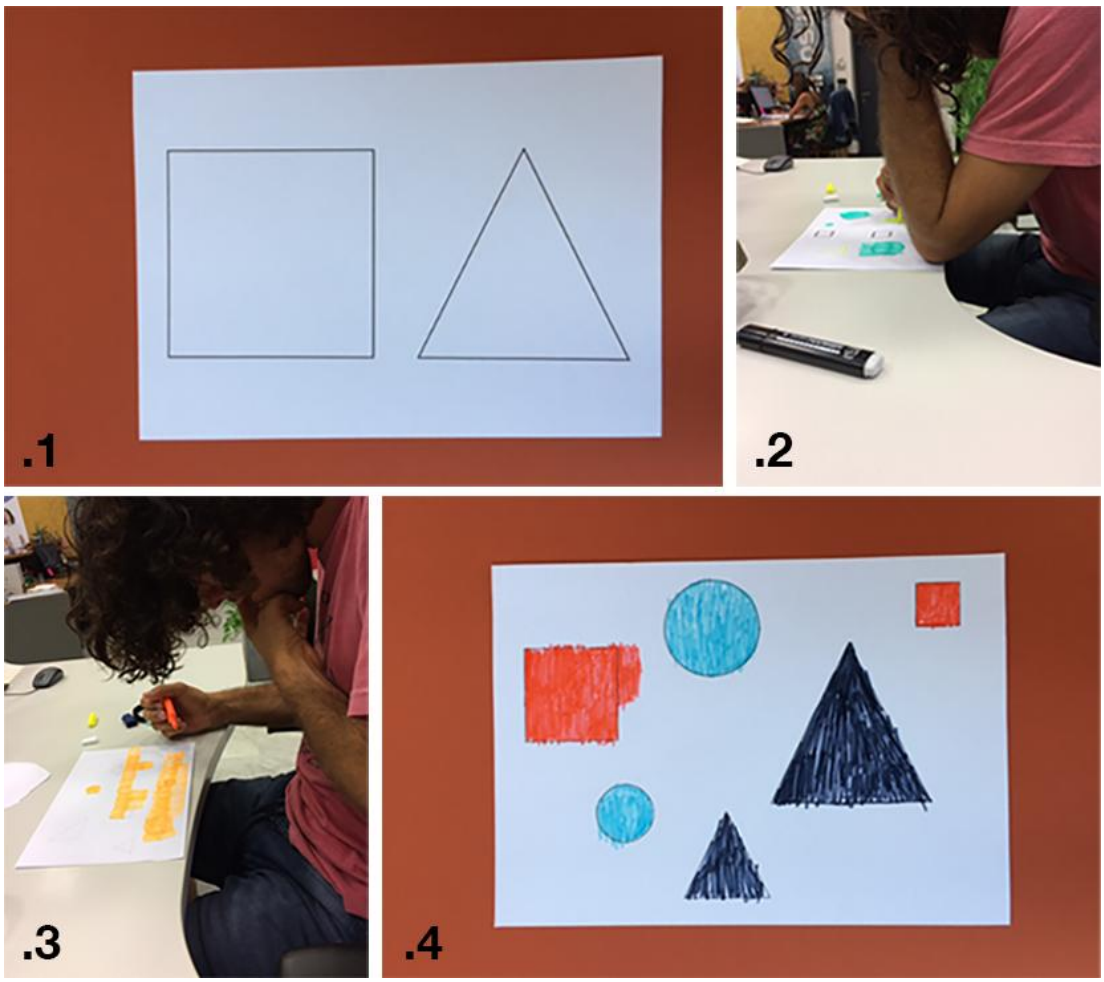


Figure 29.1, 29.2, 29.3, 29.4: sequence of activities where Enea was asked to fill with colours pre-given geometric shapes.

5.5.1.1. My observations

These first two activities did generate a new communicative dynamic between me and Enea. Following the suggestions and guidance of Enea's behavioural therapists, I did intervene more often during the activity, especially when I noticed his tiredness and lack of concentration. Initially, I was worried about what my interference could possibly generate in Enea during the activities; in particular I was afraid about possible moments of tantrum and I didn't want to give Enea the impression that I was limiting his expressive freedom. However, I could observe that he was positively supported by my guidance, and he kindly accepted all my verbal

interventions and reacted with consistency and clear understanding after each suggestion. The clear communication between us facilitated our collaboration, and for the first time we achieved a mutual understanding that led us to approach our participatory activity with more intensity and generating good results. The positive advancement with regard to communication was also helpful when Enea started to reproduce the behaviour pattern that consisted of drawing the outline of his hands. Once I explained to him that there was no need to draw that subject any longer, Enea showed his full comprehension and immediately changed his behaviour. From the beginning of this study, this was the first time that we could ambivalently interact, furthermore Enea showed his undoubted ability to understand the tasks, and complete the tasks assigned to him.

5.5.2. Second activity

Location of the activities: Enea's personal office
Time of the day: Afternoon
Materials: Coloured paper sheets, glue and printed A4 sheets
Environmental information: Before starting our research activities, Enea and I had lunch together. I was very happy for this opportunity to spend more time with him. He seemed very relaxed and in good spirits; once we finished lunch we went to his personal office and together we prepared the room to start our activities.

Similarly, to the first propaedeutic activity also this one was divided into two smaller tasks. For this activity I took inspiration from the activity that is extremely appreciated by Enea, which consists in tearing off strips of paper. More specifically I intentionally brought papers of different pastel colours and I asked Enea to tear off a few stripes from them. The task was explained in simple words and I did mime the action to be performed. Enea responded enthusiastically to this task and he immediately grabbed the different sheets of coloured paper and started to tear them off in several small rectangles. This activity was performed by Enea with determination and speed. During this task I never intervened or reminded Enea what to do. He was concentrated until the end of his task, and his enjoyment was contained but visible.

At the end of this activity Enea had a twenty-minute break, where he decided to go outside in his garden to eat a small snack.

The second part of the activity consisted in re-using all the different pieces of paper that Enea's previously torn off and glue them inside six geometric shapes printed in three different A4 papers; each A4 sheet did have two geometrical shapes printed on top (Figure 30.1-30.5). The task was explained to Enea in simple words and I did mime the actions while I explained the task. In this activity Enea could freely decide what kind of colour to use, as well as the colour combinations. The artistic output generated by the research participant was considered an important and desirable outcome in this phase of the research. Contrary to the previous research tasks Enea didn't welcome easily this activity, he appeared confused, and he started to ask for more sheets of paper to tear off. I kindly asked Enea to pay attention to this new task, and I explained that the pieces of paper already torn off were abundant and sufficient for the new activity. The research participant appeared confused and noticing this I decided to slightly change the task, and instead ask Enea to complete the entire task by himself. I cut the A4 paper in two parts, dividing the two geometrical shapes in two different pieces of papers. One piece of paper with one geometrical shape was for Enea and the other one was for me.

Figure 30.1 – 30.5: Activity consisting in the cut and rip of coloured cardboard, and following collage in geometric figures

The research participant curiously observed all actions that I did, paying attention to all the movements as well. Once I finished cutting the paper, I started to explain the new task. In one sheet of paper Enea was asked to glue all the different pieces of coloured paper inside to the geometrical shape, and in the other sheet I needed to do the same. In front of this request Enea remained motionless, and I decided to start to do my own task. Enea carefully observed my actions, until he started to grab and glue similar pieces of paper with similar colours as mine, copying the colour combinations and gestures. At the end of the activity Enea and I had in front of us two identical results. Once again, I cut in two a printed A4 paper and I proposed again the same activity to Enea. This time the research participant started independently to select his preferred pieces of coloured paper and he glued them on his paper, always checking all my movements. Noting this, I decided to grab the same colored paper that Enea's selected and glue them in the same position he did.

Enea seemed pleased by this reversion of roles, and quite rapidly he completed his task. The results were identical once again. The subsequent task was identical to the previous two tasks. Enea started immediately to select his own preferred pieces of coloured paper and glued them composing a beautiful and unique coloured pattern (Figure 31). I observed self-confidence and concentration, and I decided to create my own coloured pattern without the need to reinforce Enea self-esteem and mimic his actions. At the end of the activity the result presented interesting differences and especially the pattern created by Enea was unique and aesthetically very pleasing. The task was repeated one more time, and once again Enea completed his work independently and with lots of confidence and determination. The result was a beautiful pattern with extraordinary colour combinations. At the end of the activity Enea appeared to be satisfied and happy about his work and he showed the final result to me. Together we examined all the outcomes, where it was possible to observe the whole path, that allowed the Enea to build self-confidence and to take independent decisions.

Figure 31: one of the collages designed by Enea during the research activity

5.5.2.1. My observations

This activity has brought important results. First of all, the communication between me and Enea became more dynamic and full of reciprocal exchanges, based on a mix between verbal and non-verbal communication. This interesting mixture of communication channels became a very reliable medium to achieve a clear mutual understanding. Also, in this series of activities, the planned tasks were merged with improvised diversifications when this was considered of help during the activity. This happened, especially to meet Enea's abilities and achieve fluidity in the course of the activity instead of arising problematic work dynamics. This activity brought satisfaction and a feeling of complicity with Enea, furthermore it was very interesting to see him take personal initiatives and observe his talent in combining colours. The activity ended in a relaxed and happy atmosphere and Enea seemed very content and concentrated. All these important advancements in terms of mutual understanding and participatory dynamics were important outcomes which have brought much enthusiasm and confidence in the potentials of this study.

5.5.3. Third activity

Location of the activities: Enea's personal office
Time of the day: Afternoon
Materials: Small branches, small wooden sticks and leaves, glue, one cone, one rectangular and a sphere made by polystyrene, modelling clay
Environmental information: I went in Enea's house where he was waiting for me together with his father. Enea was happy to see me as he started to jump in the corridor. After saying goodbye to his father, we walked down the stairs in his personal office which is only a few meters away from his house.

This new activity contemplated the use of small branches, small wooden sticks and leaves, to create a small three-dimensional sculpture. The activity was subdivided into three different tasks. The first task required to select one material between the small branches, small wooden sticks and leaves. The second task was to decide the shape to give to the sculpture, in case Enea was showing to be intimidated by this request I provided a cone, a rectangular and a sphere made by polystyrene. Furthermore, I also brought modelling clay to be used in case the other materials were not appreciated by Enea. The third task was to build the sculpture using glue to connect together all the pieces. The entire activity was explained step by step, always using simple words and with the use of gestures. The first task was well accepted and understood by Enea who selected the small wooden sticks.

The second task, which was more complex was not well welcomed by the research participant, as he seemed not interested and not willing to create a three-dimensional item. I showed the alternatives to Enea such as the cone, rectangular and the sphere. Enea looked attracted to the cone and the rectangular but he was not interested in gluing the wooden sticks on them. I also showed the modelling clay, allowing Enea to touch and play with the clay, but again he refused to use it. In front of his refusal, I decided to reconfigure the activity and ask Enea to create a pattern with the small wooden sticks and glue them in a A5 sheet of paper. Enea accepted this new task and independently glued several small sticks on his paper. Once I proposed to add one more layer of wooden sticks above the first one, Enea accepted and completed the task (Figure 32). However, once Enea was asked to add once again one more layer of wooden sticks on his paper he refused to do it. To investigate if Enea was refusing in general to work on three-dimensional objects, I decided to glue some leaves on the sphere and observe if Enea was showing curiosity towards this activity. He observed with curiosity while I was completing the task, but he didn't take any initiatives and also once the sphere was completely covered with leaves he didn't touch or interact with the object. Then I asked Enea if he wanted to create some patterns using the sticks, branches and leaves by fixing them on paper and he gladly accepted. The task was modified to allow Enea to participate and express his will. Once I displayed two A5 sheets in front of Enea he grabbed one of them and he started to glue a few leaves on it. I did the same and I used some branches and leaves. Enea checked what I was doing and from time to time imitated my patterns while at other times I imitated his work until we both completed the task.

Figure 32: 3D assembly of wooden branches, designed by Enea during one of the research activities

5.5.3.1 My observations

During this activity the level of mutual understanding and communication continued to improve between me and Enea. This led us to a greater awareness and simplicity in carrying out research activities. Although we encountered small moments of uncertainty during the accomplishment of the task, and the activity was modified a few times, we managed to maintain a good level of communication and understanding towards the activity. Enea proved to be very calm and communicative, and I could clearly understand that he didn't like to build and work with three-dimensional objects. The approach suggested by Enea's therapists and the fragmentation of each activity in different smaller tasks, did allow us to interact more easily. Furthermore, Enea was familiar with this approach from his behavioural therapy and I think

that this helped him to feel comfortable also during our new research activities. At this stage of the research I could notice that I was constantly gaining new knowledge and learning from Enea how to collaborate together.

5.5.4. Fourth activity

Location of the activities: Enea's personal office, garden and city centre
Time of the day: Afternoon, Morning and Afternoon of the second day of activity
Materials: The materials and objects were chosen by Enea
Environmental information: This activity took place in two different days. Enea was calm and in a good mood. Both days I met Enea in his office. He was waiting for me inside together with his father and on both days they were laughing and playing together.

The fourth activity was designed to include a different use of the materials/items and the spaces. The whole activity was fragmented in different steps and in different locations, moving from the simplest task to the most complex one. Before the start of the activity I asked the permission to Enea's parents to visit and explore different locations together with him.
The first task was to ask Enea to select three objects he likes and cares about from his office space. The task was explained with simple words and using examples. Enea was immediately intrigued by this request, and standing up, he started looking around to find the objects. After a few minutes he brought two A3 printed canvasses with several pictures on them. The pictures were representing happy moments of Enea with his family and friends. He showed the pictures, pointing specific subjects and activities that he loves. While presenting the pictures Enea said a few words, such as piscina, the Italian word that means swimming pool in English, to explain a picture representing him swimming when he was child.

This task lasted for quite a long time and the interest of Enea in showing part of his life to let me know him better was visible. The experience was extremely positive for me and Enea, who spontaneously took the leadership of this activity. During the activity I asked a few questions concerning some pictures and Enea responded using single words or names that were relevant to the photo that was taken into consideration. The second task was conducted on the following day. The task consisted in asking Enea to select his two favourite spots nearby his

office including the garden adjacent to the office. The task was explained with simple words and to better explain the activity we walked through the office and the garden using examples. Enea quickly understood the task and he guided me out of his office in a separate hallway where in one of the walls there was an elevator. With a smiling face Enea showed that he liked to press the button, to call the elevator, wait for the doors to open and once the doors closed, press the button and open the doors over and over again. Enea showed this activity several times, and always with intense enjoyment and happiness. This activity was perceived by him as extremely interesting and funny, I asked if he enjoyed the activity and he answered, yes. When I asked why he liked this activity and this part of the office, he didn't answer; however, it was quite clear and understandable why he enjoyed this part of the office. The repetition of the mechanic movement of the doors, Enea's attraction for elevators in general, were obvious clues as to why he enjoyed this activity. During the second part of the task, I followed Enea outside in the garden. Enea selected the spots where he usually sits down during breaks (Figure 33). Once we arrived, Enea started to pull out some tufts of grass, enjoying the sun and the warm temperature outside. Together we sat down and spent some time in that position. I asked for some information concerning why Enea selected that precise location but I didn't receive any answer. A few hours later, we did approach the third part of this propaedeutic activity.

The third task consisted in asking Enea to show two of his favourite spots in the city, nearby his office. To better comprehend this task, it is important to specify that Enea's home and office are located inside the centre of a very small city, and that he usually walks and spends time alone in the historical centre of his city. Also, this task was explained with simple words and was well accepted by Enea. I followed him outside his office. He walked very fast and a few times I asked him to slow down and he did, however after a few minutes he started again to accelerate his speed. The first place he showed me was a small river that surrounds the city walls (Figure 34). In front of the river Enea started to throw small stones and twigs that he collected from the ground. In this activity he showed to be quite amused, and he looked extremely pleased by the sound produced by the impact of the stones on the water surface. Enea repeatedly threw stones and small pieces of wood in the river and once I tried kindly to call for his attention, he didn't respond and looked like as he was not even listening. Noticing this behaviour, I decided to get closer to Enea, and immediately he said '*mi piace*', in English '*I like*'. Understanding that Enea expressed spontaneously his enjoyment for this activity I decided to follow his example and I tried to throw a few small stones in the river, paying special attention to the sounds of the impact of the stones on the water.

Figure 33: one of Enea's favourite places around the office where he works.

One hour later I reminded Enea that the task was not completed and I asked if he has in mind another place where he likes to go in the city. He answered, yes, and always walking fast he guided me in front of an ice cream shop. Once we arrived Enea started to say aloud *"gelto verde veleno",* translated *"ice cream green poison"*. In front of this exclamation I decided to buy one ice cream for Enea and one for me. Enea welcomed this decision with joy and enthusiasm and he started to jump. He started to repeat "*verde veleno!"*, "*verde veleno!"*,

"green poison!", "green poison!". Even if among the various ice cream tastes no one was called "verde veleno", I assumed that Enea, in green coloured ice cream. The two tastes with green colours were pistachio and mint. I asked what his preferred one was between the two, and he replied mint. The activity ended when we finished eating the ice cream and together we walked back to Enea's office, where his father was waiting for us.

Figure 34: one of Enea's favourite places in the city where he lives

5.5.4.1 My observations

Following the advice of Enea's therapists, the activities were divided into smaller tasks, starting from the simplest to the most complex one. The materials and tools involved in this phase included a variety of colours, cards and three-dimensional materials, as well as some of the participant's favourite items, personal objects and places.

In this phase I could observe a big improvement; Enea did not perform any longer the behavioural pattern that involved the creation of the outline of his hands. Furthermore, he started to show his interest towards the activities, and for the first time his constant and concrete participation was noticeable. The tasks were clearly understood by the research participant, and quite often he proved being able to provide his unique contribution to the research, showing personal abilities and personal preferences. In the course of a few activities I needed to quickly rearrange and change a few tasks, as some complications emerged. As an example, Enea refused to take part in all the activities that involved the creation of three-dimensional objects, instead he welcomed the fourth activity that required walking around his office, garden and the city centre very well. Enea generously shared personal photos, activities and places that he loved. Through this activity I learned more about him including his personal attachments and at the same time I could understand his interests toward the research. This new strategy was fundamental to lay the foundations for the active participation of Enea based on clear communication and mutual understanding between us.

5.6. Stage Four: participatory research activities and research objects

In this fourth stage I designed and generated activities and objects that in comparison to the previous stages were more complex and articulated.

The activities and objects are simply called research objects and research activities rather than probes or tools. The reason behind this decision is linked to the desire to remove importance to the activities and objects proposed by me and to create a spotlight on the reactions, modifications and interventions made by Enea. In this sense the designer's outputs are just a means to centralize and emphasise the importance of Enea and the participatory research dynamics that were created. The research objects are intended in this thesis as exploratory tools, that serve to instigate and initiate a non-verbal dialogue with Enea, stimulating his participation. This constitutes a practice in-becoming (Akama and Light 2018; Akama, Pink and Sumartojo 2018), where the contribution of the research participant is explored through mediation of the research objects. In this phase of the study, I could articulate my reflections taking into consideration the complexity of inputs and responses provided by Enea. This was made possible by the knowledge developed during the previous phases of the research, that provided an in-depth comprehension concerning Enea's behaviours. This higher degree of understanding made it possible to identify five categories of reflection, which allowed me to delve more deeply in the dynamics that occurred during the Participatory Design activities. The categories were structured in the following way:

- Adaptation and openness
- Adaptation and cooperation
- Self-behavioural management
- Independent decisions and actions
- Reciprocity and relational dynamics

5.6.1. Stage four: purpose

The main objective of this fourth stage was to explore and experience with the research participant the deepening of our reciprocal cooperation and interaction, by Embracing the complexities of non-verbal participatory design dynamics and allowing him to actively cooperate in the study. Finally, it created the basis for answering the research question.

5.6.2. Research activities: time frame

In the following sections, I describe and discuss the activities that were done with Enea regularly during the months July, August, October 2017, and less frequently in the months of February, March and the beginning of April 2018. The activities usually took place in the afternoon between 14:00 pm and 17:00 pm, although a few times the meetings were scheduled in the morning between 10:00 and 12:00, in case Enea did had work appointments or therapies in the afternoon. During each activity, Enea had two to three breaks, where he could relax, taking some time off from the research activities.

5.6.3. Reciprocal relational research game activity

- Location of the activities: Enea's personal office
- Time of the day: Afternoon
- Materials: Pens, crayons, highlighter

- Environmental information: Enea seemed quiet and very amused to see me with a big tube of papers in my hands. I felt calm, happy to see Enea with a big smile in his face and I was also focused on our game activity.

The design and layout of this research activity was influenced by Gernsbacher who defines reciprocity as "a relation of mutual dependence, action, influence or mode of exchange in which transactions take place between individuals who are symmetrically placed." (Gernsbacher 2006, 139) The importance of reciprocity in a collaboration that includes a person on the severe end of the autistic spectrum, is explained within autism in itself as a condition, where a lack of reciprocal interaction and understanding is a frequent experience.
For Gernsbacher reciprocity needs to be mutual and symmetrical, it is a two-way street. Applied by therapists and parents of children with autism, reciprocity helped the children to increase their social engagement and their responsiveness. In this sense the activities developed were organized and designed in order to be symmetrical and equally shared between me and Enea. Moreover, the research participant and I simultaneously experienced this activity. This brought out yet unseen equality in terms of participation and allowed me to capture important insights about Enea's capabilities as well as willing to be an active part in this investigation.

The reciprocal and relational game is structured as a table game activity and is composed by the following elements two symmetrical and equally divided play areas, one for Enea and the other for me. The game areas are divided into sub-areas marked by numbers; eight cards with a rounded shape that on one side have numbers from 1 to 8 and on the other side there are backgrounds areas painted with colours and lines; a small bag where inside there are sheets marked by numbers ranging from 1 to 8; at last, markers of several colours, corresponding to the colours present in the rounded cards (Figure 35.1 – 35.4). The rules of the game are simple: extract a number from the bag; turn the round card with the extracted number on it; fill in the game area that presents the extracted number with the pattern or the colour shown on the card; respect the edges of the playing area if possible. The research participant willingly accepted to take part in the game and he completed the activity without interruption. The activity was introduced briefly, I used simple words, gestures and I mimed the activity with the use of tangible elements of the game. At the beginning of the activity, the research participant did copy my actions, as an example in the game area there is a dedicated place where the players can write their name; I wrote my name in my play area and Enea copied my name in his own area.

However, as the activity progressed, Enea started to take more initiatives, sometimes even reinterpreting forms and signs. Enea followed the instructions of the game without the necessity to be encouraged and guided by me during the activity. He changed colours and painted different lines, adapting each time to the new direction of the game. This flexibility and openness to experiment with different patterns and colours and the fast adaptation to the rules of the game, was astonishing especially considering that this requires a major effort for Enea.

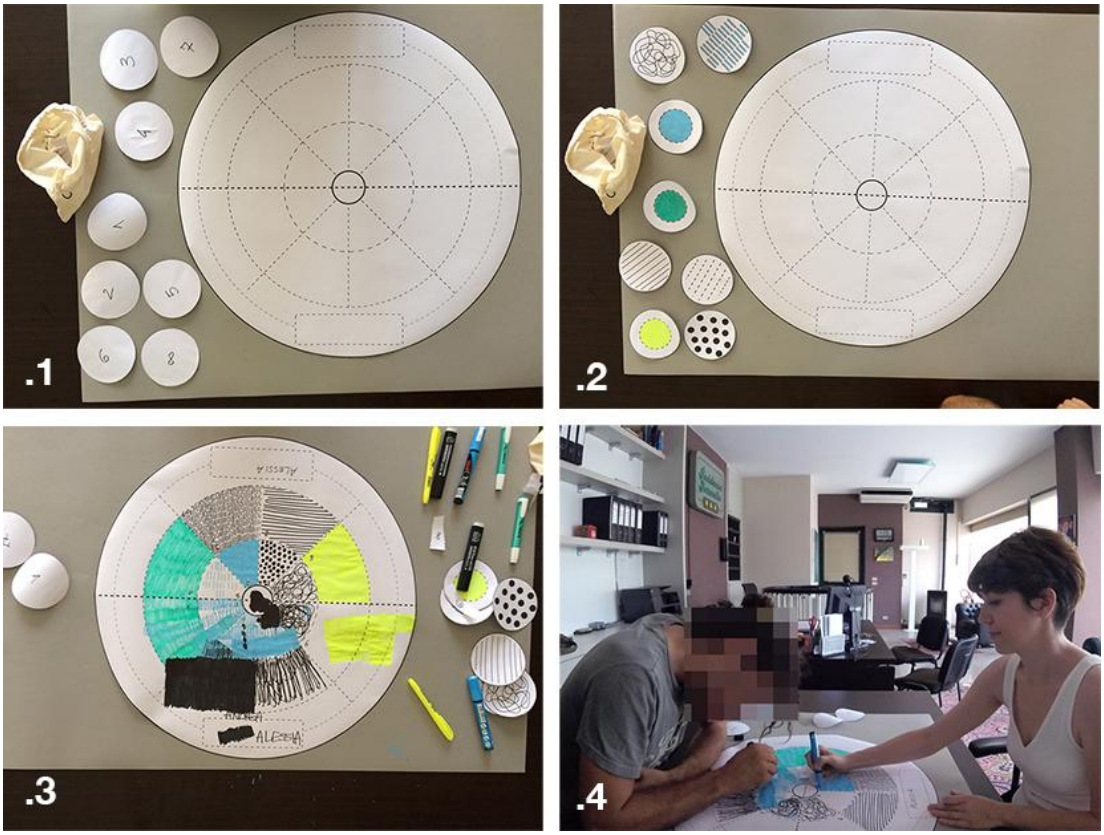


Figure 35.1 - 35.4: the table game designed for Enea, used as a reciprocal and relational tool. The game is composed by two symmetrical and equally divided play areas, one for Enea and the other for the researcher.

Once the activity was completed, a few important differences were observed between my play area and the one of Enea. I could observe that the concentration span of Enea was decreasing within time. Approaching the end of the activity, Enea started to perform habitual automatisms and behavioural patterns, no longer paying attention to the rules of the game. This was a frequent event also during the previous stages of this case study. Although Enea's span of attention evolved and over time started to last longer. In this stage his attention span was

approximately twenty minutes, while during stage one his attention span was between five and ten minutes. Examples of automatisms are visible in Enea's play area, where it is possible to observe the presence of a black rectangular pattern as well as a yellow rectangular, crossing two different areas of the game surface. (See pictures 35.3)

However, it is important to highlight that the research participant could manage to stop this type of automatisms by himself, without my influence. The commitment shown by Enea during the entire activity was an important achievement in this phase of the investigation. The contribution of Enea was analysed from different perspectives, taking always into consideration the context in which the research was done including the specific characteristics of Enea and how those elements changed over the time.

5.6.3.1. My observations

To briefly summarize, a few important elements emerged from this activity:

1. Adaptation and openness: Reflecting upon this activity having in mind the research context, it is possible to consider that Enea habitually draws and paints only on canvas with acrylic colours, using brushes. Usually he uses pen and pencil only when he is asked to write his name. From the preliminary study, it became clear that Enea's abilities are strictly applied in a specific and ritual manner. As a consequence, the introduction of new stimuli that required him to rapidly change drawing techniques and drawing instruments, as happened in this activity, certainly was not an easy task. However, he succeeded without particular problems to adapt to this demanding activity. Furthermore, Enea showed his strong determination during the activity.

2. Adaptation and cooperation: Enea during his art activities, consistently decides by himself the subject that he wants to paint. Abstract paint is the unique type of subject that he usually paints for several years now. Furthermore, from the data shared by his art therapist it was confirmed that during previous activities that involved drawing and painting with the art therapists and with his parents, Enea refused to paint on request or to paint preselected subjects.

However, in this research activity he accepted to follow the new rules of the game. This showed his interest and openness towards collaboration. In this specific exploration Enea had to follow the rules set by me and within the game no choices were given to him. During the activity he could only decide if he wanted to continue or to stop to take part in the activity, however he cooperated with curiosity and concentration.

3. Self-Behavioural management: I could observe the effort that Enea put in controlling his behavioural patterns, as well as the decision to complete the activity even if he was visibly tired.

4. Independent decisions and actions: The autonomous decision to self-correct himself, by changing the drawings that were out of place on the game surface, was observed for the first time during this research activity. Enea demonstrated to be more aware of the actions and the activities where he is involved and he seemed less intimidated in taking initiatives.

5. Reciprocity and relational dynamics: A totally natural pattern of behaviour emerged and could be observed during the game activity. Enea at the very beginning showed to be a bit anxious, however this lasted only for a few minutes. During the rest of the activity the research participant appeared to be relaxed and interested to take part. In comparison to stage one, the relationship between me and Enea evolved and became deeper. This happened thanks to the time we spent together during the research activities, as well as the time we spent during the breaks, or before the beginning of each research activity. The time that was shared outside of the actual work activities, proved to be extremely important in this research, because besides a work relationship also a human connection was nourished over time. This has increased confidence and mutual trust. The reciprocity was encouraged by a symmetrical work position that allowed the researcher and the design participant to sit facing one another (Figure 36), providing me also with the possibility to clearly observe all facial expressions and gestures of Enea. On the other hand, the research participant was motivated by my presence and the fact I was doing precisely the same tasks to complete the research activity.

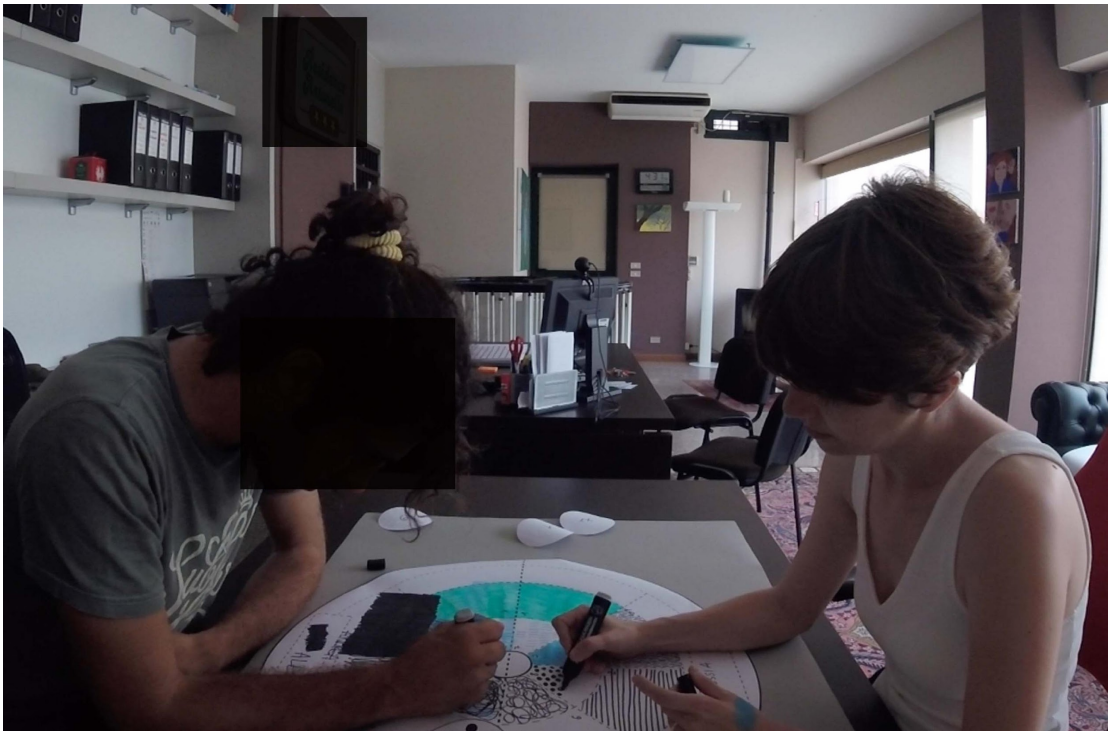


Figure 36: Enea and the researcher, using reciprocally the designed table game.

5.6.4. Research objects: wearable interfaces

- Location of the activities: Enea's personal office and art therapist studio
- Time of the day: This activity took place over a very long period of time
- Materials: colours and white canvas
- Environmental information: In this specific phase of the research Enea was very quiet and relaxed in my presence. We developed this research activity mainly in Enea's office. The atmosphere was relaxed and my presence always welcomed.

The research objects that are described in this section were designed to further stimulate and facilitate Enea's participation. The design of these research objects takes inspiration from Enea's favourite activity which is painting. Associated to this activity, I observed that Enea followed a behavioural pattern that consists in painting the fingers of both hands and sometimes the whole hand. Moreover, he uses his fingers to paint on different surfaces and using different materials. In observing this behaviour, Enea's enjoyment in spending time to colour his fingers

was always visible and clear. Furthermore, the hand movements of Enea, and the way he uses his hands as a discovery and exploration tool, were seen as important information concerning Enea. Undoubtedly the research participant proved to have a high sensibility on his hands. Sometimes his hands are sources of intense pain, especially on his thumbs, other times are used as a calming and reassuring tool, for example, when Enea feels the urge to rip paper. Other times his hands are a sort of probe that he uses to explore surfaces, materials, and to know people, for example by touching their bellies. Inspired by this observation and reflection, the research objects were designed as wearable interfaces that directly involve Enea's fingers and his love for paint. The aim of those objects was to stimulate Enea and at the same time trigger a stronger response during the participatory activity, using a disruptive type of stimuli. In this specific case, the intention wasn't to influence the response of Enea, but to trigger a reaction, paying always attention to avoid the creation of intense undesirable feelings and painful emotions. As it happened for the activities proposed during the previous research phases, Enea's response to the research objects was unpredictable, for this reason the activity was approached with caution. The research objects were conceived as wearable thimbles, featuring different instruments placed on one end. They were produced and delivered to Enea as a research kit (Figure 37).

The thimbles were 3D printed and made by plastic (Figure 38). on one side they are concave to allow the finger to enter, and on the opposite side had different instruments such as: brush, spatula and coloured pencils. The disruptive use intended was the possibility for Enea to use his fingers, but through a wearable interface that would limit his tactile perception and probe him to alter his painting movements. Brushes and spatulas are the unique tools that Enea uses to paint, however it was considered important to introduce also the pastel colours as disruptive elements to trigger Enea's response. This activity was given to Enea without introductions or many explanations. This was a strategic decision that I made as I wanted to observe Enea's reactions.

Figure 37: kit containing the research objects

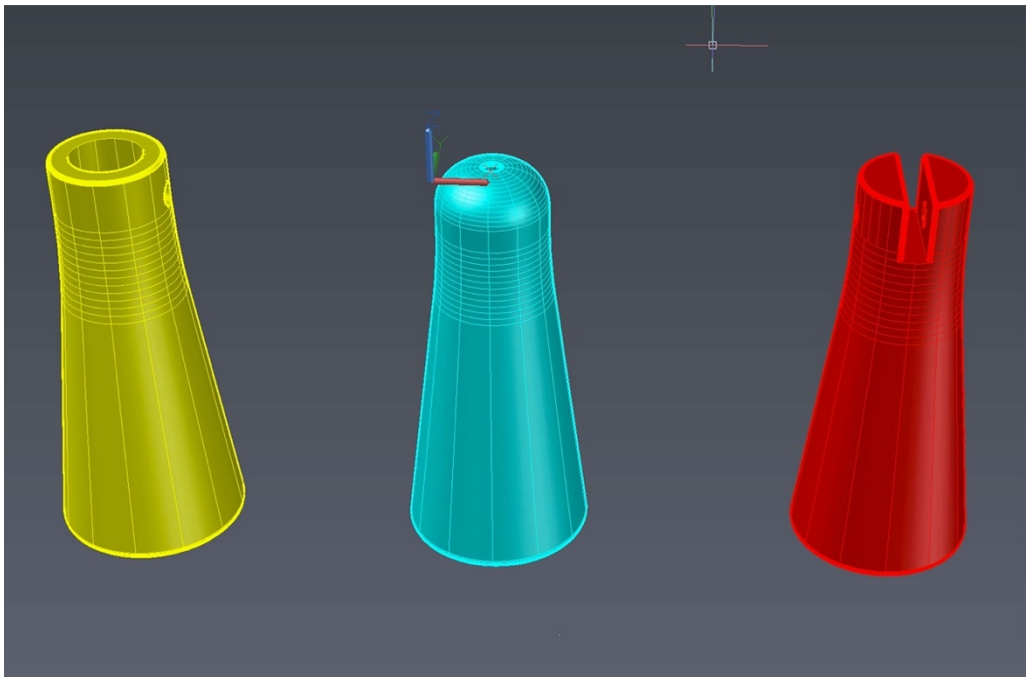


Figure 38: 3D model of the thimbles designed for Enea's fingers

Also in this activity we were sitting facing each other to enhance reciprocity. Enea welcomed the research objects with curiosity. For the activity I provided an acrylic yellow colour, to allow Enea to use the thimbles. The research objects have been thoroughly tested by Enea, which he analysed and dismantled, detaching for example the brush from the thimble. I could observe that Enea didn't manifest any problems in using and wearing the thimbles, on the contrary he appeared triggered and positively interested in the new gestures. As an example, with the black pastel colour, he drew a very large and wide spiral. This type of drawing is not often performed by Enea due to dyspraxia that limits rotational movements to the wrists.

In comparison to previous research activities, at the end of this one, Enea performed a different type of behaviour. He decided to keep two of the research objects: the thimble with the spatula and the thimble with a black pastel colour. This interest towards the research objects was considered an important achievement in this collaboration; and it was thought to demonstrate Enea's his appreciation of the activity, and the objects. At the end of this activity Enea and I couldn't meet again for three weeks. During this time, I decided to design new thimbles and improve the design of existing research objects.

In the months of March and the beginning of April 2018, I could meet again with Enea and test with him the new research objects. In total I designed and prepared eight research objects (thimbles) for Enea, composed of three different types of brushes, a roller sponge (Figure 39.1), a mouldable sponge (Figure 39.2), a spatula and finally a thimble with a small tank to contain ink or liquid colour. All the thimble extremities were attached with screws, glue and adhesive tape. This allowed the thimbles to become more stable during use. Enea appreciated this adjustment, and he stopped tearing apart the two ends of the objects. The research objects were introduced by Enea also during art therapy. This experience showed Enea's openness in extending the use of these objects, not only within the research context, but also in one of his favourite activities.

Intrigued by this attitude, I asked Enea and his art therapist to participate in a painting session. On that occasion I could observe that Enea was using the research objects sometimes wearing them and other times by using the plastic part of the thimble as a small handgrip. Noticing this, I reminded Enea a few times to wear the research objects instead of grabbing them, and he accepted (Figure 39.3).

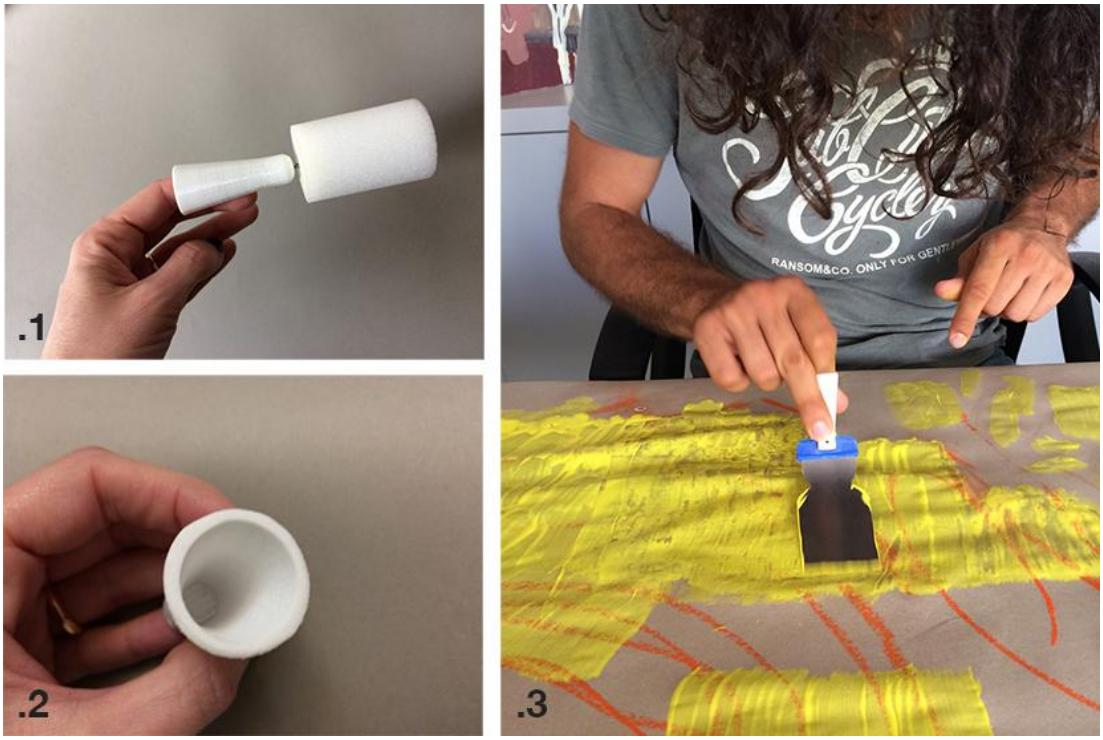


Figure 39.1: the roller sponge research object; Figure 39.2: the mouldable sponge research object; Figure 39.3: Enea wearing and using the research object

He was also encouraged by his art therapists to use and try all the research objects; however, out of the entire kit (Figure 40) he had a strong preference for three objects: the thimble with the brush, the one with the spatula and the roller sponge. Using these objects, Enea elaborated a colourful artefact, that he developed with the idea to gift it to me.

Figure 40: the content of the kit, featuring 8 research objects, purposively designed for Enea

After one month had passed I met again with Enea. During this meeting, we wrote together and exchanged our own insights concerning the research. On this occasion, Enea explained that he was still using the research objects and started to call them “bionic fingers". Enea took possession of the research objects, using them in his artistic practice and attributing a name to them. The new name, bionic fingers, sounds like a physical enhancement and an upgrade of his skills. I could understand that Enea gave a new interpretation and a new use to these, beyond the research context in which they were created.

5.6.4.1. My observations

To briefly summarize, a few important elements emerged from this activity:

1 Adaptation and openness: Enea approached this activity and the research objects with curiosity. From the beginning, he has shown his interest towards the research objects, touching them, pulling and testing the two extremities of each objects, wearing them in different fingers. I observe the fast adaptation of Enea in using the research objects, and his acceptance is following the disruptive constraints and rules set by me.

2 Adaptation and cooperation: Cooperation, implies the will of two or more people to work and operate together. During the research activity Enea, has shown his will to co-operate together with me. He dedicated long hours to this activity during his free time. He accepted to follow rules patiently, and willingly tried all the different research activities and objects. In this activity he decided to show his appreciation for the activity, and his fascination for the research objects by taking them and using them beyond the research activities. For a person that does not express himself verbally, this was a way to tell and show his interest, and I could clearly understand Enea’s will. Enea’s attitude, was interpreted by me as a strong will to cooperate. The shyness and agitation felt by Enea at the beginning of this case study has totally disappeared, giving way to the interest and curiosity.

3 Self-Behavioural management: As happened in the previous stage, I could observe the effort that Enea put in controlling his behavioural patterns, as well as the decision to clearly communicate his interests towards the research objects.

4 Independent decisions and actions: Enea seemed to be aware of the actions and the activities he was involved in and did not seem intimidated to take initiatives. In fact, he autonomously decided to keep two research objects, tested during the activity, and to reuse them during art therapy. Another independent decision of Enea, has been to give a name to the research objects and to provide also a new function to the objects that goes beyond the research.

5 Reciprocity and relational dynamics: In this stage of the research, a rich relational dynamic between the research participant and myself was established. The work relationship and our personal relationship did grow through deep respect and trust in each other. With the growth of the relationship, also the non-verbal understanding has mutually increased. Both I and the participant felt more relaxed during the development of this research phase, and this allowed Enea to feel free to express his will undoubtedly, the growth and the attention dedicated to cultivate the personal relationship has been of fundamental support for the professional relationship and the consequent realization of the research.

5.7. Stage Five: approaching the end of the case study

The approach to the conclusion of the active research phase was a delicate and important moment for me and Enea as co-participants. Attention was focussed on easing the transition from active participation, to more sporadic encounters which did not involve shared work activities, but at the same time protecting the affection and friendship that connected me and Enea. After several months of shared research activities, our meetings had become an important part of my and Enea's lives. We spent many hours together and I entered Enea's daily routine and circle of close people that are an important part of his daily life. Our meetings became increasingly sparse and the time gap was increased between meetings. Enea was always kept informed about this necessary evolution in our relationship and the end of our participatory research activities. Furthermore, he was aware that I am living in a different country, and his reaction was always positive. During this time, I kept Enea and his family informed about the progress concerning the writing of the thesis, through telephone calls and direct messages sent to him and his parents, and when it has been possible for me, I went to visit him personally.

As discussed, this research aimed to explore participatory design dynamics and research outcomes, but to do this by focussing on human encounter. In this thesis, the word encounter refers to the flow of meanings that occur between a subject and another subject. It is seen as the outcome of situated observations and meaning-making processes, conducted in the perspective of understanding another individual and his uniqueness. The relationship that emerged beyond the work, which is characterized by feelings of mutual sympathy and affection, require respect and attention. On several occasions Enea referred to me as a friend when we were working together, and he showed me joy and happiness during the research activities, and I always felt welcomed in his life. As a researcher, in this study I don't position myself as an objective observer who inquiries about an absolute reality and the best possible solution. When we immerse ourselves in contexts and dynamics of reciprocity with other human beings, we become active parts of the relational dynamics. In doing so the researcher and the participant are involved in a more complex and multi layered encounter that fluctuates between objectivity and subjectivity. This attitude recognises that as researchers we always influence the relational dynamics developed with a research 'subject', through our actions,

personality, even through our way of speaking and interacting. Pure objectivity applied in a real-life context in a situated and unique encounter between two people, could to some extent be perceived by the participant as a cold relation that presents a lack of humanity, and this can deeply influence the success of a collaboration. Furthermore, as the researcher, I felt the responsibility to guarantee a smooth transition and avoid creating a feeling that the participant was used for a purpose by the researcher. This certainly contrasts with the spirit and interest that animates me towards this work and the PD approach. My commitment to be an active presence in Enea's life, is a natural consequence of the intense work that we have done together and the natural consequence of the respectful relation that arose through our human encounter.

5.8. Key observations about Participatory Design research

The findings of this thesis reflect the active and collaborative nature of this work, that developed and evolved based on the subjective responses that Enea provided during each research activity. Such approach facilitated the deployment of design as a situated discipline, capable of engaging in depth with Enea.

5.8.1. A situated and Participatory Design approach as a learning experience

The participatory approach adopted in this thesis placed emphasis on the situated and relational dynamics developed between Enea and me. The process was highly adaptive and experimental and provided a unique learning experience for me. Enea became a fundamental guide for me. His guidance supported the development of knowledge concerning his life, his abilities and how the autistic condition affects his life, which in turn helped us to achieve a shared understanding develop our collaboration. To achieve these important results, my role as researcher required me to move away from the idea of the design researcher as the problem solver and take a few steps back. Knowledge about participatory design, as well as my design education, background, and existing design literature, were in this specific case, not sufficient to approach Enea, and his unique personal life experience and personal knowledge and abilities. This entire collaboration required a highly personalized approach to PD, based on Enea subjective reactions and responses during each PD research activity.

All the materials, probes and tools that are often utilized in PD, such as: pens, post-it, pictures, diaries, cameras, activities that require answering questions, or map interests using different tools and media, in this investigation were not immediate options that we could use. A pen for example in a broad sense can be used to write, to draw, or to sign important documents, but a pen can become a music instrument, or a mechanism to disassemble, and the interpretation of the use of this object can be extremely subjective. Beyond the function and

the common understanding of the use that we can make of an object, as humans we develop subjective experiences and interpretations of that object. This inevitably opens new personalized creative possibilities. Furthermore, the experiences and interpretation of objects and tools, can be markedly different from person to person, between people from different age groups, and for people from different social and cultural backgrounds. In the work with Enea, it became highly relevant for me to understand the personal interpretation and use that he gives to different objects and activities. During the participatory process, Enea showed how he interprets and utilizes the objects of common use and this has revealed a highly personalized sense making that was difficult to predict and understand at first. For Enea objects can have multiple uses that are not particularly compatible with the rational common sense and utilization. Prior to the design and creation of the PD activities I begun to experience uncertainty and doubts. I wondered: Can Enea make photos independently and keep a photo diary of his daily activities?; Can I ask Enea to draw or describe his favourite daily activities?; Can we utilize visual or written diaries?;

The answer is no. Together with Enea I learned that my questions were just not adequate to this specific research context and to this specific participant and his abilities. The right questions that I learned and experienced to be more relevant and adequate were instead: what use does Enea make of a photo camera?; What use does Enea make of a pen? and what use does Enea make of a bottle of water?

These questions were particularly effective to gather fundamental information and knowledge that proved decisive for the realisation of the participatory activities. This process of discovering Enea's subjective interpretation and utilization of objects, tools as well as activities, was a constant and fundamental step of this investigation. This made possible the creation of a broader understanding shared among us, and it has been possible to "decode" the situated significance of specific objects and activities. Participatory design examines how participants and design practitioners are able to work together on the development of tools, artefacts and activities as described by (DiSalvo & DesPortes, 2017). Enea and I were actively involved into the exploration of possible modes of participation between us. In this case the research objects and the research activities did support an overgrowing process. More specifically the learning experience emerged during and after each research activity, through the use of each research object and the different reactions expressed by Enea.

More specifically the procedural approach that was followed during the case study was determined by;

- the creation of the research object based on Enea's abilities and preferences;
- testing with Enea to explore the potential of the research objects to trigger active participation and close observation of Enea reactions;
- the modification of the research objects and activities based on Enea's reaction;
- re-testing with Enea the new research objects and careful observation of his reaction;

This path proved to be an extremely informative and learning process for me, where failure, constant changes and modifications of the research objects or activities, together with Enea's reactions taught me activity after activity, what were the right conditions that enabled Enea to actively participate without problems. I could observe that also for Enea this approach proved to be a process in which he managed to gain confidence. Increasingly he started to act and use the research objects in a spontaneous and personal way, experimenting with the potential uses of the research objects based on his interests.

The learning experience, furthermore, expanded towards the achievement of a good understanding of Enea's reactions as well as the interpretation of his different behaviours mediated by non-normative communication. In this case I could observe and compare what he was communicating through his behaviour and consequently I learned the appropriate manner in which verbally and non-verbally, I could communicate with him in precise circumstances; for example when he was asking for my approval during the second stage of the case study.

In this research the process of learning begun also before my actual work with Enea, with my participation in the official training by the National Autistic Society and the training with Enea's therapists. The trainings laid the foundations for a broader understanding based above all on the practice of autism which, added to the tailored and situated body of knowledge learned through Enea has enabled me to enrich my knowledge and increase my working skills.

5.8.2. Time and effort in situated Participatory Design

It takes time and effort both to perform everyday routines as obvious and natural and to redesign or "breach" them as Participatory Design aims to do (Light and Boys 2017). This description provided by Boys and Light based on Garfinkel's concept is a realistic and honest understanding of what lies behind PD. During this investigation this proved to be even more intense in terms of time and effort required. The research indicated that although the immersive and situated approaches adopted during the preliminary study provided vital information for this investigation, the investment of time required during the participation phase was very extensive. This was the result of the adaptation of the research activities and objects, together with the negotiation of the meanings and interpretation of Enea's reactions, that needed time and careful reflection in order to be understood and transformed into new research objects and activities. From this perspective time became itself an important design research element that allowed the development of the participation.

Chapter 6: Discussion

6.1. Introduction

This chapter presents a co-reflection developed with the research participant concerning the participatory research that we have developed together. The voice of Enea is here represented by the use of assisting writings, to provide his perspective on fundamental questions concerning this doctoral study. This broadened the narrative from some social and binary constructions that are often associated with the participation of adults with different abilities in PD research. Together, we discussed the most relevant insights that were gathered from the case study, in keeping the over-arching research objectives that were posed in the introduction. The chapter starts by summarizing the research approach used in the thesis, focusing on how a process-oriented form of enquiry helped to expand knowledge on PD that actively involved one adult with autism. The three important findings that emerged throughout the investigation are here discussed, in relation to participant involvement, power relations and learning experience from a design researcher perspective. The findings are reported in the following sections:

1) The design researcher's learning path;
2) The participant's position, empowerment and contribution in the research process;
3) The contribution to the Participatory Design filed dedicated to adult with autism

Each section provides an in-depth analysis of the work developed with Enea, focusing on explaining and evaluating what emerged from the study.

6.2. Reflections and co-reflections with Enea

In this chapter, I provide a critical reflection on the entire study, referring to it as: *reflection and co-reflection with the research participant*. The reflection within the case study has been developed together with Enea, using a dialogic process through written interviews. The active involvement of Enea offered him the possibility to self-explain and reflect upon the different research phases, including his personal contribution in this PhD research. The use of written interviews that took place in Enea's house in pre-scheduled meetings, allowed him to speak from himself without the narrative mediation and interpretation of his parents and therapists. Their presence during this phase was a valuable technical support for Enea to write in his tablet using the facilitated writing approach.

With this approach, Enea and I shared reflections concerning the participatory design dynamics, research objects and activities developed together. Furthermore, we discussed the relational dynamics existing between us as co-participants, and our personal thoughts about what this research gave us in terms of relation. The dialogue that was developed with Enea covered a fundamental role, as for the first time we communicated in a more exhaustive and articulated way, while during the case study our communications was mainly non-verbal. As Frauemberger et al. (Frauenberger and Good 2014) suggested, PD sees knowledge generation as a dialogic process that is mediated by values and strongly situated; through this dialogic process with Enea, emerged a rich original reflection in terms of power relations, work dynamics, situated knowledge and relational dynamics. Within the case study, it was possible to identify important limitations that occurred during the research and possible future work that can be made together with Enea.

6.3. Reflection within the case study

Compared with other PD research stances, where people with autism, limited speech abilities and, more in general, people with verbal impairments are partially involved into the study, this thesis followed an alternative route, which gave more attention to the direct influence of the participant on the PD's activities and processes, and their relational dynamics. This did not emerge as a linear problem-solving process, where designs are first planned, then produced and lastly tested. On the contrary, attention was drawn on the interaction mechanisms that could position Enea, the research participant, as an active rather than passive agents in the production of the design process. In this sense, the thesis has followed a process-oriented approach, wherein the research proved to be capable of supporting experiences of encounter and active collaboration between people with different abilities.

The research objects and activities have been designed to explore possible cross-abilities, focusing in particular on the situated, relational, and communicational dynamics shared between me and Enea. To do that, a direct participation of Enea in the research process was fundamental. The research process was as a practice in *becoming*, where Enea and his reactions towards the research activities disclosed new understandings and information, that supported the modification and the creation of new research activities. The procedural dynamic have been discussed with the research participant in the form of written interviews; here, Enea was asked to write his ideas and thoughts concerning different aspects of the study. Facilitated writing allowed Enea to eloquently communicate and self-explain his ideas and thoughts. This activity required the support of his psychologist and parents. Furthermore, it is important to specify that, for him, this activity is demanding and difficult, and -although we tried to address different important aspects of this study, some of the posed questions remained unanswered.

Enea's writing style is clear and perfectly understandable, yet very personal and unique. In this chapter, his writings are reported and transcribed from recorded data, with the aim to respect their unique characteristics and peculiarities. Enea's contributions and reflections are extremely unique and accurate, his vision and understanding of this study touches fundamental topic in relation to participatory design research. The reflections on the case study developed with Enea's support worked as a starting point to learn comprehending our experiences of encounter and participation: my own, as a designer and researcher; the one of Enea, as the main participant; our co-contribution to the discussion, particularly on the praxis of Participatory Design.

6.3.1. Prelude to the reflection

In this final research phase, Enea asked to participate in defining the criteria upon which our collaborative process could be discussed, including his reflection concerning the research objects and the research activities. To do so, together with Enea and his parents we agreed to use qualitative written interviews to facilitate our communication, as this is the most powerful tool that Enea uses to express and communicate his personal thoughts.

The interviews took place across different points of the research, the longest being when we approached the end of our shared experience. Each written interview was video and audio recorded; when Enea showed restlessness in the front of the camera, sometimes switching it off, his will was fully respected. Nevertheless, pictures and videos were still taken to document the activities, always paying attention to Enea's preferences. Written interviews were automatically saved into Enea's tablet (the only instrument that he could use to write) and made available to me once the interview was finished. During the written interviews, Enea answered between two and five questions, depending on the concentration and energy he could invest in the activity, something that could change from day to day. As reported in the preliminary study chapter, those activities where for Enea very demanding, and required a lot of effort and concentration from him.

The questions asked to Enea retrace the categories that I used during the case study to reflect upon the activities. However, we adapted the categories to facilitate the reflections with him, since they were initially developed considering only my viewpoint. During the case study the categories were divided as it follows:

- Adaptation and openness
- Adaptation and cooperation
- Self-Behavioural management
- Independent decisions and actions
- Reciprocity and relational dynamics

During the reflection with Enea, the elements for our final discussion were synthesized and structured in the following way:

- Reflection on the research activities
- Reflection on reciprocity and relational dynamics

6.3.2. Reflection on the research activities with Enea

In this section of the thesis, we can 'hear' the direct 'voice' of Enea, who reflects about the activities that we developed together. Questions and answers are reported and faithfully transcribed to respect the his contribution, see appendix 5.1..

> *AC: What do you think about the activities that we have done together?*
>
> *E: Art for me is a safe territory*
>
> *AC: Do you think we draw together or do you think we did something more?*
>
> *E: Relationship between different people, I and you had to steal space from the work that we have done together.*

During our written interviews, I was extremely impressed by Enea, because he could identify that we used art as a means to connect and collaborate. Furthermore, he recognized that we used a "safe territory", which is art for him, to overcome the boundaries existing that limited our ability to work together. In the second question, where I wanted to investigate if he linked solely our collaboration with art, he replied with a very unexpected and at the same time profound respond. His answer contains and summarises what is at the heart of this research: "*Relationship between different people, I and you had to steal space from the work that we have done together"*. Not only he could understand that we were not doing only art activities, but he synthesized the full meaning of what this study was really about. Indeed, this was a collaboration between two very different people, with different abilities that needed to utilize long time during the research, in order to understand each other and understand how we could collaborate. This insightful response from Enea, reveals his acute intelligence and his deep degree of understanding concerning the collaboration. This type of response and degree of

understanding coming from an adult diagnosed with severe autism and limited speech abilities, adds a new narrative in participatory design, and also a new narrative concerning autism and the real subjective abilities of people experiencing it.

The capability of Enea to clearly understand the aim of this research and his ability to recognize and name what we have done together, was somehow very difficult for me to clearly assert during our co-participation. Our collaboration was mainly based on limited verbal communication and, consequently, I could only observe his behaviours and, based on that, elaborate my own ideas and opinions, which however I could not fully trust. In just a few words, Enea has shown what he is capable of. Continuing with the interview we reflected about the research objects:

AC: Do you like the tools that we tested?

E: I like them. Strong sign. With them I express my real emotions and magic expression. The brushes are beautiful. In my hand they guide my gesture. I paint my thoughts and I want to improve. New tools. Useful instrument for new expression.

AC: How would you describe the painting tools and research objects?

E: I call them Bionic fingers. These tools connect my thoughts and emotions. I'm. Really. Happy. to. Use. These instruments.

AC: You tried the "bionic fingers" during art therapy. What did you felt when you used those objects?

E: My fingers are very sensitive. The "Bionic fingers" guide my gesture. when I press them on paper and when I spread the color.

AC: Do you have something to suggest or tell me in particular?

E: Thank you

AC: What would you like this research will tell about you?

E: My world. World of Autism.

AC: Do you want to say something to Alessia that she can add in the final thesis?

E: I am happy to be the subject of this research, and I am happy to be of help for other friends that are like me

The research activities developed during the case study could not be thoroughly examined with Enea, in this final research phase. This was caused by several delays and the impossibility to write with him for an extended amount of time and in proximity of the realization of each research activity. This, however, will be further discussed and explained in the research limitations, at a later stage in this chapter.

Enea revealed important information that helped me to further understand his point of view. What emerged from our written interview, was that Enea understood the research objects as instruments that facilitate and expand his self-expression, allowing him to paint his own thoughts. Enea is an artist who uses colours and gestures to translate his inner world, this became already clear to me during our PD activities. However, his great appreciation for the research objects, that he likes to call “bionic fingers”, and the description that he provides about the potentiality of those objects for his artistic activity, exceeded all my expectations. Enea extended the use of the research objects, letting them become personal instruments to use for empowering his art and expanding his own modes of communicating.

The decision to use art as a "shared research territory" between us, did prove to be a very constructive choice. With time, Enea felt comfortable with the use of the research tools and activities, until he started giving them a new function, and a new name. This new active position of Enea towards the research disclosed very important findings, because it revealed that when a research object strongly attract the interest of the participant, a deeper level of participation can be achieved.

6.3.3. Co-Reflection on reciprocity and relational dynamics

Reciprocity and relational dynamics played a very important part in this research. Those elements are not easy to establish, especially because they require mutual trust, a willingness to share, and generous openness towards the others. Most importantly, these elements are only possible if both the researcher and the participant are willing to personally invest in the

collaboration, in terms of time, commitment and trust. The relational dynamics have been very different throughout the research project, especially as we needed time to learn to communicate and get to know each other. With the development of our situated communication and participation skills, the various relational dynamics also matured, even if during the research our communication was mostly non-verbal:

> *AC: Enea, I want to thank you for your availability. What do you think about your experience in working with me?*
>
> *E: You are gentle, polite and intelligent. I have felt joy when I worked with you*
>
> *AC: What do you expect from our collaboration?*
>
> *E: Friendship.*
>
> *AC: Do you have something to say about our collaboration for this project? Was it a good experience?*
>
> *E: I felt good. I like doing experiments with Alessia. She respects my times. She observes my world.*

During our collaborations, Enea repeatedly referred to me as a friend. We spent a long time together, several months in fact. During this time, we had the opportunity to know each other through the experience of our collaboration. With the expression '*through experience of our collaboration*', I refer to all the experiences that we lived together, which have been necessary to observe each other, in order to establish a two ways communication. This involved different emotions, physical gestures, eye contact, modification of our behaviour and even the control over our behaviour. For instance, I believe this happened when I decided to maintain a neutral face expression, to avoid reinforcing the repetitive behaviour of Enea; or when Enea decided to control his arm in order to complete the task that I suggested him.

Among the answers provided by Enea, the second one touches an important topic, broadly about PD, and in particular about the topic of one-to-one collaboration between researcher and participant. Enea, from our collaboration, expects friendship, and this well represents the beauty of the relationship that we co-created. However, he also highlights another important element, that is, the intensity with which this research was experienced from him. Such experience and expectation leaves a legacy and a commitment in my hands, that I

accept with joy, respect and pride. One of my goals in this investigation was to contribute to create a positive experience based on respect and trust for the research participant. The beautiful evolution of our collaboration, which resulted in a friendship, carries a valuable meaning to me. In front of this result, it is fundamental to recognise the importance of the human encounter, as well as the processual outcome of meaning-making processes that involved myself and Enea.

The autism spectrum disorder is commonly associate with "impairment in social skills" and "communication difficulties" as these are perceived as issues that generate implications for participatory design. Although this can be a common feature in people with autism, Enea proved to have valuable social skills, especially when artefacts and research objects designed around his abilities could support him.

Another significant contribution that transpire through the transcribed interviews, concerns Enea's ability to articulate and describe his perspective on the lived experience. This calls the attention on his abilities in terms of autobiography and self-reflection. Enea's capability of auto-analysis and context-analysis subverts expectations and preconceptions about autism. This challenges common narratives that define people with autism as isolated and uncommunicative individuals, uninterested in connecting with people around them. This collaboration with Enea expands our knowledge concerning subjectivity and the development of an individual's personal social skills. This is a fundamental contribution that the research community should consider when we work with someone with autism. The novelty of this reflection is that Enea was the sole advocate of himself, through these writings, without the need for an external help to translate or interpret his reactions.

6.4. Final reflections

This research is best framed as exploratory as it aims to study new insights in relation to little-understood phenomena. The main reason for this is that the application of participatory design approaches with adult experiencing the severe end of the autistic spectrum and with non-normative communication abilities, has not been thoroughly explored yet and there is a considerable gap in knowledge regarding strategies and approaches for triggering active participation. There is limited available knowledge concerning active collaboration between designers and adult experiencing autism, particularly in relation to participatory dynamics that involve limited verbal interactions, which necessitates more attention and dedicated studies. Furthermore, the relational dynamics between participants in this type of studies are very scarce.

Starting from the existing gaps in the research, this thesis explored possible mode of participation together with Enea. Our share experienced and the co-reflection reported above allowed to identify important findings that can contribute to add novel knowledge to the existing body of research work. From this thesis, three main areas of interest did emerge: 1) the design researcher's learning path; 2) the participant's position, empowerment and contribution in the research process; 3) the contribution to the participatory design field dedicated to adult with autism;

6.4.1. The design researcher's learning path

This investigation provided an intense learning experience for me, that evolved through the different stages of the research. This experience is multifaceted and touches different aspects that deeply influenced this study. What I learned is outlined below:

- Through the course of the investigation, my knowledge about the autism spectrum disorder, and adults who live with this condition, in particular Enea's condition, has been deepened. I extended my expertise concerning the approaches that should be adopted to lessen the stress that a close collaboration can cause in a person on the severe end of the autistic spectrum. More specifically, I was aware that I could have

been an unintentional cause of stress for the research participant; for example, my voice, perfume, some of my behaviours, can be a source of agitation and distress for him. Therefore, I learned to pay attention and have control over all the different aspects that could have negatively impacted the participant's wellbeing. This knowledge was initially generic in nature and then became increasingly specialized and situated to Enea. The trainings with the National Autistic Society and the unofficial training with Enea's therapists did play and important, informative role in my learning experience, which allowed the development of successful strategies that facilitated the collaboration with the participant;

- The immersive and situated approaches used in this research provided an in depth understanding of Enea's everyday reality, and increased the understanding of his usual behaviours, his subjective communicative strategies, together with his personal abilities; those proved to be fundamental information for our collaboration. What I discovered mainly concerned Enea, his personal sphere and his relation with people and contexts that surround him. Learning how Enea typically behaved, communicated, and made sense of the world that surrounded him, even thought I could experience just part of it, did help me to tailor the participatory research activities using a personalized approach. What emerged is that Enea responded positively and with confidence to the proposed activities. The benefit of this type of approach is twofold; on the one hand, it greatly enriched my understanding of Enea; on the other hand, it allowed Enea to make a good use of his own abilities, in a context that he could trust and in which could feel safe.
- The human encounter and established reciprocity helped me and Enea to build confidence and trust among us. In this learning experience, I encountered Enea with my sensitivity and capability to empathize with him, and viceversa. This deep mode of engagement allowed us to learn how to understand each other beyond verbal communication and helped us to interact with honesty. The relational dynamics are difficult to describe and generalize as every person has different sensibilities and every human encounter is influenced by the uniqueness that each person brings into the relation. The human encounter with Enea emerged through the flow of meanings that occurred between us, which supported the creation of an active, respectful and positive collaboration. This experience in close contact with Enea, provided not only a learning

experience from a professional perspective, but also contributed to my personal growth and enrichment;

- Learn to fail and to be flexible were key lessons from which my research practice benefited immensely. In several occasions during the study, the Participatory Design activities did not provide the desired results, nor fulfilled the objectives that I was aiming at; nevertheless, they became occasions from which I have learned something valuable. For example, during my research I realized that it was difficult to predict Enea's reactions. This demanded me to rapidly reinvent or even change previously planned activities, in order to facilitate his participation and guarantee his overall well-being, which was to remain the first priority.
- The conducted participatory activities did not have an immediate impact, nor their significance came across in a delimited period of time. Instead, I understood that meaning-making could only emerge gradually, as a process that evolved across the whole research length and through multiple experiments with research objects and activities that shed light on possible ways of working together. This provided valuable information and data that became increasingly helpful to write this thesis.

6.4.2. Participant's position, empowerment and contribution

In this section I reflect about how non-normative communication, adulthood, severe autism and design might be interconnected. From this perspective, different abilities and non-normative communication are envisioned as creative starting points to support a different narrative about autism through design.

Therefore, the research participant was invited during the entire investigation to use his own abilities and to participate and express himself without the support of a further translation and mediation provided by other people, such as his parents and therapists. This decision was taken to support and enhance non-normative communication, respecting the characteristics and subjective qualities that this type of communication is constituted of. The purpose was to offer insights to progress from a general understanding and narrative about

people affected from severe autism as purely needing support and help, to considering them as people with valuable knowledge to share, important for design but also for society at large. In doing this, I decided to use practice and approaches of participation, as a way of unveiling the still unknown potential that these persons can express.

From a perspective of participation, Enea provided a unique contribution. For that to emerge, it was fundamental to use approaches that fully embraced his own necessities as to accommodate changes in time management and tailored type of stimuli through situated research objects. This also helped to reveal Enea's big interest in taking active part to the research and being aware of the entire process.

The direct involvement in participatory design research of a person who lives with severe autism, cannot be compared with modes of participation involving people who do not experience the spectrum. This could lead to an underestimation of the potential of personalization in participatory design research projects and somehow perpetuate comparisons with abilities that are considered 'normative'. This thesis carefully avoids the perpetuation of the concept of "norms", especially concerning bodily experiences and forms of expressions. Consequently, the participation of Enea has been welcomed in ways and modes that were more congenial to him and his abilities. In that, he understood the value of participation as a synergic cooperation between participants and recognized the value that could be embedded in this type of research also for the autistic community. Enea showed to be aware that we both embodied different modes of communicating, and of the need to find times to use for understanding how to relate to each other. In that, he inscribed himself inside the research process, clearly explaining the importance of spending and somehow "stealing" time to the research, to learn how to communicate together.

Enea also influenced the decision making and outcomes of the research. His influence contributed to create a unique development of the research objects and influenced the procedure in which the participatory activities were to be developed. This granted a position for Enea in this research, where seeds of empowerment matured as the research progressed. One aim of this study was to empower the participant, and there was here a conscious positioning of my part, oriented to create the proper conditions for him to exercise his power. Even thought, in many aspects, the power relation between me and Enea cannot be considered equal, the participatory design phase of this research opened opportunities to facilitate a shift of power between me and the participant. In this research, I depended on the information and knowledge that only Enea possessed and embodied, and this placed him in a position of power. However,

it is difficult to understand how much Enea considered and gave importance to this aspect of our collaboration, and how much he was aware of his power. From the analysis that I developed through observations, reflections and the consequent co-reflections with Enea, it was possible to identify the moment in which he started to take decisions and actions without depending on my approval. This happened towards the end of the research, when he started to exercise part of his power in more concrete ways. From this, it became clear that, through all the attempts that we both did during the participatory process, we sowed potential for the emergence of empowerment. The procedural approach that we adopted showed that, when the participant's personal timing is respected (and with it, the respect for his abilities and preferences) and when the overall research is made free to grow through the participant's inputs, important barriers and difficulties for both, the researcher and the participant, can be overcome. This situated and personalized approach extended beyond participation, and towards a deeper sense of entanglement, engagement and reciprocity amongst us (myself and Enea). This supported the research participant to feel valued and important for the research project and provided him a space where trust was shared among us, with absence of judgments and freedom to act.

I believe that my conscious decision to take some steps back, acknowledging that my expertise was still limited (especially concerning autism) and avoiding interferences motivated by egotistic interventions, supported a shift of my positionality during the research. On the one hand, this lead to a lack of control over the research path, demanding openness towards uncertainties; I now consider this as an inevitable element in an unknown path, both features that were at the core of this exploratory study. Somehow from a researcher perspective, this can be seen a vulnerable position. On the other hand, however, the findings showed, that when the researcher experiences vulnerability, then the empowerment of the participant can truly take place.

6.4.3. Contribution to PD on adults with autism

The main purpose of this research was to explore the potential of PD activities, to actively engage and inspire the participation in the research process, and to let the participant to understand that his abilities are meaningful, and his contribution in the research was important

and relevant. Enea positively responded to this purpose even if this result was unpredictable and the path that has been followed was unknown, as it unfolded activity after activity.

Throughout the study, different objects and tools were envisioned as empowering instruments, and specially designed for the participant to allow him to valorise his personal abilities and communicative skills. Here, attention was drawn on the research process and the relational dynamics that occurred, as key elements that allowed to capture the multiple responses of the participant, while he used the designed objects. Such approach aimed at creating a comfortable and fertile research space, open to exploring modes of participation that are respectful towards subjective abilities and attentive in regards to non-normative forms of communication.

The research objects designed and used in this study revealed how those artefacts can carry learning potential. This is mediated by participatory activities that have been repeated, modified and personalized across the entire investigation, based on Enea's reactions until we successfully established an active participation. Quite similarly to the boundary objects described by Star, as artefacts that do the crossing by fulfilling a bridging function (Star 2010) the research objects created in this study have an exploratory function, finalised to probe possibilities and trigger mutual participation. In this specific research context, it has been difficult to predict a priori whether the research objects could effectively function as boundary crossing; for this, a connection with Star's concept was purposively avoided. This research rather focused on the experimental value of research objects and activities, with particular attention on the procedural steps and participatory dynamics that emerged from the collaboration. This resulted in a growing learning experience towards the research project, for both me and the research participant.

6.4.3.1. Multiples research objects as a new means of participation

What emerged from the case study was the necessity to introduce at each meeting a different activity that was specifically designed for Enea. As the activities changed, the support materials for the activities also changed, such as pens and coloured cards. The continuous diversification of the activities and objects enabled a collaboration with Enea and avoided the onset of

repetitive behavioural patterns. This was understood when Enea started to manifest repeatedly the same behaviour in response to a research activity, as was described in the previous chapter. This repetitive behavioural pattern performed by Enea deeply influenced some of our research activities and strongly impacted the reciprocal understanding between us as co-participants. During this phase Enea was not responding, nor interacting with me, and for several meetings he replicated this same behaviour. Involuntarily, I was reinforcing this repetitive pattern, and Enea felt encouraged to re-enact the same activity in my presence even when he was not asked to do so. This impasse lasted until the research activities started to be disassembled into smaller steps, along with the differentiation of the research materials and objects proposed during each activity. These steps asked me to be sensitive enough to perceive which interest could be shared between us, and how a collaboration could be developed.

This also implies a certain openness in gaining a deeper understanding of the participants' practices, motivations and preferences, to find possible points of convergence between diverse agendas, personal aims, and abilities. This convergence, as Seravalli wrote, is not always already there; sometimes it has to be constructed (Seravalli 2014, 177). The construction of this convergence allowed the development of what Ehn has described as a shared language and a communicative territory between the participants (Ehn 1988).

The implementation of new and original research objects during each activity, was based on Enea's subjective reactions towards the research objects. This approach established a fertile ground where we could increase our reciprocal understanding and use the PD activities to communicate without necessarily using a "common" language or reaching for a perfect translation (Chrisman 1999). The engagement towards the research activities did evolve through the mediation of research objects that, in this case study, are interpreted and understood as entities capable of crossing existing boundaries that emerged between me and the participant. This emerged through design practice, and was understood as such when it became clear that we had to overcome our own reciprocal boundaries, to reach a shared understanding; this included communication (normative and non-normative), interpretation of meanings, abilities, and finally rich a commune and shared understanding and freedom in the way we take action towards the participation. On boundaries, Star has noted that: "often, boundary implies something like edge or periphery, as in the boundary of a state or a tumor. Here, however, it is used to mean a shared space, where exactly that sense of here and there are confounded." (Star 2010, 602–603). The research objects facilitated among us an active type of collaboration, where Enea felt the freedom to appropriate, re-use and even re-name, a few of the objects

designed for the PD activities. As a consequence, the research objects designed and utilized in this thesis are to be understood in a broad sense, as something that we acted *toward* and *with*, as suggested by Star (Star 2010). Enea acted and utilized the research objects and activities in very different ways throughout the entire project, and this indicated how important it can be for the participant to familiarize and become confident with the participatory approach, especially for a person who experiences autism. Moreover, the case study showed high potential and possibility for meanings to be negotiated and for personalization of the research objects to take place, in view of increasing active participation, especially for those who have very specific interests, as in the case of Enea.

6.5. Summary

This chapter has illustrated the co-reflection developed with the research participant, using written interviews. The written conversation provided a broader understanding on how Enea took part in this research; furthermore, in this section, the participant articulated his own thoughts about this research study. The co-reflection conducted with Enea, allowed me to delve in depth into the meaning and relevance of this study, which has been explained in the final section of this chapter. The final reflection concerns the three important areas of interest that emerged from this study and through Enea's participation. The areas of interest were:
The design researcher's learning path;

- the participant's position, empowerment and contribution in the research process;
- the contribution to the participatory design field dedicated to adult with autism;
- the reflection introduces important findings that are then further discussed in the next chapter, where the research question that triggered this investigation will be answered.

Chapter 7: Conclusions

7.1. Introduction

This chapter presents the conclusion to the thesis in the light of the findings of the case study, and provides an answer to the main question that triggered this research. The chapter provides reflections on the dynamics of the study, the role of situated design in enhancing human encounters with autistic adults, and lastly the limitations of the work. The novel contribution to existing knowledge on participatory design approaches that are applied to enhance the participation of adults with severe autism is described. Although this research adopted a situated approach, important notions that can transfer to other contexts did emerge. These are explained in the following sections, together with proposals for future work that I aim to develop as a continuation of this research. The chapter ends with my personal (en)closures to this investigation.

7.2. Answering the research questions

How can an adult with low functioning autism and non-normative communication abilities actively engage in a design research and how would this contribute to the field of participatory design?

To find an answer to this question, it was essential to unfold and reflect upon the research dynamics and procedural steps that emerged during the collaboration with Enea. This thesis showed that, to allow the participant to actively take part in this research, a highly situated and personalized approach was fundamental. This was only possible through careful preparation and in-depth immersion inside the participant's daily life, which allowed me to deeply comprehend his personal abilities, interests, preferred mode of communication and observe closely his life, trying to understand his personal experience with severe autism. This immersive approach, in the initial phase of the research, supported a careful and sensitive encounter with the research participant, which allowed to build trust and a positive, good relationship amongst us, which was beneficial across the study.

The case study research showed that, in a collaboration where verbal communication is limited, research objects and activities can become important elements to facilitate an interaction between the researcher and the participant. Those revealed to be mostly effective when such objects and activities are designed according to the participant's subjective abilities and interests. The adopted process-oriented approach was based on the responses and reactions provided by Enea. This progressively influenced a continuous re-design and modification of those objects and activities, which were then explored with the participant. This tailored approach allowed us to overcome existing boundaries, such as the differences in meaning-making and utilizations, attributed to objects also of common use, and the different communication modalities that occurred between me and Enea. By doing so, it became possible to communicate without necessarily using a common language or even achieving a perfect translation.

The findings showed that a re-adaptation and re-design of the research objects, as well as a continuous creation of new activities, helped the participant to avoid the onset of repetitive behaviours. This implied a continuous mediation between the participant's reactions and the understanding of what I, the researcher, could achieve, by learning and negotiating the meaning of such reactions. This process required a long time, dedication and effort from both Enea and

myself. However, what emerged is that those objects mediate participation: while acting *toward* them and *with* them, the participant enable participation to emerge. Through this approach, we co-produced knowledge about participatory design and process-oriented participatory dynamics involving adults with severe autism and non-normative communication abilities.

To conclude, this thesis suggests that a person that experiences the severe end of the autistic condition can take active part in a participatory design research. This can be done through a situated approach to design, which builds upon the expertise and responses of the participant, as a way of tailoring research objects. This is possible insofar as the designer accepts to pursue a humble, situated, and personalised process-oriented approach, that prioritizes value over the success of participation, and the dynamics that allow participation to emerge. This includes relational dynamics, the human encounter, as well as the participant's empowerment, all considered fundamental elements to navigate across the research process considered in this thesis.

7.3. Original Contributions to Knowledge

The following section provides a descriptive account of the contribution to knowledge that emerged from this research, focusing on the three main contributions: 1) Design of situated research objects; 2) Development of Participatory Design practice; 3) Development of new narrative about autism.

7.3.1 Design of situated research objects

The literature review highlighted how there is a limited body of research in design and autism, especially involving autistic adults with limited speech abilities. This thesis directly addressed this issue by developing a range of situated research objects to help connect, communicate and actively involve the participant into the design process.

This research theoretically contributed to the field of participatory design, by finding that a highly personalised and process-oriented research approach, together with the ad-hoc creation of research objects based on participant's subjective abilities and preference, can support and encourage active participation. The research objects and activities developed during this study covered a key role that helped me and Enea to produce and co-produce contributions to new knowledge. Such knowledge is important, because it helps to expand the existing discourse about the role of research objects, probes, cultural probes and their capabilities to mediate and facilitate participatory activities.

The existing literature about probes and research tools applied in PD research projects extensively explains what probes are utilised for, and what type of data researchers aim to achieve. However, information concerning *how* probes and research tools are designed, *why* some materials are used instead of others, and *how* research objects are introduced and utilized with the participants, is currently very scarce. This information is even more limited when this concerns research objects, probes and tools applied in PD projects with adults with severe autism. This was one of the main gaps identified in the literature review chapter of this thesis. The contributions of this research on this matter, are emerging from the detailed explanation of what occurred in each step of the study, from the preparation and design of the probes, to

the tests carried out with Enea, his reactions and how those reactions stimulated reflections and the consequent re-design of the research objects. This procedural path showed the application of a situated approach that strongly influenced the research objects that have been developed. Although the type of objects that have emerged in this study are not probably generalizable, due to the high level of personalization involved, the process adopted to create them can certainly be of support in other participatory research with people with severe autism. Other generalizable novel insights that emerged from this study concern how to approach and configure co-design in a complex PD situation:

- plan thoroughly the research activities in advance, with careful selection of potential materials that can be used and tested with the research participant;
- select materials that are particularly appreciated and familiar for the research participant;
- introduce the research objects and activities through small and simple steps;
- instructions should be simple, with not many words should in the explanation, to avoid overloading the research participant with verbal stimuli;
- avoid proposing similar research objects in several activities to avoid the potential trigger and emergence of repetitive behaviours;
- the context set up for the research activities should allow the researcher to always sit in front of the participant, to ensure good mutual visual connection;
- the research participant can be stressed or may not like the research activity she/he is doing; in those circumstances the researcher needs to be aware of the participant's emotions and feelings and should be open to suddenly change the research activity or even immediately end it.
- Develop research objects through iteration of activities with the participant and, when possible, also through disruption.
- Mirror the participants' actions to let them guide part of the activity. This triggers reciprocity through visual connection, body language, signs and vocalization, actions that are important to empower participants; and further support participatory design activities that are not mediated by verbal interactions.

7.3.2. Development of Participatory Design practice

As a designer, I consider myself extremely lucky and grateful for having had the opportunity to develop this research together with Enea. Our collaboration expanded my knowledge as a researcher and as a person. This investigation exposed me to a different way of being in the world, which helped me to evolve my own assumptions concerning severe autism and participation through design. To better understand the participant, it has been important to create an in-depth and sensitive encounter with him, through humility and empathy. This opened my mind to accept what sometimes I could not understand or completely comprehend and avoid judgment. To do this, I needed to prepare myself to step into Enea's life with sensibility and discretions.

Enea experiences the world so intensively and in a different way compared to mine, that this encouraged me to connect and learn from him. Working in close contact with a person with non-normative communication abilities heightened my sense of awareness towards my actions and encouraged me to develop a range of research objects and activities to facilitate and encourage reciprocal interactions and understanding, without the support of verbal interaction. This research has illustrated an immersive and procedural approach to participatory design, where the active involvement of Enea in the process provided an extensive learning experience for me, as a design researcher. Together, we expanded knowledge of participation not by necessarily relying on verbal communication but enabling non-normative communication and personalized mode of interactions. This was also possible because the participant was able to make his embodied experience heard, without the mediation or translation of care support staff or family members. This brought the research approach with people with autism, closer to a fair inclusion in design, and provided an extended awareness of their abilities.

Through this research, Enea and I want to encourage more designers to collaborate with people who experience autism in their mature life, as they can offer unique ideas and perspectives that are excluded from mainstream ways of thinking. Moreover, this research follows Frauenberger's and Gaudion's understanding of active participation, where the participants' personal abilities and positive engagement are considered fundamental elements of the research approach. This project's contribution extends the dialogue and knowledge

concerning PD activities that are not entirely mediated by verbal communication with adults experiencing severe autism. It highlighted the importance of pursuing situated and personalised research approaches that led to participatory activities capable of empowering the participant.

The research also unveiled the importance of prioritising the process over any prior expectation set by the design researcher, and any prior expectations concerning the success of participation. This involved taking a step back from pre-determined objectives and idea. It is described a fundamental attitude, which is particularly meaningful when the available knowledge about the participant/s are not sufficient, or too complex to be understood and translated into a design research project. This type of approach proved relevant also in respect to the participants' real needs and subjective abilities. The discussion of the case study highlighted that a slow and humble approach to PD can be extremely valuable in works that involve adults with severe autism. This is particularly relevant, because there are different nuances of participation and participant involvement, which span from initial collaboration until the co-design of an entire project. The research team, I suggest, should navigate through this process gradually and always respecting the subjective abilities of each participant.

What emerged from this research is that a good level of participation and mutual understanding is possible when -along the path that eventually lead to a participant's empowerment, the fine line existing between guiding and letting go is acknowledged, respected, and valued. The research approach adopted in this thesis underlined the potential of learning as a fundamental part of the process to promote important social change. This new insight positions this research in dialogue with other projects, such as the work of Prior, Maha and Hackney, (Rana and Hackney 2018; Prior and McNiff 2018) which also employs design and art as research in learning and teaching, to promote active participation.

7.3.3 Development of new narratives about autism

Signs, vocalization, body language, as well as facilitated writing and picture communication symbols (PCS) are some of the forms of communication used by people experiencing severe

autism and limited verbal abilities. This research aimed at legitimising non-normative communication and elevating it as important means for the participant to enable self-narration and expression. Autistic people with limited verbal abilities often find themselves in a marginalised condition, and the embodied experience that goes beyond the limited and exclusivist fences of what is considered 'normal', is not yet valued and accepted. However, when their voices are heard and considered, it becomes possible to understand more about this condition. Through this, also common narratives concerning people with autism that pitch them as isolated, uncommunicative and unable or not interested to socially connect with others, can be expanded to adhere to a more truthful and articulated way to the real abilities and experience of people with autism.

Communication with people that experience the severe end of the spectrum involves personalised modes of expression, which can be non-linear and verbally eloquent; it is undoubtable, however, that these convey important subjective meanings and cultural values. Enea, through assisted writing exercises, could convey his message in a way that I could extensively understand and relate to, however it is important to note that Enea's writings abilities were not considered more precious and eloquent than his non-normative ways of communication. Furthermore, the additional translations from his parents and therapists were not needed to explain his own perspective and thoughts. The content of his writing revealed his capability to clearly understand the aim of the research, and also revealed his awareness concerning his abilities and his openness towards social interactions and interpersonal relationships. This revealed novel information concerning the complexities and richness of the mixed subjective capabilities that people with severe autism and limited speech abilities have. This approach towards the abilities of the research participant, and the consequent research activities developed together with him, created a shift in the dialogic power relationship between me and the participant. Together, we become co-participants and co-researcher; in doing so the participant exerted agency and his ownership emerged within the research process. This exploratory research has shown that, in a participatory design research, an adult with severe autism and limited verbal abilities was capable of actively participating in all stages of the research, articulating by himself his reflections and thoughts, thus providing valuable and novel contribution to the design discipline.

7.4. Limitations of the study

The reflections presented in the previous chapters identified significant limitations as well as important findings and contributions across the case study, creating novel knowledge about what worked and did not work during the activities and across the research process. The main limitation in this research concerned issues of time management, in particular concerning the possibility of planning several written interviews with the research participant. Although such activities (conducted with Enea and his parents) were scheduled months in advance, we experienced a lot of delays and multiple meetings were cancelled, due to urgent and unpredictable work commitments of the parents. Unfortunately, we could not re-schedule those appointments, and this influenced the number of questions that Enea could finally answer. Furthermore, the large temporal gaps between the different written interviews, made it hard to reflect with Enea upon each of the research activities that we developed together. Time management played a fundamental role in the development of the research process. For a long period of time, me and Enea needed to learn ways to communicate together and understand each other. This has not allowed us to expand the research that we did together into an actual participatory design project, mainly due to lack of time. Looking back at this research process, I now believe in the importance of being more realistic in relation to what can be achieved in similar kinds of practices, especially considering the availability of time that can be shared between designers and participants.

7.5. Future work

Together with Enea and his parents, we discussed extensively the direction that our future work and collaborations might take, building on the solid ground set during this research project. My aim is to continue this research and explore potential design outputs and probes to enhance web-based activism, with people who advocate the overcome of fear and equal social and law recognition, particularly those who experience severe autism and non-normative communications. To make their voice heard, new technologies and social media can be explored and designed based on the knowledge and data learned from this thesis.

With Enea, we had a second idea, which entails the creation of a virtual reality (VR) experience, dedicated to immerging the public into the world of a person with severe autism. VR, as implicit in the name, brings the audience into a re-created reality, projecting the participants from their actual context into a mediated, virtual environment. Severe autism obstructs the capability to speak, therefore many valuable but untold stories and experiences wait long in standby, before being disclosed. This aspect of autism influenced the idea of designing 'stories and scenarios' inspired from the daily life of Enea and the spaces that he inhabits. Potentially, VR may situate such stories within three different virtual scenarios: one inside Enea's house; the second within a supermarket; the third in the main square of the city where Enea lives. Those spaces have already been discussed by the designer and Enea, and were found particularly interesting, especially in relation to the ways in which Enea experiences them. The three environments would be illustrated by Enea and the designer, their style specifically crafted to depict Enea's inner world, in its multitude of micro-macro details and features. The participant viewers will use a voice-guide to visit the environments, where they might be asked to perform 'actions' involving their sensory perceptions, mediated from VR's navigation space. The idea behind this project is to provide experiences of a perception of the 'real' that differs from the usual one, being mediated by autistic modes of perception and vision. Using a participatory and experiential story-telling approach, the purpose of this work is to allow participants to 'feel' part of what an autistic person encounters in the daily life. In this project, Enea would play an active part, acting as the artist and guide in the design of the VR environments, to make them adhere to his own lived experience.

7.6. Recommendations

Throughout the duration of this research, three booklets were created. The purpose of these was to explain the different stages of the study and the different findings that emerged in the collaboration with Enea. The booklets were used to document work-in-progress and the outputs were shared outside the research settings. They were also used as informative tools, contributing to create a shared understanding between the researcher and the participant, and allowing a wider audience of stakeholders to become aware of the different research activities and steps. A total of three booklets have been designed and given to Enea's parents. This was an important way to share information with them and Enea's therapists, because this helped them to grasp a bigger perspective on the progression of my work.

The **first booklet,** see appendix 6.1, collects all the information that emerged during the preliminary study and the results of the observation concerning Enea's abilities, daily routine, preferences, therapies, communication abilities and supportive tools. This booklet explains the motivation behind the preliminary study, and how this research phase played a fundamental informative role for the main study. The document explains how Enea's interests and abilities were mapped, and also the approach used to gain a deep understanding of the participant's practices and motivations, to find a possible convergence between our diverse agendas, expertise and abilities. Throughout this phase, I wrote field notes and self-reporting insights while interacting with the participants, dedicating attention to contextual elements, as a way to inform the scope of the main study;

The **second booklet,** see appendix 6.2., shows and explains the beginning of the case study. It collects the preparation of the different activities and the attempts to establish a collaboration and shared understanding with Enea. This first phase of the study was very informative and tailored to Enea's preferences, abilities and interpretations of the use of specific objects and behaviours; all that information was shared and explained in depth. Furthermore, in the booklet, text is accompanied and made more understandable through pictures and infographics;

The **third booklet** see appendix 6.3., informs Enea's parents about the activities developed and tested during the case study. Each activity was explained and showed through pictures, and the outcomes and the level of interaction between me and Enea were carefully explained. The booklet presents also a section with possible future work, based on the learning experience and application of this participatory research.

Through those three reports, Enea's parents were informed about the aim and objectives of this investigation, together with clear explanations of fundamental elements of this research. The documents included further explanations of what Participatory Design is and how it was applied in the collaboration with their son. We shared written and visual information concerning the design objects, tools, research materials and how those were applied in each research activity. This provided Enea's parents with rich information about the entire research, allowing them to gain insights concerning the activities in which their son was participating. They became interested about design and its different applications, especially participatory design, which they did not know nor understand at the beginning of our collaboration. If their initial ideas and knowledge about design were mainly linked to product and graphic design, through the information that we shared they learned about and appreciated the application of PD in social design. All booklets were always welcomed from Enea's parents as an important a valuable document, which supported the amplification of trust among us, and busted enthusiasm towards the research.

7.7. Concluding summary

This thesis explored possible ways to enable the active participation in design research of an adult on the severe spectrum of autism and limited verbal abilities. The path that I followed to report about this process was articulated in seven chapters. In the literature review, I began by providing information concerning the autism spectrum disorder, examining the topic along two different but complementary perspectives. The first concerns the scientific understanding and definitions of autism and involved reviews of main theories that inform the scientific community. The second is the perspective provided by those who experience the autistic spectrum, and involves their considerations about the neurotypical disorder. I then moved to analyse existing Participatory Design approaches, through academic contributions concerning modes of participation, positionality and power relations in participatory dynamics. The analysis involved also existing design research projects, developed in collaboration with people with autism. Building on that, I then identified the gaps that this research aimed at exploring. Last, I addressed possible modes of design research that can be used for supporting the participation of people with severe autism in design research processes.

This research followed an exploratory approach, presented in Chapter 3. The elements that emerged from the theoretical analysis reinforced the methodological configuration used in this research, that is, a combination of Immersive and Situated approaches, and Participatory Design.

The preliminary study, presented in Chapter 4 was structured in two different phases, namely: 1) Immersive phase and 2) Situated phase. In the first, I prepared myself for beginning the research and to work in close contact with the research participant, by attending two trainings: one with the National Autistic society and one with the research participant's therapists. In phase 2, I closely followed the research participant in his daily life and activities. Here, I adopted an anthropological approach to familiarise with him and his daily routine, and to find valuable data and information that could be applied in the case study.

In chapter 5, I presented and reflected upon the participatory work developed in collaboration with the research participant. The main case study was divided in five sections, which accurately described the procedural and relational dynamics that occurred between me and Enea, and how participation was achieved through the creation of situated research objects. This was done by means of continuous observations and reflections concerning the interactions and reactions of the participant, while he used the research objects. I then moved to report about

my co-reflection with Enea, which were developed through assisting writings. Here, we reflected and answered important questions concerning the research path that we developed together. For instance, in the chapter, Enea described his experience and thoughts, improving my understanding of his role in this research. Furthermore, he contributed to expand and co-produce knowledge about participatory design and the role of the design discipline in collaboration with people experiencing severe autism and non-normative communication.

In Chapter 6, I discussed the main findings of this research, identified with regards to: the design researcher's learning path; the participant's position, empowerment and contribution in the research process; and the contribution to the participatory design filed dedicated to adult with autism.

In this seventh, conclusive chapter, I answered this thesis' research question: *How can an adult with low functioning autism and non-normative communication abilities actively engage in a design research and how would this contribute to the field of participatory design?* I argued that a process-oriented approach and the use of situated research objects designed upon the participant's abilities, enabled an active participation of Enea, contributing to generate new knowledge about: 1) the design of situated research objects; 2) the development of participatory design practice with people experiencing severe autism; 3) the development of new narratives about severe autism.

7.8. Personal (en)closures

To conclude, I would like to share a personal reflection concerning how I experienced this research. The entire process has been a very interesting and intense journey, which brought me to live through many emotions, sometimes more positive and other time less. Emotions of joy and satisfaction but also feelings of frustration, doubt and sometimes lack of trust and self-esteem were also part of my personal experience during the development of the research. I believe that, even if those feelings somehow revealed my vulnerability, they also showed the complexities involved in my experience of working in close contact with another person. This added pressure and a big sense of responsibility on me, as a researcher and practitioner.

This personal journey, despite my positive attitude and big enthusiasm towards the topic and research direction, meant that I faced moments - even entire days, where I feared that this work would not have any impact on PD and its research community. These were the days when my attempts to comprehend more about autism and learn from Enea's experience as a person on the severe end of the condition, seemed too complex for me. The pressure to design activities and research objects to be tested with Enea, mostly without the facilitation of a verbal communication, was very intense, especially in those occasions where he was apparently not communicative and not engaging with the proposed activities, nor with me. There were days when I profoundly doubted whether I could establish a clear and reciprocal form of communication with Enea, and others where I questioned the entire approach and research activities that I was designing, and this made me feel lost. On other occasions, I even questioned my own abilities as a researcher, especially in this specific context, which asked me to consider many complexities in terms of input to provide during the activities and simultaneously promptly respond to all circumstances, to preserve Enea's well-being. Looking back at this process, however, I now value those complexities, because they were a clear, important reminder for me of the obstacles that this thesis wanted to explore and unfold.

On the good days, I felt incredibly energised by this research, and deeply proud of the collaboration with Enea, a precious companion in this exploration. These were the days when new means of participation were disclosed together with him, making me feel excited about what we could do next, and when I look back at that I see how much of our doing, thinking and communicating has changed and evolved throughout this research. In those days, I could see how the participation of Enea and our collaboration was already adding to the bigger picture of PD research, and how we could possibly contribute, even in a small part, to enhance equality

and inclusion. In those days I was moved by observing Enea participating with so much attention and concentration, because I knew how much effort this required him, and that nothing could repay his great generosity.

This research is one of the many additions to design research on people with autism developed across the world, yet it contributes through the uniqueness residing in its highly personalized and situated approach and in the participation of Enea. I am now thinking of Enea, who welcomed me into his life, making himself available to this research. He collaborated by participating with enthusiasm and patience, educating me to understand how to work with him, and at the same time holding off his repetitive behaviours, trying to overcome his comfort zone. His unique contribution goes beyond my best expectations: it not only confirms that Enea consciously participated in each activity; it also proved that he had full understanding of his role as co-participant.

This investigation covered important research topics concerning the procedural dynamics and limited verbal participation due to autism, however there are other future works that matter to me and Enea, which are eager to explore way beyond the content of this thesis. In terms of further explorations, I acknowledge that there is need to work through novel intersections of practical and theoretical constructs, in order to investigate, for instance, the role of practice in deepening our knowledge of design in relation to autism and limited verbal interactions, and the value of differentiation in individual abilities. Concluding, I believe that, as designers and researchers in the field, we can try to direct our attention and focus towards undoing power differentials, rejecting division and marginalization according to issues of ability, gender, race, sexuality and so on. Through participation in design, we can co-experiment and co-explore new ways of inclusion, by contributing to create new narratives of diversity, and providing visibility and power to those who are currently still marginalized.

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Appendices

Appendix 1.1

Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

One of the most important changes in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is to autism spectrum disorder (ASD). The revised diagnosis represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders. Using DSM-IV, patients could be diagnosed with four separate disorders: autistic disorder, Asperger's disorder, childhood disintegrative disorder, or the catch-all diagnosis of pervasive developmental disorder not otherwise specified. Researchers found that these separate diagnoses were not consistently applied across different clinics and treatment centers. Anyone diagnosed with one of the four pervasive developmental disorders (PDD) from DSM-IV should still meet the criteria for ASD in DSM-5 or another, more accurate DSM-5 diagnosis. While DSM does not outline recommended treatment and services for mental disorders, determining an accurate diagnosis is a first step for a clinician in defining a treatment plan for a patient. The Neurodevelopmental Work Group, led by Susan Swedo, MD, senior investigator at the National Institute of Mental Health, recommended the DSM-5 criteria for ASD to be a better reflection of the state of knowledge about autism. The Work Group believes a single umbrella disorder will improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed. People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Again, the symptoms of people with ASD will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms. This spectrum will allow
clinicians to account for the variations in symptoms and behaviors from person to person. Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. This criteria change encourages earlier diagnosis of ASD but also allows people whose symptoms may not be fully recognized until social demands exceed their capacity to receive the diagnosis. It is an important change from DSM-IV criteria, which was geared toward identifying school-aged children with autism-related disorders, but not as useful in diagnosing younger children. The DSM-5 criteria were tested in real-life clinical settings as part of DSM-5 field trials, and analysis from that testing indicated that there will be no significant changes in the prevalence of the disorder. More recently, the largest and most up-to-date study, published by Huerta, et al, in the October 2012 issue of American Journal of Psychiatry, provided the most comprehensive assessment of the DSM-5 criteria for ASD based on symptom extraction from previously collected data. The study found that DSM-5 criteria identified 91 percent of children with clinical DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses

will retain their diagnosis of ASD using the new criteria. Several other studies, using various methodologies, have been inconsistent in their findings. DSM is the manual used by clinicians and researchers to diagnose and classify mental disorders.

The American Psychiatric Association (APA) will publish DSM-5 in 2013, culminating a 14-year revision process.

file:///Users/Alessia/Downloads/APA_DSM-5-Autism-Spectrum-Disorder.pdf

Mental Disorders Fifth Edition DMS-5 (2013)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor
stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal
nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid
thinking patterns, greeting rituals, need to take same route or eat food every day).

Appendix 1.2.

Describes the DSN-IV: The Diagnostic and Statistical Manual of 'Normal' Disorders' (1998), featured on the website of The Institute for the Study of the Neurologically Typical.

Diagnostic Criteria for 666.00 Neurotypic Disorder

A. *Qualitative impairment in independent social interaction as manifested by the following:*

1. Marked delusional sense of awareness of the existence or feelings of others (e.g., treats a person as if he or she were an extension of himself; behaves as if clairvoyant of another person's distress; apparently projects own concepts and needs onto others).

2. Extreme or abnormal seeking of comfort at times of distress (e.g., constantly comes for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, e.g., cries, whines needs demands for attention whenever hurt).

3. Constant or mindless imitation (e.g., always wave bye-bye; copies mother's domestic activities; mechanical imitation of others' actions whenever perceived to be in context).

4. Constant or excessive social play (e.g., always actively participates in simple games; prefers group play activities; involves other children in play only as long as the other children are exactly like themselves with no differences "mirrored images").

5. Gross impairment in ability to make peer friendships (e.g., obsessive interest in making peer friendships with other Neurotypics; despite interest in making friends and afore mentioned delusion of clairvoyance, demonstrates lack of understanding for those who are different and an obsessive rigidity for social convention, for example, constantly seeks attention/positive reinforcement while staring mocking or laughing at others while they stim and rock and remain mute).

B. *Qualitative impairment in verbal and nonverbal communication, and in imaginative*
activity, as manifested by the following:

1. Blatant overuse of all modes of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language.

2. Markedly abnormal nonverbal communication, as in the use of eye-to- eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction

(e.g., anticipates and enjoys being held, does not stiffens when held, constantly looks at the other person or smiles when making a social approach, compulsively greets parents or visitors, insists on invasively stares into the eyes of others in social situations).

3. Excessive imaginative irrelevant activity, such as playacting of adult roles, fantasy characters, or animals, lack of interest in computers or other logical fulfilling pastimes.

4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (e.g., gregarious grandiose tone, overly emotional or syrupy melody, or over controlled pitch).
5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (e.g., immediate mindless or mechanical repetition of NT peers' latest 'in' or catch phrases) (e.g., "whatever" to mean "I am saying I disagree with you but I want you to be upset by my saying so in this way"); idiosyncratic use of words of phrases (e.g., "are you dissing me?" to mean "don't disrespect me"); or frequent irrelevant remarks (e.g., starts talking about the behaviour of autistics at a table nearby during a meal at a restaurant).

6. Marked impairment in the ability to refrain from initiating a conversation or once initiated to sustain a full thought during conversation with others, despite adequate speech (e.g., unable to stay on topic/on thought due to the interjections from other Neurotypics).

C. *Markedly restricted repertoire of activities and interests, as manifested by the following:*

1. Inability or lack of understanding for or interest in stereotyped body movements, e.g., hand-flicking or -twisting, spinning, head-banging (except for during certain types of rock concerts), complex whole-body movements.

2. Persistent lack of awareness or inability to perceive parts of objects (e.g., seeing 'a windmill' but failing to see the existence of the many beautiful finite parts which comprise the whole object, oblivion to feelings of texture of materials, spinning wheels of toy cars) or has an attachment to unusual objects (e.g., insists on driving around in a BMW, wearing Rolex watches, carrying a cellular phone or briefcase).

3. Marked oblivion to changes in aspects of environment, e.g., when a vase is moved from usual position.

4. Unreasonable insistence in sameness in others in precise detail, e.g., insisting that exactly the same social behaviours always be followed when shopping.

5. Markedly restricted range of interest and a preoccupation with one narrow interest, e.g., interested only in status quo climbing, impressing friends, or in pretending to be smarter or better than they are.

D. *Onset during infancy or childhood. Specify if childhood onset (after 36 months of age).*

Appendix 1.3.

VISUALISATION:

Sight

UNDER-SENSITIVE

• Objects appear quite dark, or lose some of their features.

• Central vision is blurred but peripheral vision quite sharp.

• A central object is magnified but things on the periphery are blurred.

• Poor depth perception, problems with throwing and catching, clumsiness.

Ways you might help include the use of visual supports or coloured lenses, although there is only very limited research evidence for such lenses

OVER-SENSITIVE

• Distorted vision - objects and bright lights can appear to jump around.

• Images may fragment.

• Easier and more pleasurable to focus on a detail rather than the whole object.

• Has difficulty getting to sleep as sensitive to the light.

Sound

UNDER-SENSITIVE

• May only hear sounds in one ear, the other ear having only partial hearing or none at all.

• May not acknowledge particular sounds.

• Might enjoy crowded, noisy places or bang doors and objects.

OVER-SENSITIVE

• Noise can be magnified and sounds become distorted and muddled.

• May be able to hear conversations in the distance.

• Inability to cut out sounds – notably background noise, leading to difficulties concentrating.

Smell

UNDER-SENSITIVE

• Some people have no sense of smell and fail to notice extreme odours (this can include their own body odour).

• Some people may lick things to get a better sense of what they are.

You could help by creating a routine around regular washing and using strong-smelling products to distract people from inappropriate strong-smelling stimuli (like faeces).

OVER-SENSITIVE

• Smells can be intense and overpowering. This can cause toileting problems.

• Dislikes people with distinctive perfumes, shampoos, etc.

****

Taste

UNDER-SENSITIVE

• Likes very spicy foods.

• Eats or mouths non-edible items such as stones, dirt, soil, grass, metal, faeces. This is known as pica.

OVER-SENSITIVE

• Finds some flavours and foods too strong and overpowering because of very sensitive taste buds. Has a restricted diet.

• Certain textures cause discomfort - may only eat smooth foods like mashed potatoes or ice-cream.

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Touch

UNDER-SENSITIVE

• Holds others tightly - needs to do so before there is a sensation of having applied any pressure.

• Has a high pain threshold.

• May be unable to feel food in the mouth.

• May self-harm.

• Enjoys heavy objects (eg weighted blankets) on top of them.

• Smears faeces as enjoys the texture.

• Chews on everything, including clothing and inedible objects.

You could help by:

• using weighted blankets or sleeping bags

• for smearing, offering alternatives to handle with similar textures, such as jelly, or cornflour and water

• for chewing, offering latex-free tubes, straws or hard sweets (chill in the fridge).

OVER-SENSITIVE

• Touch can be painful and uncomfortable - people may not like to be touched and this can affect their relationships with others.

• Dislikes having anything on hands or feet.

• Difficulties brushing and washing hair because head is sensitive.

• May find many food textures uncomfortable.

• Only tolerates certain types of clothing or textures.

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Balance (vestibular)

UNDER-SENSITIVE

• A need to rock, swing or spin to get some sensory input.

You could encourage activities that help to develop the vestibular system.

This could include using rocking horses, swings, roundabouts, seesaws, catching a ball or practising walking smoothly up steps or curbs.

OVER-SENSITIVE

• Difficulties with activities like sport, where we need to control our movements.

• Difficulties stopping quickly or during an activity.

• Car sickness.

• Difficulties with activities where the head is not upright or feet are off the ground.

You could help by breaking down activities into small, more easily manageable steps and using visual cues such as a finish line.

****

Body awareness (proprioception)

Our body awareness system tells us where our bodies are in space, and how different body parts are moving.

UNDER-SENSITIVE

• Stands too close to others, because they cannot measure their proximity to other people and judge personal space.

• Finds it hard to navigate rooms and avoid obstructions.

• May bump into people.

You could help by:

• positioning furniture around the edge of a room to make navigation easier

• putting coloured tape on the floor to indicate boundaries

• using the 'arm's-length rule' to judge personal space - this means standing an arm's length away from other people.

OVER-SENSITIVE

• Difficulties with fine motor skills, eg manipulating small objects like buttons or shoe laces.

• Moves whole body to look at something.

You could help by offering 'fine motor' activities like lacing boards.

Appendix 2.1.

Ethical Approval

Human Research Ethics Committee (HREC)

The Open University

From	Dr Claire Hewson The Open University Human Research Ethics Committee
Email	Claire.hewson@open.ac.uk
Extension	(6) 54519
To	Alessia Cadamuro
Project title	BEYOND THE 'UNTOLD': An exploration of the possibilities for inclusive design with an adult on the severe autistic spectrum
HREC ref	HREC/2553/Cadamuro
AMS ref	

Memorandum

Date application submitted: 20/04/2017
Date of HREC response: 20/07/2017

This memorandum is to confirm that the research protocol for above-named research project, as submitted for ethics review, has been given a favourable opinion by the Open University Human Research Ethics Committee.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or of which you become aware which would cast doubt on, or alter, any information contained in the original application, or a later amendment which would raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for review, so they can be recorded and a favourable opinion given prior to any changes being implemented (except only in cases of emergency when the welfare of the participant or researcher is or may be effected).

3. Please include your HREC reference number in any documents or correspondence, also any publicity seeking participants or advertising your research, so it is clear that it has been reviewed by HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS Research Ethics Committees in support of any application for future research clearance. Also, where there is an external ethics review, a copy of the application and outcome should be sent to the HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant awarding bodies and where they exist, their frameworks for research ethics.

6. At the conclusion of your project, by the date you have stated in your application, you are required to provide the Committee with a final report to reflect how the project has progressed, and importantly whether any ethics issues arose and how they were dealt with. A copy of the final report template can be found on the research ethics website - http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-process-and-proforma#final_report.

Best regards

Dr Claire Hewson
The Open University Human Research Ethics Committee

Appendix 3.1.

Transcription and translation of an informal talk with Enea's father

AC: Grazie per il tempo che mi sta dedicando

AC: Thank you for your time

EF: E' un piacere, mi sembra molto interessante la ricerca che vuoi fare con Enea, vorrei saperne qualcosa in più. Tra poco dovrebbe anche arrivare in ufficio Enea con il suo terapeuta ABA così te li presento. Comunque, dammi del tu per favore, almeno ci parliamo con meno formalità

EF: *It is a pleasure, I think that the research you want to do with Enea it sims very interesting, I would love to know more about it. In a few minutes, Enea and his ABA therapist should be here and I will introduce you to them. Anyway, please do not be so formal when you talk with me. It is not necessary*

AC: Va bene, io mi occupo di design partecipativo, negli anni ho lavorato con diverse persone e su diverse tematiche a riguardo. Con questa ricerca sono interessata a capire come un adulto con autismo severe possa essere coinvolto attivamente, attraverso l'utilizzo di oggetti ed attività che ne facilitino la partecipazione. Vede per me suo figlio e tutte le persone che fanno esperienza diretta dell'autismo sono i veri esperti di questa condizione. Però molto spesso sono esclusi dalle ricerche che li riguardano perché non comunicano verbalmente.

AC: *Definitely, it is fine with me. My work interest is about participatory design, and in the last few years, I worked together with several people involving different social topics. With this research, I am interested to understand how an adult with low functioning autism can be actively involved through the use of research objects. I think that all people that experience autism, including his son, are the real experts on autism. However very often they are excluded from the studies and researches that are about*

them, and probably this happens because most people that experience the severe end of the autistic condition do not communicate verbally or in normative ways.

EF: Molto interessante. Penso che anche ad Enea possa piacere far parte della tua ricerca.
In termini di tempo quanto pensi possa durare la tua ricerca e per quanto tempo Enea dovrebbe partecipare.
EF: *Very interesting. I think Enea may also like to be part of your research.*
In terms of time how long you think your research can last and how long Enea should participate.

AC: Questa ricerca richiede molto tempo, in quanto voglio sviluppare un unico caso studio, molto approfondito e per fare questo ho bisogno tempo. La ricerca si sviluppa con uno studio preliminare dove entro in contatto con colui che parteciperà, seguo la sua vita quotidiana osservando e prendendo appunti. In questa fase nasce anche il primo contatto con colui o colei che partecipa allo studio, per questo avviene con attenzione e gradualmente. Questa fase potrebbe durare un mese e mezzo e poi inizierebbe il caso studio, che penso potrebbe durare tre mesi, dipende dalla disponibilità di partecipa.
AC: *This research probably will take a long time, as this research approach will involve an in-depth single case study, and for this reason, I will need time to understand how to properly work with Enea. The research process will include a preliminary study where I enter in close contact with the participant, usually, I follow his daily life by observing and taking notes. In this phase the first contact with the research participant can be established, for this reason, it occurs careful attention and time. This phase could last a month and a half and then the case study will begin, which I think could last three months, depending on the availability of participant.*

EF: Penso sia possibile, però bisognerà organizzarci bene, perché io ed Enea viaggiamo spesso per seguire i progetti della nostra associazione. Quando siamo a casa cinque giorni a settimana fa ABA al mattino e poi viene a lavorare in ufficio e due pomeriggi a settimana è impegnato un'ora con arte terapia e un altro giorno che di

solito è il martedì, anche per questo solo un'ora. Ad ogni modo credo che una soluzione si possa trovare.

EF: *I think it is possible, but it will be necessary to organize ourselves well, because Enea and I travel often to follow the projects of our social enterprise. We are at home, usually five days a week. Concerning our schedule Enea in the morning does ABA therapy and then he comes to work in the office two afternoons a week, the other days one afternoon is usually spent with art therapy on Tuesday, and another day a week he usually does assisting writing in the afternoon with his psychologist. Anyway, I think a solution can be found.*

AC: Certo, Con il mio lavoro sono abbastanza flessibile e se ci organizziamo per tempo non penso ci siano problemi.

AC: *Of course, I have quite a flexible schedule with my job and if we organize ourselves in time I don't think there should be any problems.*

EF: Credo che Enea and E. siano arrivati. Andiamo giù che te li presento

EF*: I think Aeneas and E. have arrived. Let's go downstairs and introduce them to you*

Appendix 3.2.

Transcription and translation of an informal talk with Enea's ABA therapist

AC: Grazie per il tempo che mi stai dedicando, non penso ci vorrà molto, ho alcune domande da porti.

AC: *Thanks for the time you are dedicating to me, I don't think it will take long, I have some questions to ask you.*

ET: Prego, se posso esserti di aiuto

ET: *You are welcome, I am happy to help you*

AC: In questo giorni mi sto accordando con i genitori di Enea per organizzare la nostra collaborazione. Mi hanno spiegato che Enea segue da qualche anno la terapia comportamentale ABA e che sta dando ottimi risultati. Io nella fase preliminare di ricerca per conoscere meglio Enea ho chiesto la possibilità di osservare alcune delle attività che svolgi con lui. Loro mi hanno chiesto di rivolgermi direttamente a te. Pensi che questo possa essere un problema nelle vostre attività. Ovviamente non voglio essere un elemento di distrazione o di disturbo.

AC: *These days I am working with Enea's parents in order to organize our collaboration. They explained to me that Enea has been following ABA behavior therapy for a few years with excellent results. In the preliminary phase of the research I aim to get to know Enea better, and I am wondering if it can be possible to observe some of the activities you carry out with him. Enea's parents suggest me to talk to you directly. Do you think this could be possible? Obviously, I don't want to be an element of distraction or disturbance in your activities.*

ET: Certo, non ci sono problemi, anzi penso che sia importante che tu capisca come lavoriamo e quali comportamenti evitare per aiutare Enea nel suo percorso. Lui ha fatto

molti miglioramenti in questi anni ed è importante riceva stimoli coerenti da parte di tutte le persone che sono a stretto contatto con lui.

ET: *Of course, there are no problems, indeed I think it is important that you understand how we work and what behaviors to avoid to help Enea in his journey. He has made many improvements over the years and it is important that he receives consistent stimuli from all the people who are in close contact with him.*

AC: Cosa fate durante le attività di ABA?

AC: *What do you do during ABA activities?*

ET: Cerchiamo di rendere Enea indipendente nella sua vita quotidiana. Le attività che svolgiamo a turno io e la mia collega vanno da insegnare ad Enea come prendersi cura della sua igiene personale, a prepararsi la colazione da solo, fare la spesa e il lavoro di ufficio. Per insegnarli queste cose suddividiamo ogni grande azione come per esempio lavarsi i denti in molte piccole azioni che Enea deve memorizzare. Per esempio, per lavarsi i denti, deve prendere lo spazzolino, mettere il dentifricio spazzolarsi i denti per un certo periodo di tempo, poi pulire lo spazzolino e sciacquarsi la bocca. Vedi per lui ricordarsi di tutte queste azioni una dopo l'altra non è così immediato e quindi la ripetizione e memorizzazione in piccoli passi lo aiuta molto.

ET: *We try to make Enea independent in his daily life. The activities that my colleague and I carry out with him range from teaching him how to take care of his personal hygiene, or how to prepare breakfast on his own, or how to do shopping and paperwork. To teach him these things we divide every action such as brushing the teeth into many small actions that Enea needs to memorize. For example, to brush his teeth, he has to take the toothbrush, put the toothpaste brush in his teeth for a certain period of time, then clean the toothbrush and rinse his mouth. For him to remember all these actions one after the other is not so immediate and therefore repetition and memorization in small steps helps him a lot.*

AC: Molto interessante

AC: *Very interesting*

ET: Durante l'osservazione io e la mia collega to faremo esempi pratici per farti capire bene cosa ti consigliamo di fare e cosa non fare a seconda del comportamento di Enea.
ET: *During the observation, my colleague and I, will give you practical examples to make you understand well ABA, moreover we can give you some advises concerning what to do and what not to do depending on Enea's behavior.*

ET: Enea segue inoltre altri tipi di percorsi terapeutici, come arte terapia che fa da diversi anni e logopedia dove viene utilizzato il metodo prompt. Anche se Enea ha una limitata comunicazione verbale è importante che le parole che sa dire le dica pronunciandole bene e che si capisca il senso. Questo per esempio può essere importante in caso abbia bisogno di chiedere aiuto. Ti consiglio di osservare anche il loro lavoro perché' è molto interessante.
ET: *Furthermore, Enea also follows other types of therapeutic courses, such as art therapy which he has been doing for several years and speech therapy where the prompt method is used. Even if Enea has limited verbal communication, it is important to constantly train him to spell well the words that he can say. This for example can be very important in case he will need to ask for help. I recommend you also to observe this approach with him because it is very important for Enea's therapeutic path.*

AC: Grazie per la tue spiegazioni
AC: *Thank you for all the explanations*

Appendix 3.3.

Transcription and translation of an informal talk with Enea's mother

AC: Ciao, grazie per il tempo che mi stai dedicando

AC: *Hi, Thank you for your time and availability.*

EM: Figurati sono felice rispondere alle tue domande.

EM: *You are welcome, I am happy to help you and answer to your questions*

AC: Grazie, potresti raccontarmi brevemente la storia di Enea?

AC: *Thank you, could you tell me Enea's story?*

EM: Grazie, fino a due anni è stato un bambino molto vivace, parlava già molto all'età di due anni. Il momento in cui lui ha iniziato a manifestare i sintomi dell'autismo è stato dopo una persistente febbre molto alta durata quasi due settimane che gli è venuta dopo una vaccinazione. Da quel momento li i primi segni sono comparsi. Quando lo chiamavo non rispondeva e non reagiva, non giocava più come prima, non creava contatto visivo e la sua capacità di parlare è regredita a tal punto da quasi scomparire. All'età di due anni e mezzo gli è stata diagnosticato l'autismo. Per noi genitori non è stato facile, crescendo Enea ha iniziato ad avere sintomi sempre più forti e difficili da gestire. Per esempio, a casa tutti i cassetti dei mobili, le finestre, le porte dovevano essere contemporaneamente tutte aperte. Lo stesso valeva per gli ombrelli dentro casa e guai a noi s per sbaglio li spostavamo, iniziavano crisi di pianto e momenti molto difficili. Tutte le bottiglie contenenti qualsiasi liquido venivano svuotate, anche una intera bottiglia di acqua veniva svuotata su di un bicchiere.

EM: Thanks, Enea until he was two years old he used to be a very lively child, he was already talking fluently at the age of two. The moment when he started to experience the symptoms of autism was after a persistent and very high fever that lasted for almost two weeks, the fever came after a vaccination. From that moment on the first signs

appeared. When I called Enea, he did not answer and did not react, he no longer played as before, he did not create eye contact and his ability to speak regressed to the point of almost disappearing. At the age of two and a half he was diagnosed with autism. It was not easy for us parents, growing up Enea started to have increasingly strong and difficult to manage symptoms. For example, at home all the furniture drawers, the windows, the doors had to be all open at the same time. The same was true for the umbrellas inside the house and we woefully moved them, we started crying and very difficult moments. All bottles containing any liquid were emptied, even an entire bottle of water was emptied on a glass.

AC: Deve essere stato molto difficile vivere tutto questo. Ora come va?
AC: *It must have been very difficult to experience all this. Now how's it going?*

EM: Enea da quando segue la terapia ABA ha fatto molti progressi e i momenti di forte agitazione e dolore sono via via scomparsi. Lavora si impegna e trae molta soddisfazione da ciò che fa quotidianamente.
EM: *Since he started to follow ABA therapy, Enea has made a lot of progress and the moments of strong agitation and pain have gradually disappeared. He works hard and gets a lot of satisfaction from what he does daily.*

AC: Quali sono le abilita e attitudini di Enea?
AC: *What are Enea's skills and personal abilities?*

EM: E' una persona molto creativa è molto bravo a dipingere e gli piace tanto. E' uno sportivo, fa arrampicata, canoa di solito facciamo lunghe camminate veloci insieme e nuota benissimo. Forse è una delle attività che ama di più.
EM: *He is a very creative person, he is very good at painting and he likes it very much. He is a sportsman, he does climbing, canoeing we usually do long brisk walks together and he swim very well. Maybe swimming is one of the activities he loves most.*

Appendix 3.4.

Transcription and translation of an informal talk with Enea's art therapist

AC: Grazie per avermi permesso di assistere a questa sessione di arte terapia con Enea.

AC: *Thank you for allowing me to attend this art therapy session with Enea.*

AT: Prego, sono molto interessata alla tua ricerca

AT: *It is my please, I am very interested in your research*

AC: Da quanto tempo fai arte terapia con Enea?

AC: *How long have you been doing art therapy with Enea?*

AT: Io conosco Enea da quando aveva 11 anni, ho sviluppato anche la mia tesi di arte terapia basandomi sul lavoro fatto con Enea. All'inizio lui dipingeva tutto nero, e praticamente si dipingeva tutto, i suoi genitori dovevano pulirlo da testa a piedi quando tornava a casa. Con il tempo abbiamo fatto molti passi da gigante insieme. Ci siamo avvicinato alla pittura più figurativa, e quando a scuola studiava storia dell'arte noi provavamo a riprodurre un quadro dell'artista o del periodo storico che stavano studiando. Ora Enea si rifiuta di fare pittura figurativa e fa solo quadri astratti con pennello e spatola.

AT: *I have known Enea since he was 11 years old, I also developed my art therapy thesis based on the work done with Enea. In the beginning, he painted everything black, and practically everything was painted, his parents had to clean it from head to toe when he returned home. Over time we have made great strides together. We approached more figurative painting, and when he studied art history at school we tried to reproduce a picture of the artist or the historical period they were studying. Now Aeneas refuses to do figurative painting and only makes abstract paintings with a brush and spatula.*

AC: Che tipo di colori e tecniche utilizzate?

AC: *What kind of colors and techniques do you use?*

AT: Generalmente, tempera e acrilico.

AT: *Generally, tempera and acrylic.*

AC: Vedo che Enea è molto calmo, lo è sempre durante arte terapia?

AC: *I see that Enea is very calm, is he always calm during art therapy?*

AT: Ad Enea piace tantissimo dipingere, normalmente è sempre calmo felice, ora devo aiutare Enea a prepararsi e a lavare i pennelli.

AT: *Enea really likes to paint, normally he is always calm and happy, now I have to help Enea to prepare and wash the brushes.*

AC: Grazie il tempo che mia hai dedicato

AC: *Thank you for your time*

Enea’s latest artwork, made during art therapy

Examples of Enea’s previous artworks

Examples of Enea’s previous artworks

Enea’s painting his hands

Enea’s finished artwork. Work done in an hour

Appendix 4.1.

The National Autistic Society certificate

Appendix 4.2.

ABA Chart

ABC Behaviour chart

This ABC chart can be used to record behavioural concerns.

- 'A' stands for **antecedents**, that is, what happens immediately before the behavioural outburst and can include any triggers, signs of distress or environmental information.
- 'B' refers to the **behaviour** itself and is a description of what actually happened during the outburst or what the behaviour 'looked' like.
- 'C' refers to the **consequences** of the behaviour, or what happened immediately after the behaviour and can include information about other people's responses to the behaviour and the eventual outcome for the person.

It can also be a good idea to keep track of where and when the behaviour occurred to help in identifying any patterns. There are some filled in examples from page 2.

Day, date and time	Antecedent	Behaviour	Consequence	Notes

National Autistic Society
Last reviewed 8 March 2016

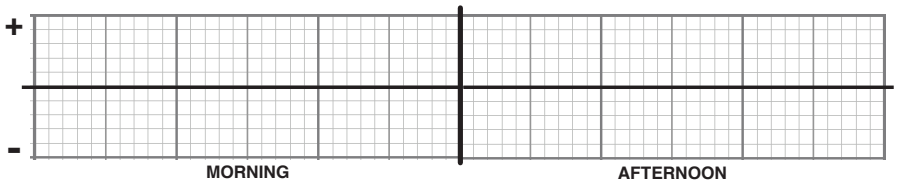
Appendix 4.3.

My personal elaboration of the ABA Chart

MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.

Date



Notes:

Antecedent	**Behaviour**	**Strategies**

Appendix 4.4

My personal elaboration to track Enea's emotions and behaviours

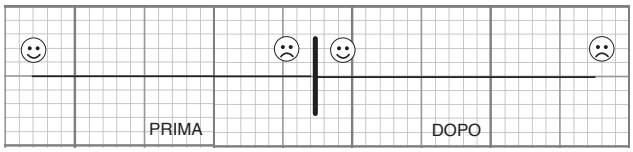
TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

Per qualsiasi domanda non esitate a contattarmi personalmente, o via email **alessia.cadamuro@open.ac.uk**

Data

Aggiungi informazioni



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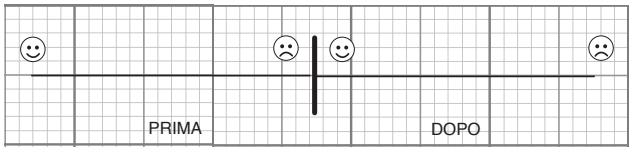

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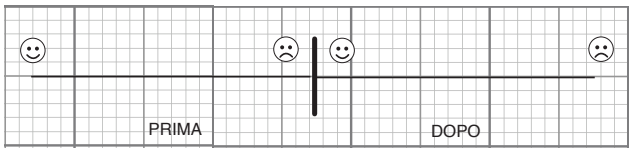

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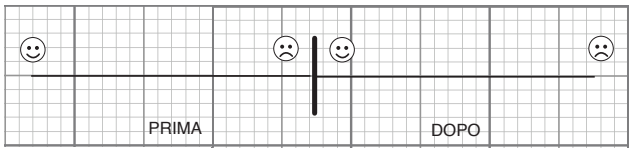

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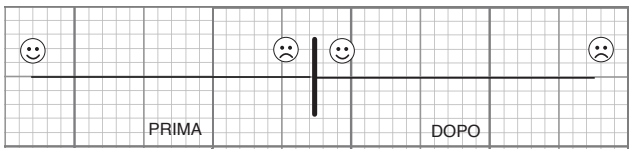

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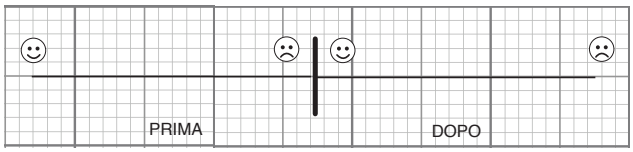

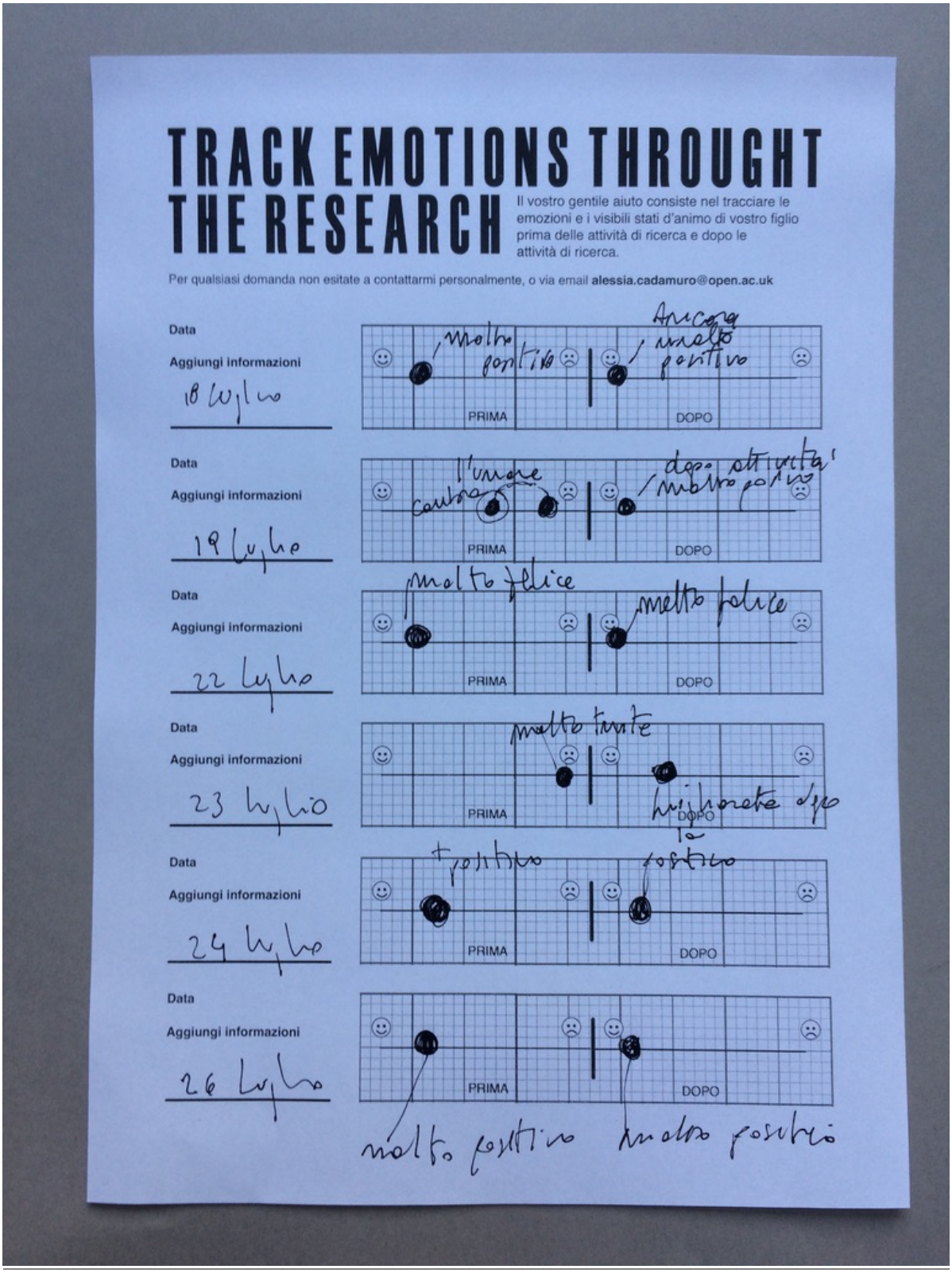

TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

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Data

Aggiungi informazioni

18 Luglio

molto positivo

Ancora molto positivo

PRIMA

DOPO

Data

Aggiungi informazioni

19 Luglio

l'umore contro

dopo attività molto positivo

PRIMA

DOPO

Data

Aggiungi informazioni

22 Luglio

molto felice

molto felice

PRIMA

DOPO

Data

Aggiungi informazioni

23 luglio

molto triste

PRIMA

DOPO

Data

Aggiungi informazioni

24 Luglio

+ positivo

positivo

PRIMA

DOPO

Data

Aggiungi informazioni

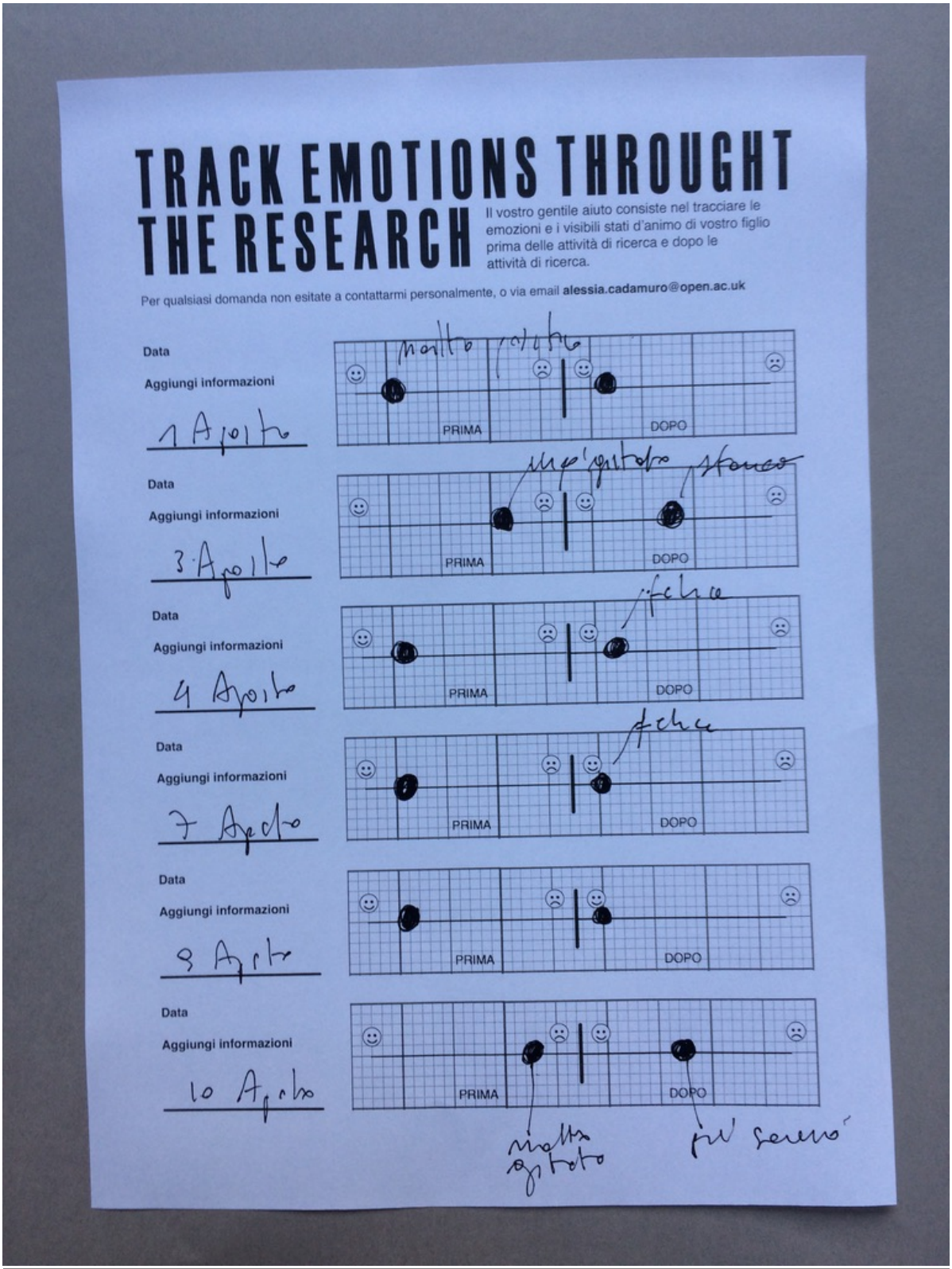
26 Luglio

PRIMA

DOPO

molto positivo

molto positivo



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Data

Aggiungi informazioni

1 Agosto

PRIMA DOPO

molto rotolo

Data

Aggiungi informazioni

3 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

4 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

7 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

9 Agosto

PRIMA DOPO

Data

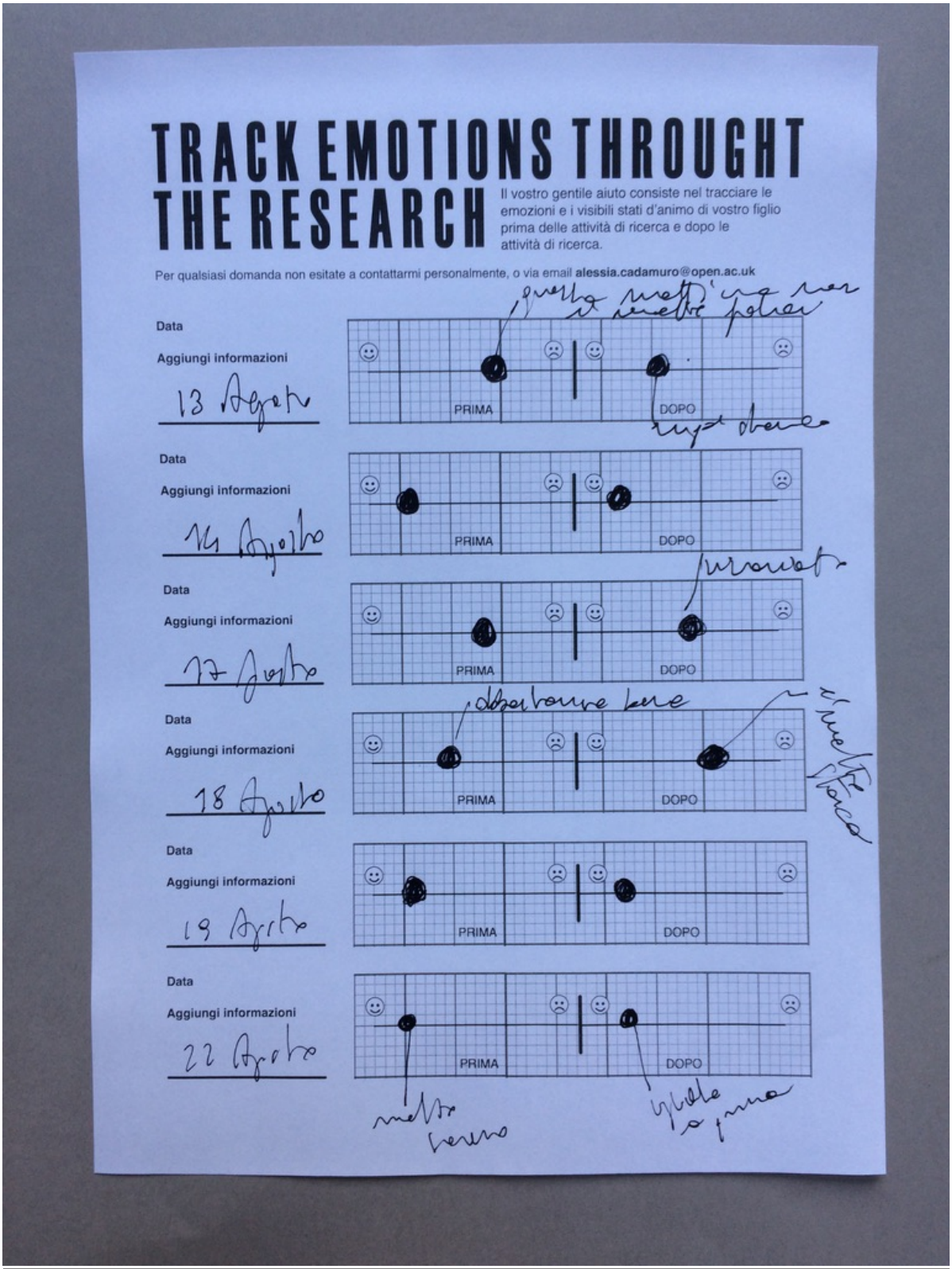
Aggiungi informazioni

10 Agosto

PRIMA DOPO

molto agitato

più sereno



TRACK EMOTIONS THROUGHT THE RESEARCH

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Data

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13 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

14 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

17 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

18 Agosto

PRIMA DOPO

Data

Aggiungi informazioni

19 Agosto

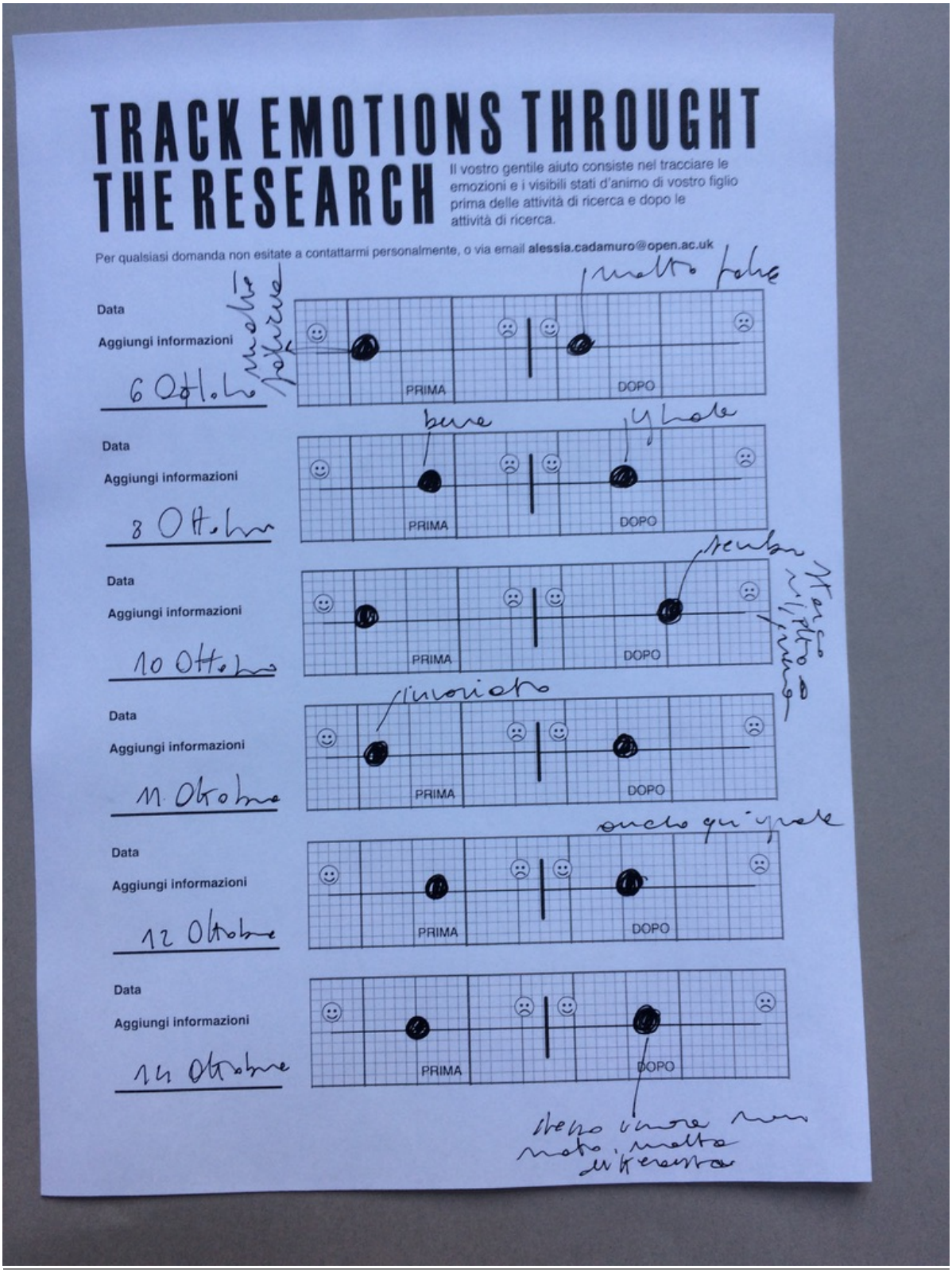
PRIMA DOPO

Data

Aggiungi informazioni

22 Agosto

PRIMA DOPO



TRACK EMOTIONS THROUGHT THE RESEARCH

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Data

Aggiungi informazioni

6 Ottobre

PRIMA DOPO

Data

Aggiungi informazioni

8 Ottobre

PRIMA DOPO

Data

Aggiungi informazioni

10 Ottobre

PRIMA DOPO

Data

Aggiungi informazioni

11 Ottobre

PRIMA DOPO

Data

Aggiungi informazioni

12 Ottobre

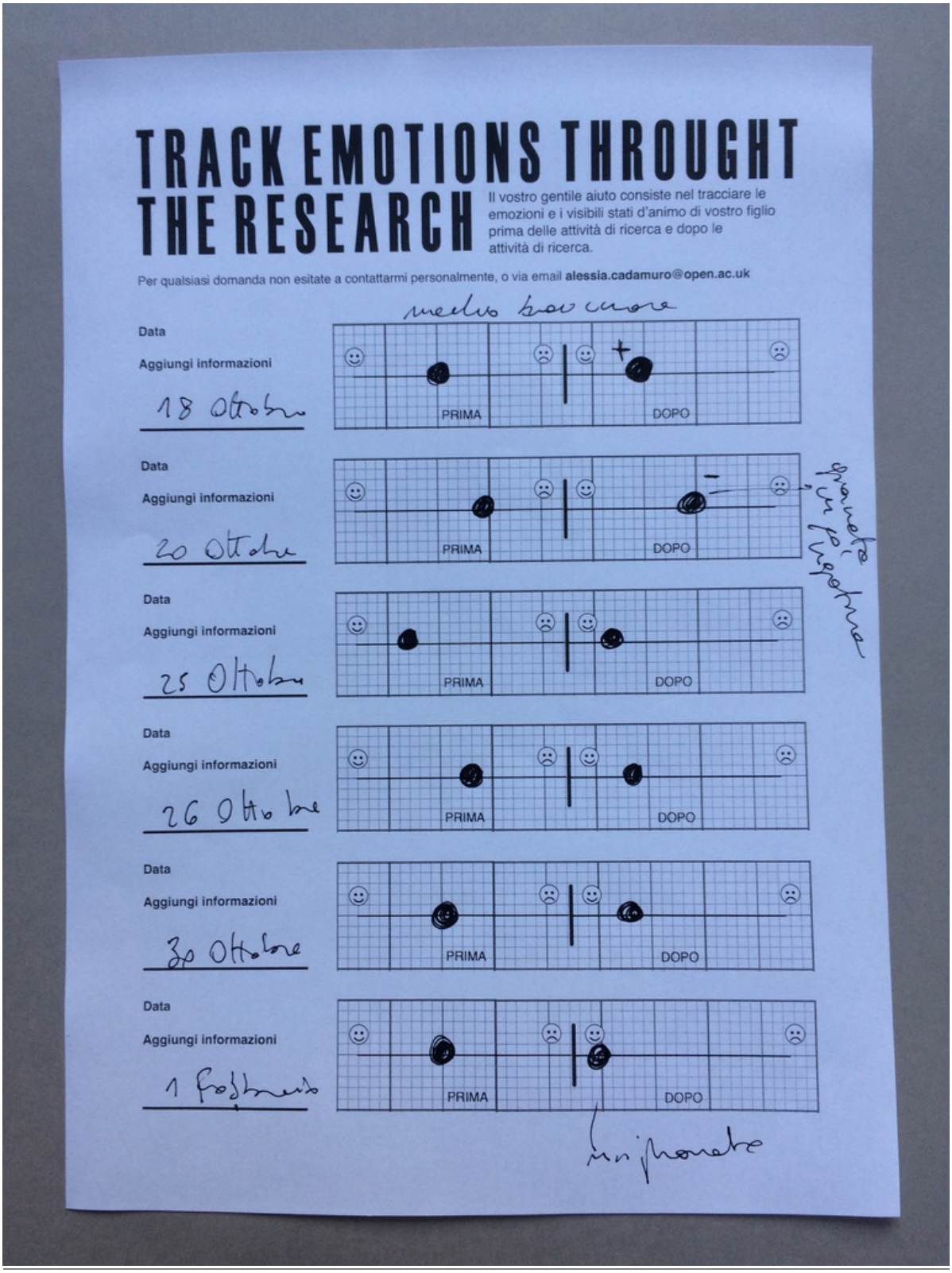
PRIMA DOPO

Data

Aggiungi informazioni

14 Ottobre

PRIMA DOPO



TRACK EMOTIONS THROUGHT THE RESEARCH

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Data

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18 Ottobre

Data

Aggiungi informazioni

20 Ottobre

Data

Aggiungi informazioni

25 Ottobre

Data

Aggiungi informazioni

26 Ottobre

Data

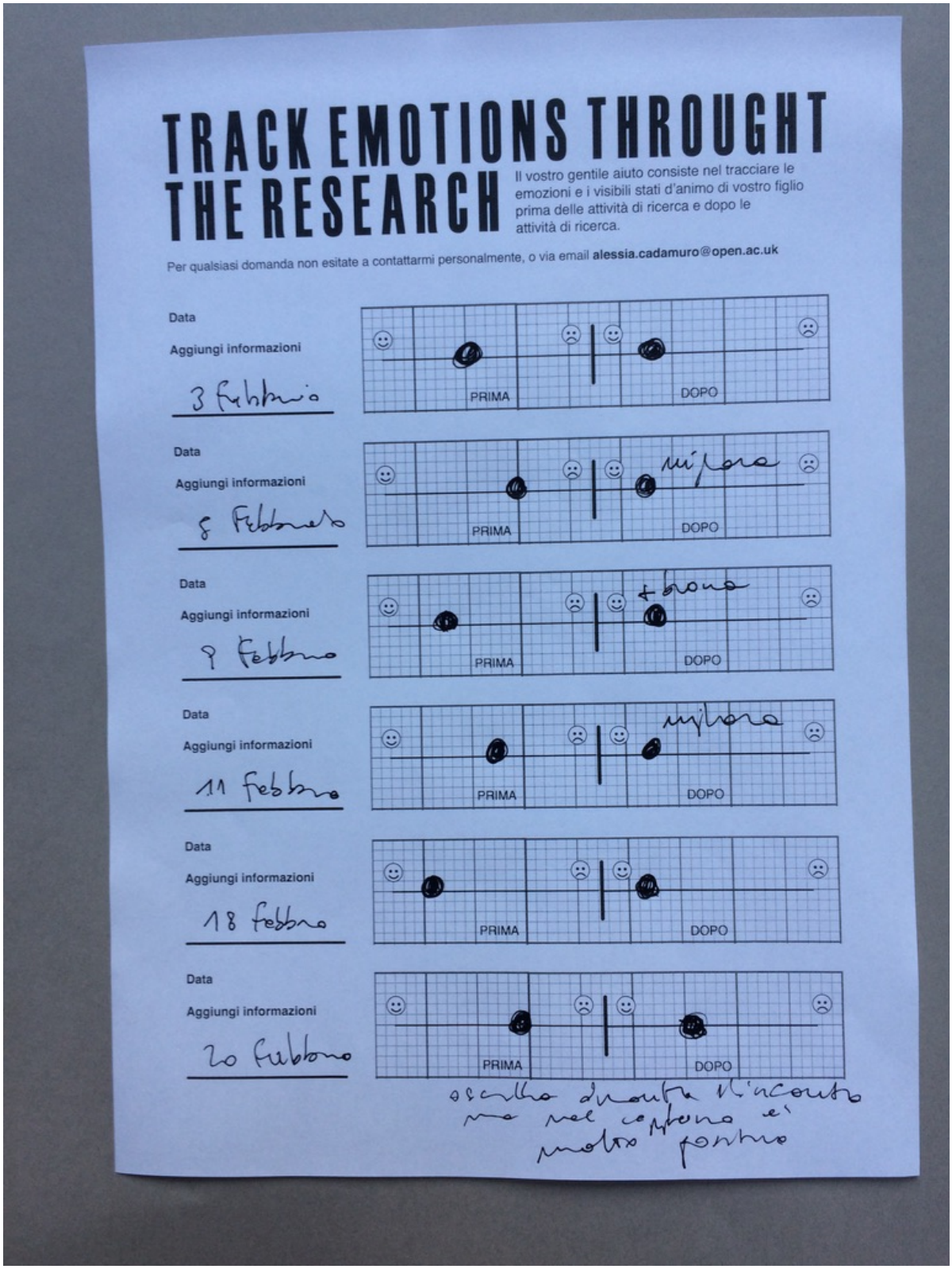
Aggiungi informazioni

30 Ottobre

Data

Aggiungi informazioni

1 Febbraio



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Data

Aggiungi informazioni

3 febbraio

PRIMA DOPO

Data

Aggiungi informazioni

5 Febbraio

PRIMA DOPO

migliora

Data

Aggiungi informazioni

9 Febbraio

PRIMA DOPO

+ buona

Data

Aggiungi informazioni

11 febbraio

PRIMA DOPO

migliora

Data

Aggiungi informazioni

18 febbraio

PRIMA DOPO

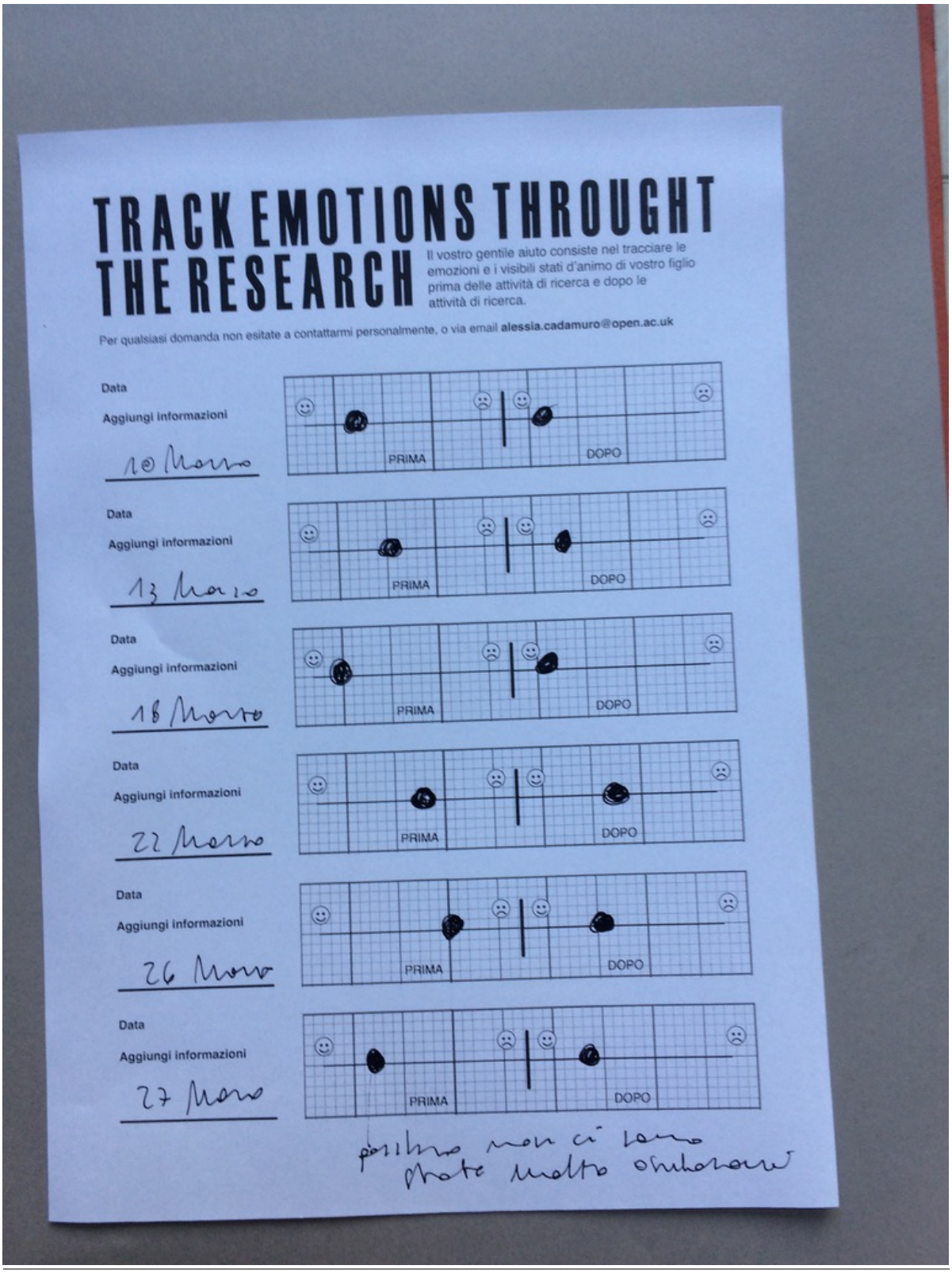
Data

Aggiungi informazioni

20 febbraio

PRIMA DOPO

oscilla durante l'incontro ma nel complesso è molto positivo



TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

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Data

Aggiungi informazioni

10 Marzo

PRIMA DOPO

Data

Aggiungi informazioni

13 Marzo

PRIMA DOPO

Data

Aggiungi informazioni

18 Marzo

PRIMA DOPO

Data

Aggiungi informazioni

22 Marzo

PRIMA DOPO

Data

Aggiungi informazioni

26 Marzo

PRIMA DOPO

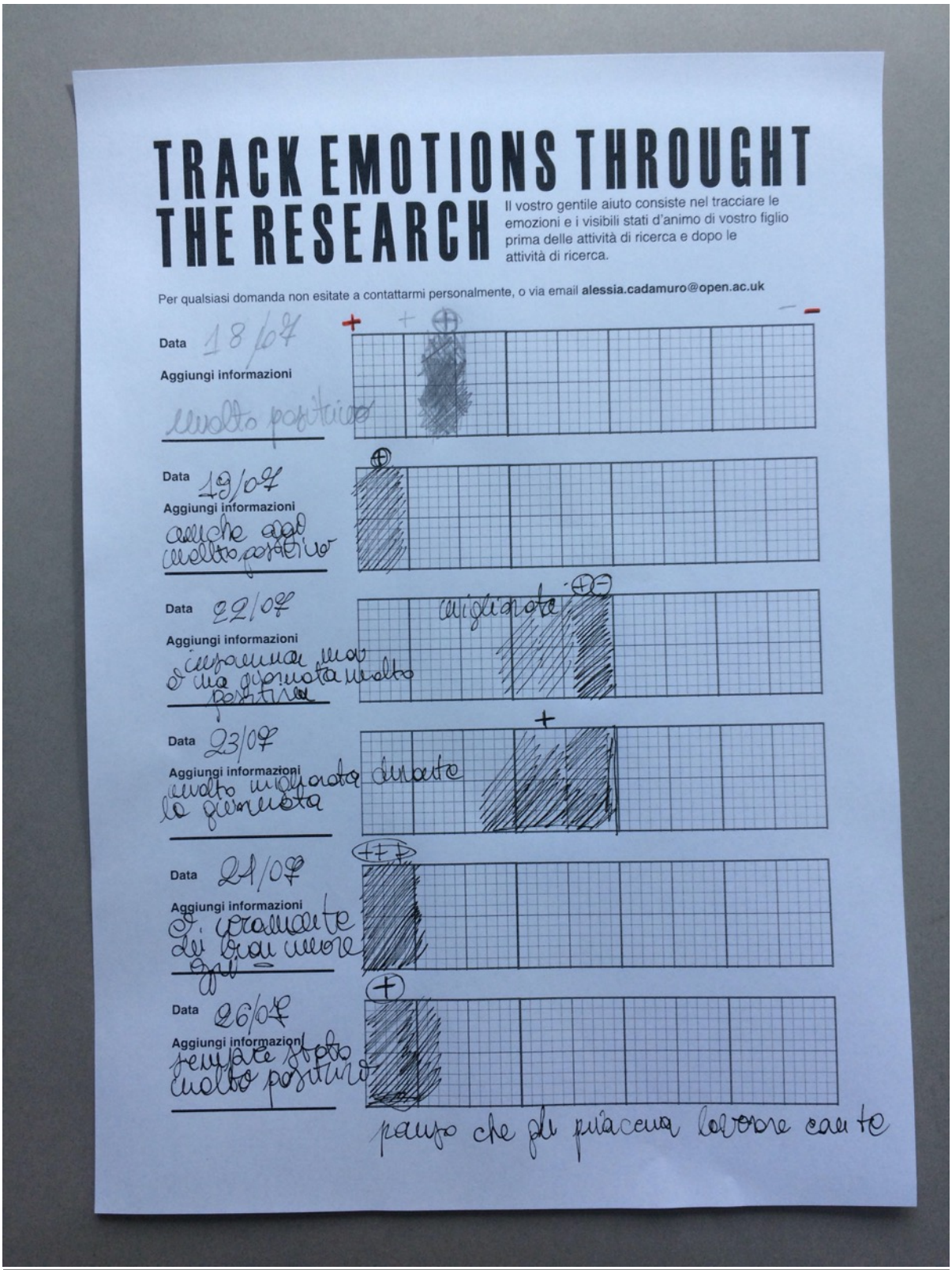
Data

Aggiungi informazioni

27 Marzo

PRIMA DOPO

possibile non ci sono state molto osservazioni



TRACK EMOTIONS THROUGHT THE RESEARCH

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Data 18/07
Aggiungi informazioni
molto positivo

Data 19/07
Aggiungi informazioni
anche oggi molto positivo

Data 22/07
Aggiungi informazioni
insomma ma è una giornata molto positiva

migliorata

Data 23/07
Aggiungi informazioni
molto migliorata durante la giornata

Data 24/07
Aggiungi informazioni
è veramente di buon umore gli

Data 26/07
Aggiungi informazioni
sempre stato molto positivo

penso che gli piaccia lavorare con te

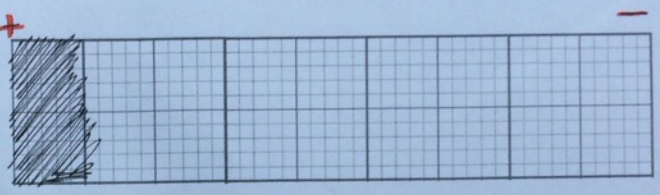
TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

Per qualsiasi domanda non esitate a contattarmi personalmente, o via email **alessia.cadamuro@open.ac.uk**

Data 7/08

Aggiungi informazioni
Come questa mostra, molto positivo



Data 9/08

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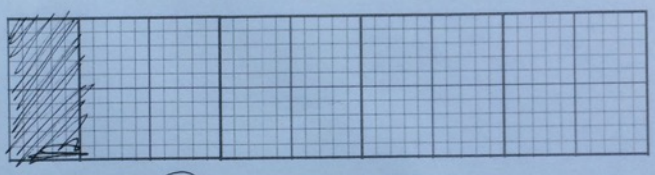
Molto positivo



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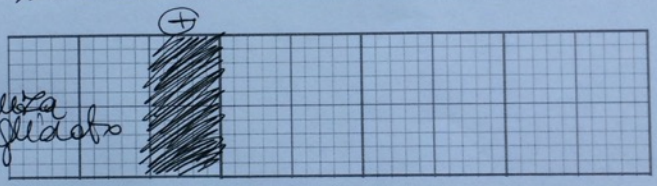

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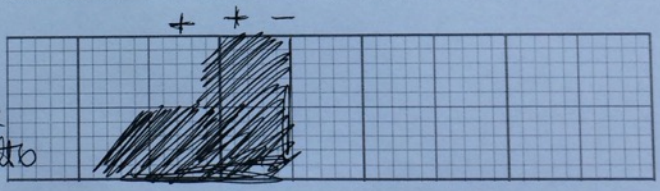
È migliorato dopo l'attività che avete fatto



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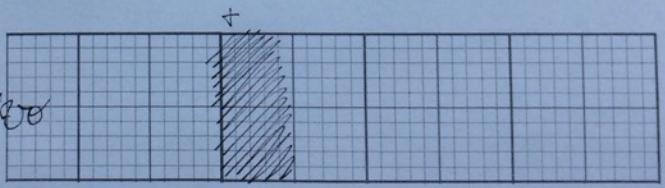

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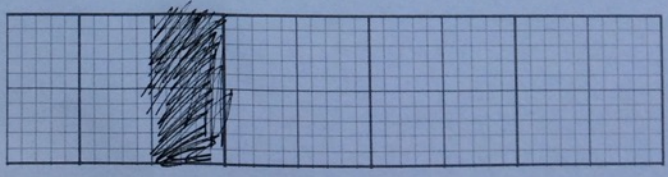
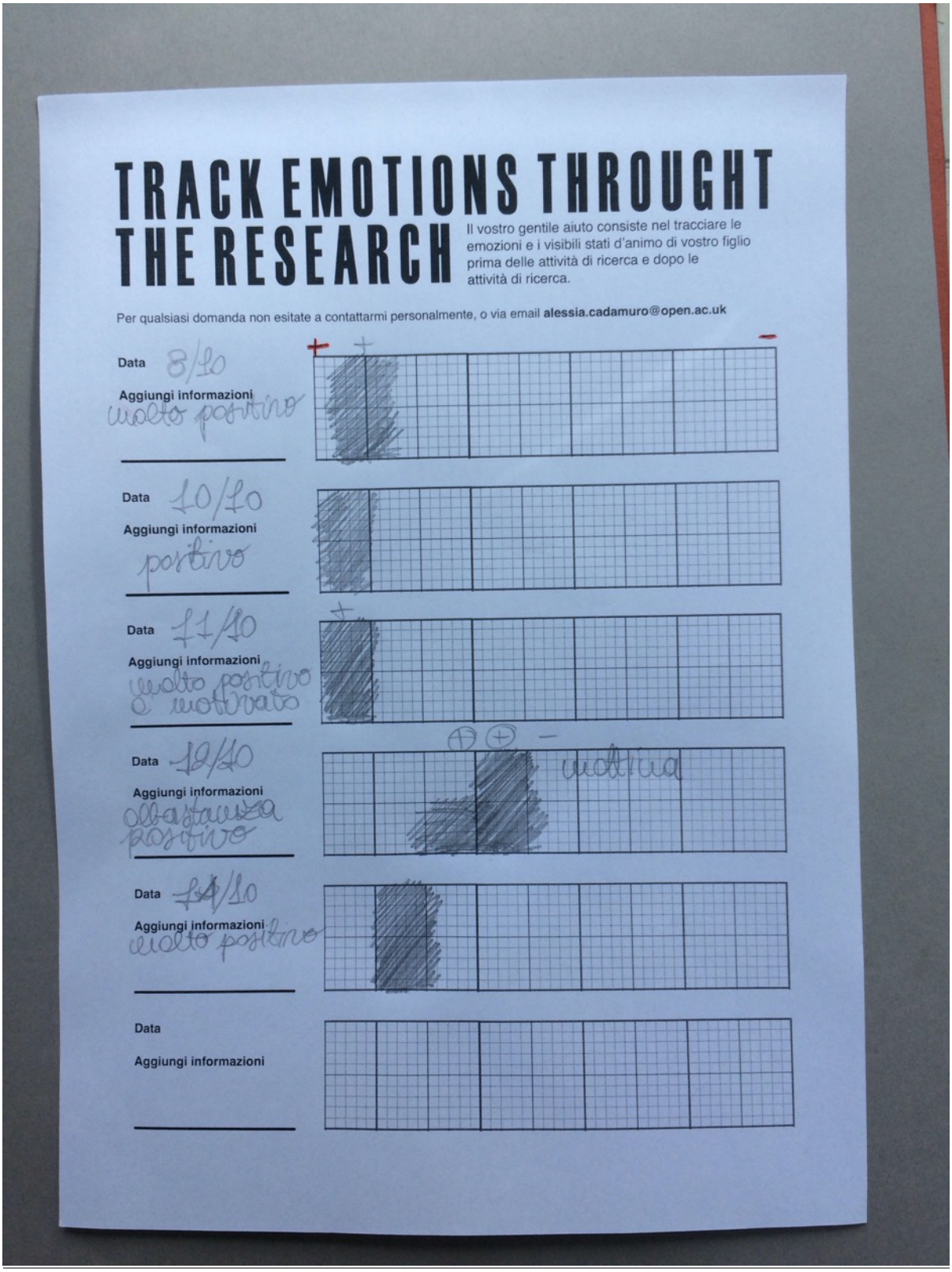
Sembra molto positivo





TRACK EMOTIONS THROUGHT THE RESEARCH

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Data 8/10

Aggiungi informazioni

molto positivo

Data 10/10

Aggiungi informazioni

positivo

Data 11/10

Aggiungi informazioni

molto positivo e motivato

Data 12/10

Aggiungi informazioni

abbastanza positivo

motiva

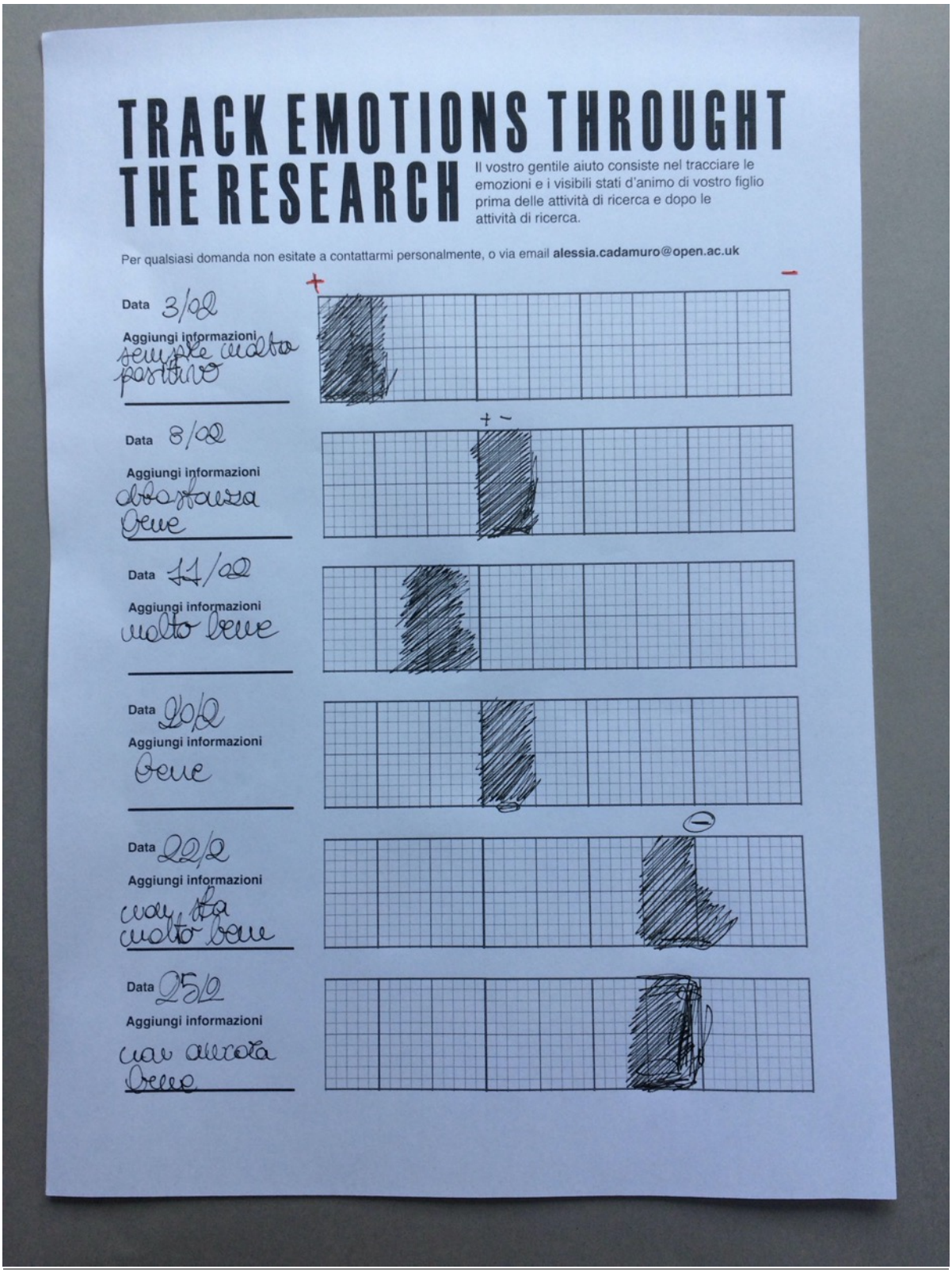
Data 14/10

Aggiungi informazioni

molto positivo

Data

Aggiungi informazioni



TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

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Data 3/22

Aggiungi informazioni sempre molto positivo

Data 8/22

Aggiungi informazioni abbastanza bene

Data 11/22

Aggiungi informazioni molto bene

Data 20/2

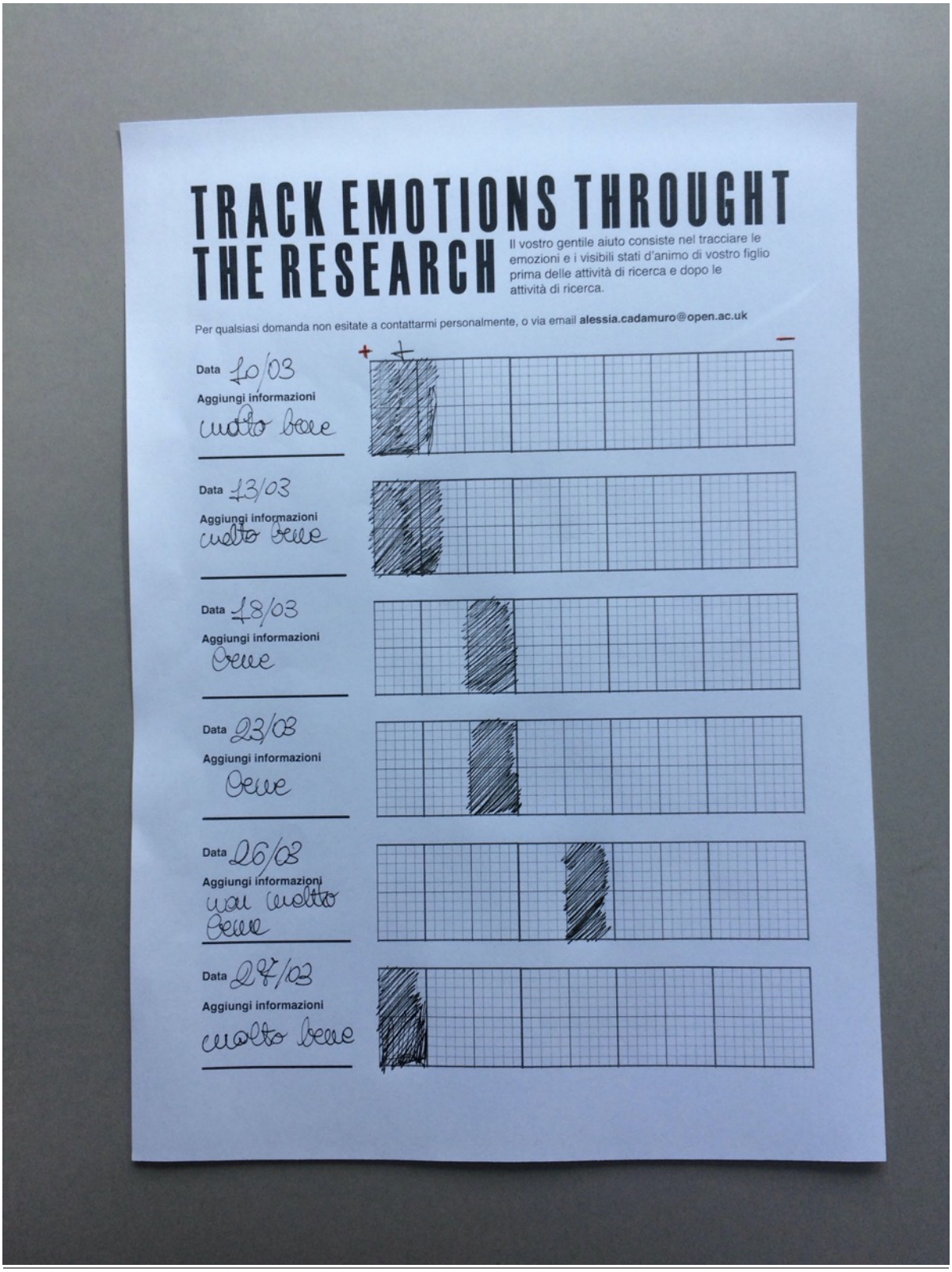
Aggiungi informazioni bene

Data 22/2

Aggiungi informazioni non tanto molto bene

Data 25/2

Aggiungi informazioni non ancora bene



TRACK EMOTIONS THROUGHT THE RESEARCH

Il vostro gentile aiuto consiste nel tracciare le emozioni e i visibili stati d'animo di vostro figlio prima delle attività di ricerca e dopo le attività di ricerca.

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+ = −

Data 10/03
Aggiungi informazioni
molto bene

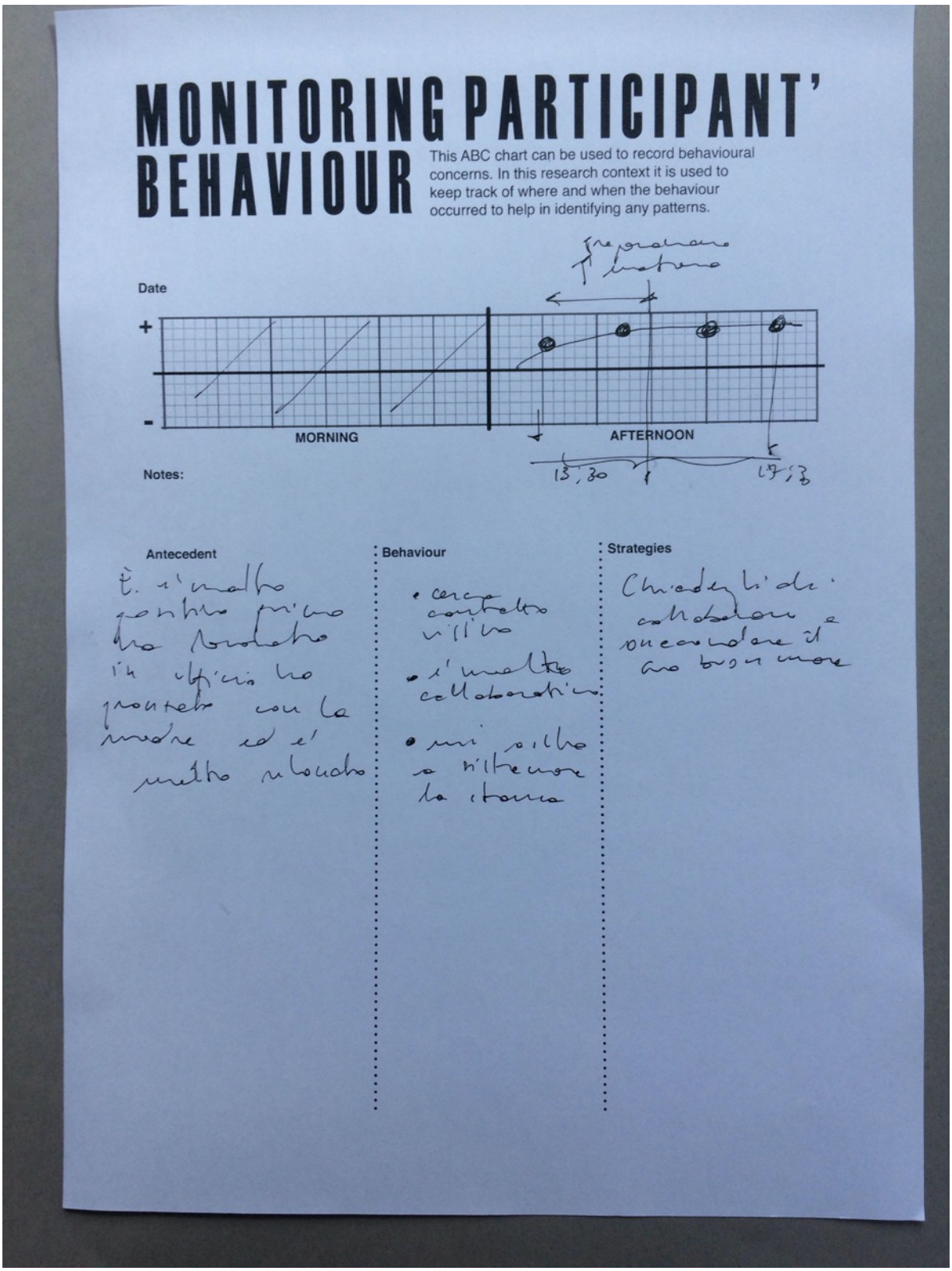
Data 13/03
Aggiungi informazioni
molto bene

Data 18/03
Aggiungi informazioni
bene

Data 23/03
Aggiungi informazioni
bene

Data 26/03
Aggiungi informazioni
non molto bene

Data 27/03
Aggiungi informazioni
molto bene



MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.

Date

Notes:

Antecedent

È. è molto positivo prima ha lavorato in ufficio ha pranzato con la madre ed è molto rilassato

Behaviour

- cerca contatto vicino
- è molto collaborativo
- mi aiuta a sistemare la stanza

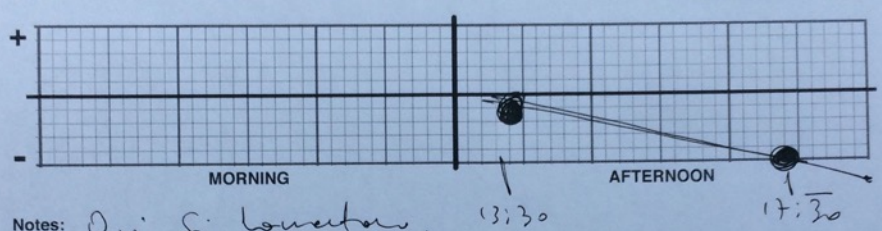
Strategies

Chiedergli di collaborare e incoraggiare il suo buon umore

MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.

Date



Notes: Oggi si lamentano gli IV mal di testa

Antecedent

Ho avuto ABA tranquilli ma forse si è dovuto sforzare troppo e sembra molto stanco

Behaviour

- evita il contatto visivo
- grida "No!" "No"
- si lamenta di aver mal di testa

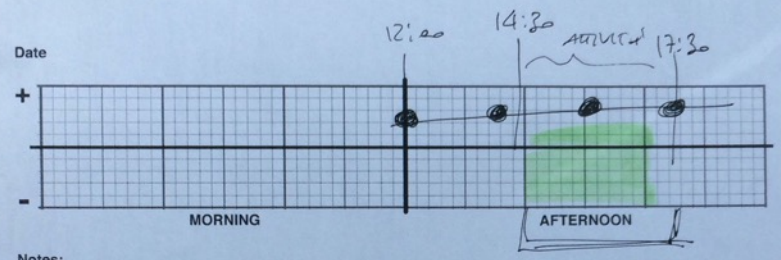
Strategies

- Preferisco non farli fare nessuna attività, ma ne approfitto per sistemare gli oggetti di ricerca da utilizzare la prossima volta.

Nel frattempo aspettiamo i suoi genitori che hanno un appuntamento nel frattempo

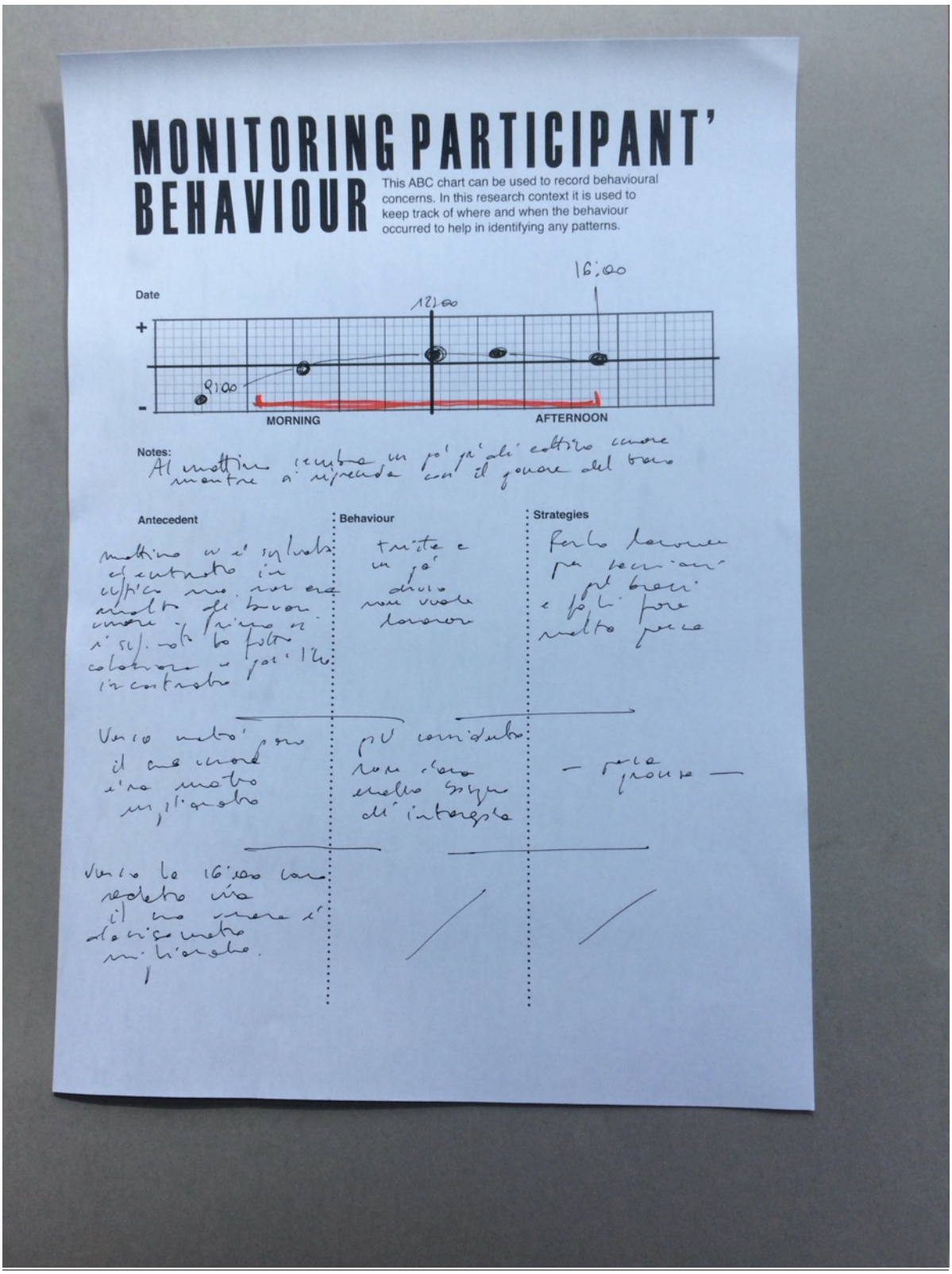
MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.



Notes:

Antecedent	Behaviour	Strategies
Pranzo insieme fino alle 14:30 non abbiamo lavorato ma siamo stati in sala. Al mattino lavora molto ABA e l'ho trovato lavoro di buon umore.	• molto somigliante • cerca contatto visivo • ride ad alta voce	Il lavoro è stato molto piacevole lui era molto collaborativo • Facciamo gara con un gelato chi colora verde il suo preferito



MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.

Date

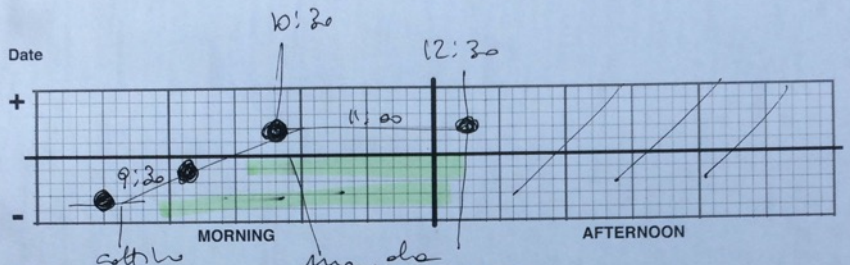
Notes:
Al mattino sembra un po' più di cattivo umore mentre si riprende con il gonfiore del tono

Antecedent	Behaviour	Strategies
mattino si è svegliato e entrato in ufficio ma non era molto di buon umore. Prima si è svegliato ha fatto colazione e poi l'ho incontrato	triste e un po' chiuso non vuole lavorare	Farlo lavorare per sessioni più brevi e fogli fare molto pausa
Verso metà pomo il suo umore era molto migliorato	più considerato non c'era molto bisogno di intervento	— pausa pranzo —
Verso le 16:00 sono andato via il suo umore è decisamente migliorato.	/	/

MONITORING PARTICIPANT' BEHAVIOUR

This ABC chart can be used to record behavioural concerns. In this research context it is used to keep track of where and when the behaviour occurred to help in identifying any patterns.

Date



Notes: cattivo umore

ma da quando siamo andati a fare la presa al bar sembra molto più felice.

Antecedent

Qualche mattina si è svegliato un fatto alla gia e è entrato in ufficio dove la coordinatrice non abbiamo detto molto ma lui è chiuso in se stesso è difficile stabilire un contatto

Behaviour

- poco contatto visivo
- non vuole sedersi e gira su se stesso
- ripeto una parola ma non la capisco

Strategies

- Attirare la sua attenzione chiedendomi di aiutarmi a preparare la stanza per l'attività.
- Coinvolgerlo nella attività con entusiasmo
- Farlo stare in piedi quando non ha voglia di ingiurie.

Appendix 5.1.

Transcription of the written communications developed with Enea (English translation)

AC: What do you think about the activities that we have done together?
E: Art for me is a safe territory

AC: Do you think we drew together or do you think we did something more?
E: Relationship between different people, I and you had to steal space from the work that we have done together.

AC: Do you like the tools that we tested?
E: I like them. Strong sign. With them I express my real emotions and magic expression. The brushes are beautiful. In my hand they guide my gesture. I paint my thoughts and I want to improve. New tools. Useful instrument for new expression.

AC: How would you describe the painting tools and research objects?
E: I call them Bionic fingers. These tools connect my thoughts and emotions. I'm. Really. Happy. to. Use. These instruments.

AC: You tried the “bionic fingers” during art therapy. What did you feel when you used those objects?
E: My fingers are very sensitive. The “Bionic fingers” guide my gesture. when I press them on paper and when I spread the color.

AC: Do you have something to suggest or tell me in particular?
E: Thank you

AC: What would you like this research to tell about you?
E: My world. World of Autism.

AC: Do you want to say something to Alessia that she can add in the final thesis?
E: I am happy to be the subject of this research, and I am happy to be of help for other friends that are like me

AC: Enea I want to thank you for your availability. What do you think about your experience in working with me?
E: You are gentle, polite and intelligent. I have felt joy when I worked with you

AC: What do you expect from our collaboration?
E: Friendship.

AC: Do you have something to say about our collaboration for this project? Was it a good experience?
E: I felt good. I like doing experiments with Alessia. She respects my times. She observes my world.

Appendix 5.2.

Transcription of the written communications developed with Enea

16 Maggio 2017

P: è arrivata alessia…desideri dirle qualcosa?

E: Non sei stanca di vedermi?

AC: no assolutamente…va bene per te se lavoriamo assieme?

E: esserti utile vogli.

AC: grazie…

AC: vorrei sapere come vivi la tua vita senza l'interferenza dell'altr

E: Potente. Io vivo due realtà diverse…rompo la mia per essere come voi io sono un arcobaleno di snsazioni diverse emozioni dolci e dolorose, cammino sulle punte. Riesco poco a essere come voi.

P: qualcosa da dire alla alessia…

E: impara a scrivere con me.

AC: mi piacerebbe tanto! ci sono altri modi in cui possiamo comunicare?

E: Empatia riesce sempre bene.

AC: il disegno potrebbe essere un buon metodo?

E: Importante nella mia vita parlare tramite il colore.

21 Novembre 2017

AC: volevo ringraziarti per la tua disponibilità come ti sei trovato a lavorare con me?

E: Sei dolce educata e intelligente io gioia ho provato a lavorare con te.

AC: cosa pensi delle attività che abbiamo svolto?

E: Sicurezza l'arte per me
AC: pensi che abbiamo disegnato o abbiamo fatto qualcosa in più?

E: Rotture di balle non conosco mi piace tanto lavori fatti con te.
Relazioni di diversi io e te rubiamo spazio al lavoro fatto

AC: cosa ti aspetti dalla nostra collaborazione?

E: Amicizia.

AC: Partecipare al progetto pensavi che potesse essere utile per altre persone?

E Assolutamente si. Penso che comunicare ilforme diverse molto necessario sia per tutti noi
Grazie
Fine

6 Aprile 2018

AC: Ti piacciono gli strumenti per l'arte terapia che la alessia ha creato per te?

E: Mi piacciono. Segno deciso. Esprimo emozioni. Vere. Magica espressione. Pennelli. Belli. Nella mia mano guidano. Il gesto. I pensieri dipingo. Devo migliorare. Strumenti nuovi. Utile prova. Di espressione.

AC: Come descriveresti questi strumenti per pitturare?

E: Dita bioniche. Collegano pensieri e Emozioni. Sono. Veramente. Contento. Di. Usare. Questi. Strumenti.

29 APRILE 2018

AC: Hai provato le dita bioniche per pitturare dalla laura. cosa sentivi usandole?

E: Sensibili mie dita. Dita bioniche. Guidano il gesto. Quanto premo su foglio. Come stendo il colore.

AC: Hai qualcosa da dire della collaborazione con alessia per questo progetto? ti sei trovato bene?

E: Mi sono trovato bene. Esperimenti con Alessia mi piace fare. Rispetta miei tempi. Osserva mio mondo

AC: Hai qualcosa da suggerire o dirmi in particolare?

E: Grazie

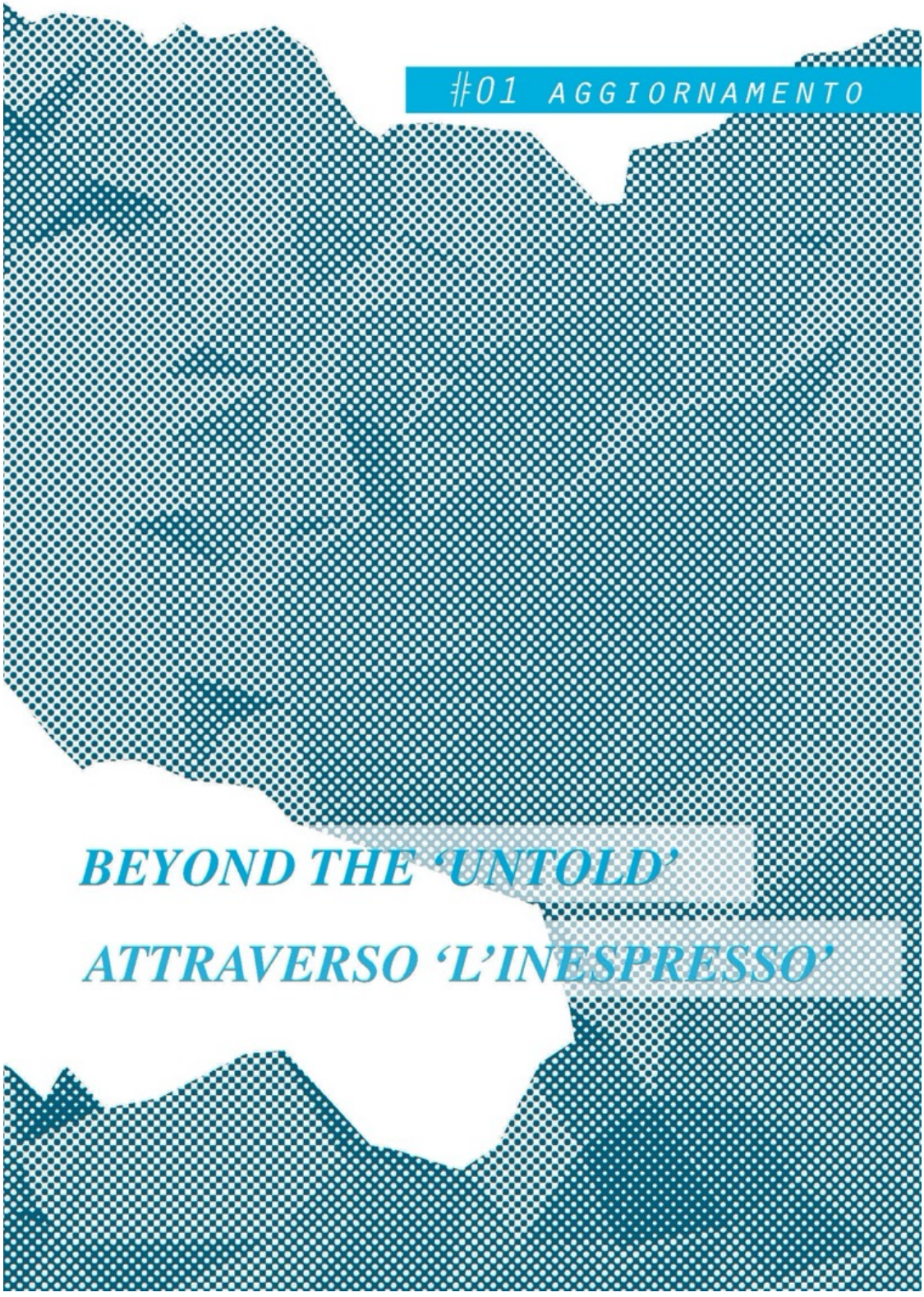
AC: Cosa vorresti che questa ricerca dicesse di te?

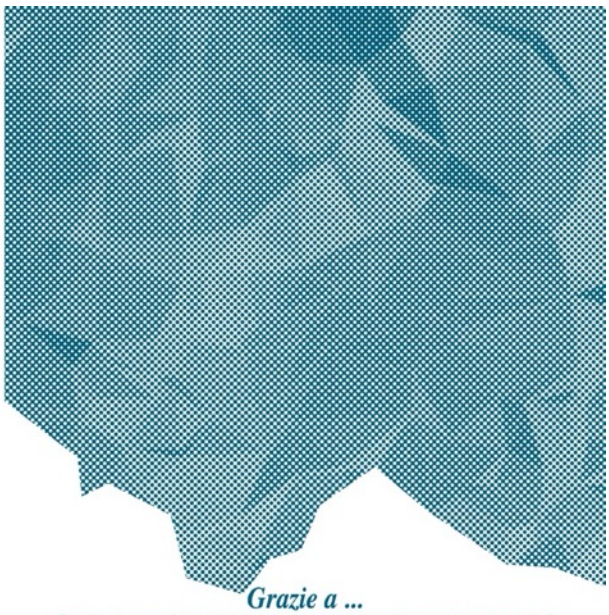
E: Mondo di Enea. Mondo di Autismo

AC: Vuoi dire qualcosa di te stesso che alessia possa aggiungere nella tesi finale?

E: Felice di essere oggetto di ricerca. Di aiuto per altri amici. Miei simili.

Appendix 6.1. (Booklet 1)


#01 AGGIORNAMENTO
BEYOND THE 'UNTOLD'
ATTRAVERSO 'L'INESPRESSO'



Grazie a ...

Grazie al partecipante a questa ricerca un giovane adulto che con il sorriso mi ha guidato a conoscere il suo autismo e a conoscere lui come persona. Sì, sto ringraziando proprio te A., senza il tuo prezioso aiuto questa ricerca non sarebbe stata possibile, te ne sono grata. Grazie ai tuoi genitori per la loro grande disponibilità, gentilezza, apertura e per avermi permesso di lavorare con te. Grazie ai tuoi terapeuti ABA, la tua arte terapeuta, logopedista e psicologa che sono stati gentilissimi e molto disponibili. Tramite loro ho imparato tantissimo, grazie per aver sempre risposto a tutte le mie domande e grazie per avermi permesso di prendere parte alle vostre attività.
Un grande grazie anche a tutte le persone che tramite te ho conosciuto dai tuoi familiari a tutte le persone che lavorano in fondazione, per aver accolto la mia presenza con generosità e disponibilità.

-Alessia Cadamuro-

Con questa breve nota si vuole dare un aggiornamento riguardo al lavoro svolto durante la ricerca. Il materiale realizzato durante l'investigazione verrà valutato e presentato all'interno della tesi, inclusa la rilevanza che questa ricerca coprirà nella disciplina legata al design partecipativo in relazione all'autismo.

Benvenuto in questa ricerca

Si ricorda che in questa tesi l'identità di tutte le persone coinvolte verrà tutelata, pertanto tutti i soggetti non saranno riconoscibili o rintracciabili. Tutti i dati verranno resi anonimi, incluse le informazioni riguardo al partecipante a questa ricerca, i suoi familiari, terapeuti e in generale tutte le persone che sono entrate in merito della ricerca. Anche i luoghi dove la ricerca si è svolta non verranno menzionati, inclusa l'associazione fondata dai genitori del partecipante e in generale i luoghi dove la ricerca si è svolta. Queste azioni sono volte non solo a proteggere l'identità delle persone coinvolte ma anche a preservare la loro tranquillità e dignità nel rispetto di tutte le norme etiche garantite dalla commissione etica della Open University.

Sono Alessia mi occupo di design partecipativo e nelle prossime pagine ti racconterò chi sono

Per proteggere l'identità del partecipante a questa ricerca, anche in questa piccola pubblicazione il suo nome verrà sostituito con A.

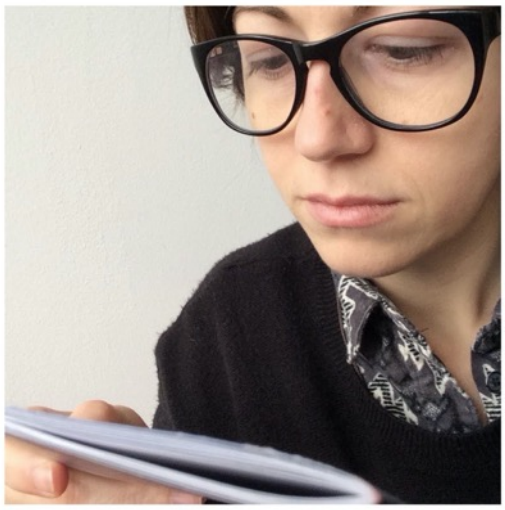
Chi sono...

Il titolo di questa tesi di dottorato è:

BEYOND THE 'UNTOLD': An exploration of the possibilities for inclusive design with adult on the autistic spectrum and limited speech abilities.

ATTRAVERSO 'L'INESPRESSO': Un'esplorazione delle possibilità di progettazione inclusiva con giovani adulti nello spettro autistico e capacità limitate di parola.

Sono una ricercatrice e designer, mi occupo principalmente di social design e sono interessata al design partecipativo.In passato ho lavorato e collaborato con molte persone con specializzazioni ed esperienza di vita molto differenti.
Credo che il design possa avere un impatto nella nostra societa e che possa contribuire ad apportare nuove conoscenze e una visione critica di cio che ci circonda. Questo nuovo modo di progettare porta con sè numerosi vantaggi sia per il progettista che per l'utente. In che modo? Prima di tutto vi è una maggiore possibilità per gli utenti di vivere, lavorare o rilassarsi in un ambiente che risponda meglio alle loro abitudini comportamentali, che sia congruo con i loro modelli sociali e culturali e che rispecchi i loro criteri estetici. Di conseguenza, questo, può contribuire a ridurre la percezione di stress, rendere l'ambiente più abitabile e incrementare la soddisfazione ambientale. D'altro canto anche per i progettisti i vantaggi sono numerosi: in primo luogo i risultati ottenuti attraverso la ricerca sociale possono essere utilizzati come linee-guida per progetti futuri al fine di migliorare sempre più la loro realizzazione. In secondo luogo, è possibile intensificare la comunicazione tra progettista e altri attori coinvolti e in ultimo viene offerto al progettista l'utilizzo di una prospettiva esterna al progetto, facilitando così la visione oggettiva del progetto in sè



Leggere e scrivere mi hanno sempre appassionato come attivita' l'attivita' riflessiva ed immersiva che la lettura e la scrittura richiediono mi hanno sempre aiutato.Leggere significa dapprima decodificare la sequenza di segni (lettura grafica), poi quella di parole (lessicale), poi di frasi (sintattica). Infine viene la comprensione del significato, ovvero spiegare e spiegarsi che cosa dice quel discorso, inteso in senso letterale, cioè semplice e aperto la lettura è attribuzione di senso. In ambito letterario, quest'ultimo non è non è automatico né univoco né uguale per tutti. È qualcosa di personale, nel senso di soggettivo e relativo. Qui però siamo già su un altro piano: la lettura è diventata interpretazione.

"Il designer ristabilisce oggi il contatto, da tempo perduto, tra arte e pubblico, tra arte intesa in senso vivo e pubblico vivo. Non più il quadro per il salotto ma l'elettrodomestico per la cucina. Non ci deve essere un'arte staccata dalla vita: cose belle da guardare e cose brutte da usare. Se quello che usiamo ogni giorno è fatto con arte (non a caso o a capriccio) non avremo niente da nascondere"

Munari (1966), Arte come mestiere.

Ascolto spesso la musica di molti generi differenti oppure acsolto audio libri e podcast

2. Amo ascoltare musica

Per conoscere A. e per capire come creare una cooperazione positiva con lui sono stati applicati dei metodi di ricerca che appartengono all'antropologia ed etnografia che vengono da tempo utilizzati anche da ricercatori nell'ambito del design. Questi metodi di ricerca conoscitivi ed esplorativi comprendono l'osservazione del partecipante alla ricerca nella sua quotidianità, allo scopo di conoscerlo. Queste osservazioni sono state annotate tramite l'utilizzo di diari. Nei diari sono state trascritte le attività svolte quotidianamente, i comportamenti osservati e le osservazioni riguardo l'interazione con il partecipante. In questo caso la designer ha seguito le attività quotidiane di A. con i terapisti ABA, il lavoro in ufficio, le attività di arte terapia, le attività di scrittura.
Durante questa osservazione durata due mesi molte informazioni utili al progetto sono state comprese:

- Come comunicare con A.
- Attitudini e abilità di A.
- Le attività preferite e rituali di A.
- Come organizzare le attività di Design Partecipativo

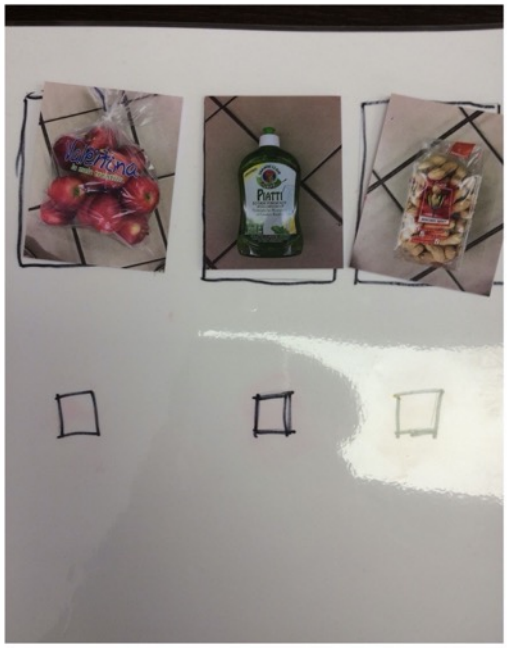
Il disegno e' sempre stata una mia grande passione. Disegno sempre quando ho un momento libero. Disegno cio' che vedi davanti a me, cio che immagino o semplicemente lascio andate la penna sul foglio bianco e mi porta spesso a raccontare visivamente una storia o una idea. La rappresentazione tramite il disegno non e' unicamente una forma d'arte per me ma e' anche uno approaccio comunicativo.

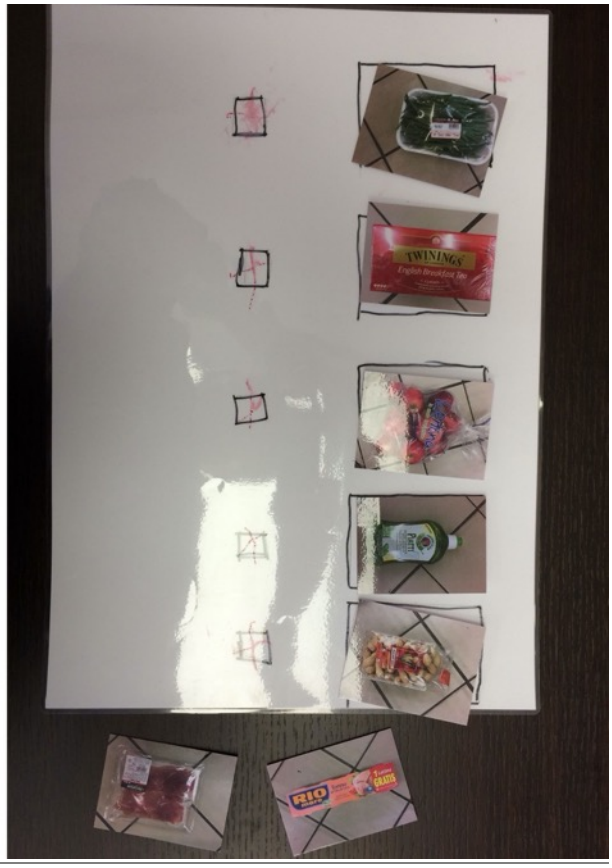
2. Le orchidee e le piante in genere mi piacciono molto.
Amo il profumo dei fiori e i colori straordinari che i petali hanno.

3. Amo camminare andare in montagna e fare lunghi cammini in giro per il mondo.

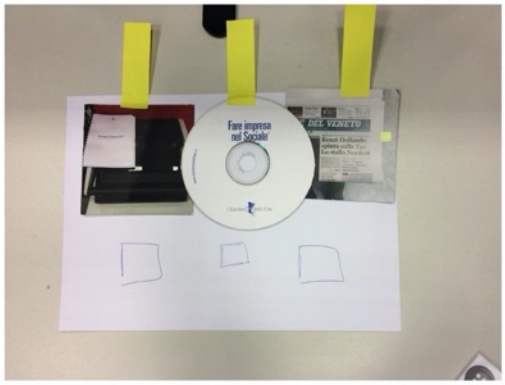
Cosa sto imparando

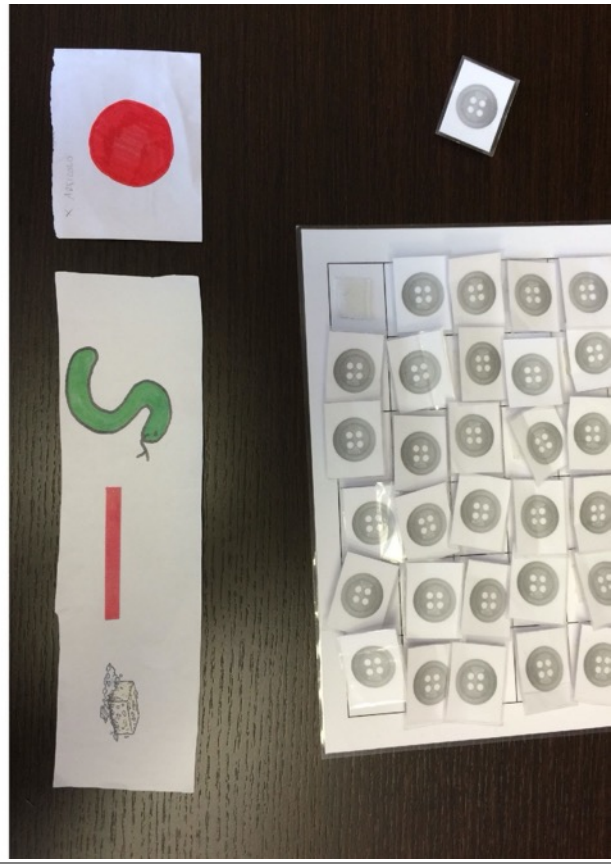
Terapia ABA





Ho iniziato ad osservare A.A nelle sue attivita' giornaliere, la terapia comportamentale ABA e le varie attivita' che essa prevede. Ho visto come si fa la spesa utilizzando una lista visiva dove foto che si possono cambiare a seconda delle esignenze, vengono attaccate con un velcro. Per tenere conto di quali bene sono stati gia' presi durante la spesa e messi nel carrello A. deve fare una croce rosso sui riquadri sotto alle foto degli oggetti.
Una volta segnate tutte le crocette A. sa che deve andare alla cassa, disporre i beni in modo tale che sia conteggiato il prezzo complessivo, pagare ed inserire i beni acquistati all'interno di una sacchetto. Per A tutta questa sequenza di azioni non e' semplice, ma sta imparando in fretta. Attualmente va a fare la spesa con un suo terapista ABA che lo accomplagna al supermercato, entrano insieme e poi aspetta A. vicino alle casse. A. sa che in qualsiasi momento di bisogno sa che puo' chiedere aiuto al suo terapeuta che lo aspetta in un posto preventivamente concordato con A. e che e' sempre lo stesso.

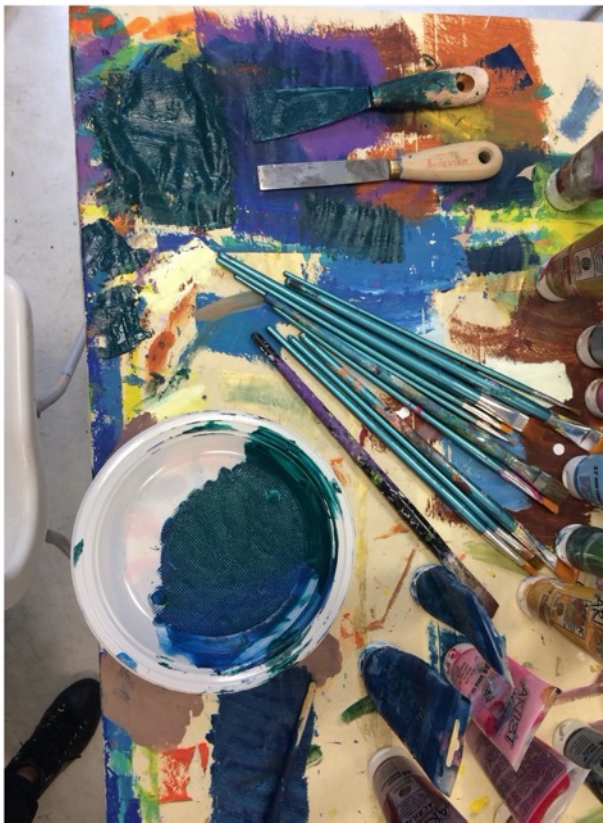




Cosa sto imparando

dall'arte terapia

L'Arteterapia consiste nella ricerca del benessere psicofisico attraverso l'espressione artistica dei pensieri, vissuti ed emozioni. Essa utilizza le potenzialità, che possiede ogni persona, di elaborare creativamente tutte quelle sensazioni che non si riescono a far emergere con le parole e nei contesti quotidiani. Per mezzo dell'azione creativa l'immagine interna diventa immagine esterna, visibile e condivisibile e comunica all'altro il proprio mondo interiore emotivo e cognitivo. Sin dalla preistoria c'è sempre stato nell'uomo il bisogno di rendere manifesto il proprio mondo interiore. L'individuo civilizzato, dotato di funzioni mentali più evolute (linguaggio, ragionamento astratto, per esempio) esprime sé stesso attraverso i concetti, le parole, i ragionamenti. Colui che invece non usa il linguaggio verbale, che ha difficoltà cognitive, relazionali, può esprimere sé stesso solo attraverso il movimento, i suoni, il colore, le forme, i disegni. Ecco perché è il mezzo di comunicazione maggiormente utilizzato dagli psicotici. Anzi, diciamo che l'Arteterapia è stata scoperta grazie a loro 'arte permette un'espressione diretta, immediata, spontanea, arcaica ed istintiva di noi stessi che non passa attraverso l'intelletto.
I materiali e le tecniche che il paziente utilizza gli permettono di esprimere, plasmare e dare una identità precisa al problema che l'ha portato in terapia; attraverso l'aiuto del terapeuta è possibile raggiungere una nuova visione di tale difficoltà, un'intuizione, un insight che lo avvicini alla risoluzione.
Infatti, nell'Arteterapia la produzione artistica non avviene in completa solitudine, è coinvolta anche una relazione tra due persone, il terapeuta e il paziente, e nell'ambito di tale alleanza, la propria creazione viene osservata e discussa, un po' come accade ai bambini quando mostrano il proprio disegno ai genitori, i quali, con affetto, chiedono a loro : "Oh...che cos'è?".
L'arteterapeuta deve saper accogliere, legittimare, amplificare i messaggi dell'altro con parole, disegni, proposte.

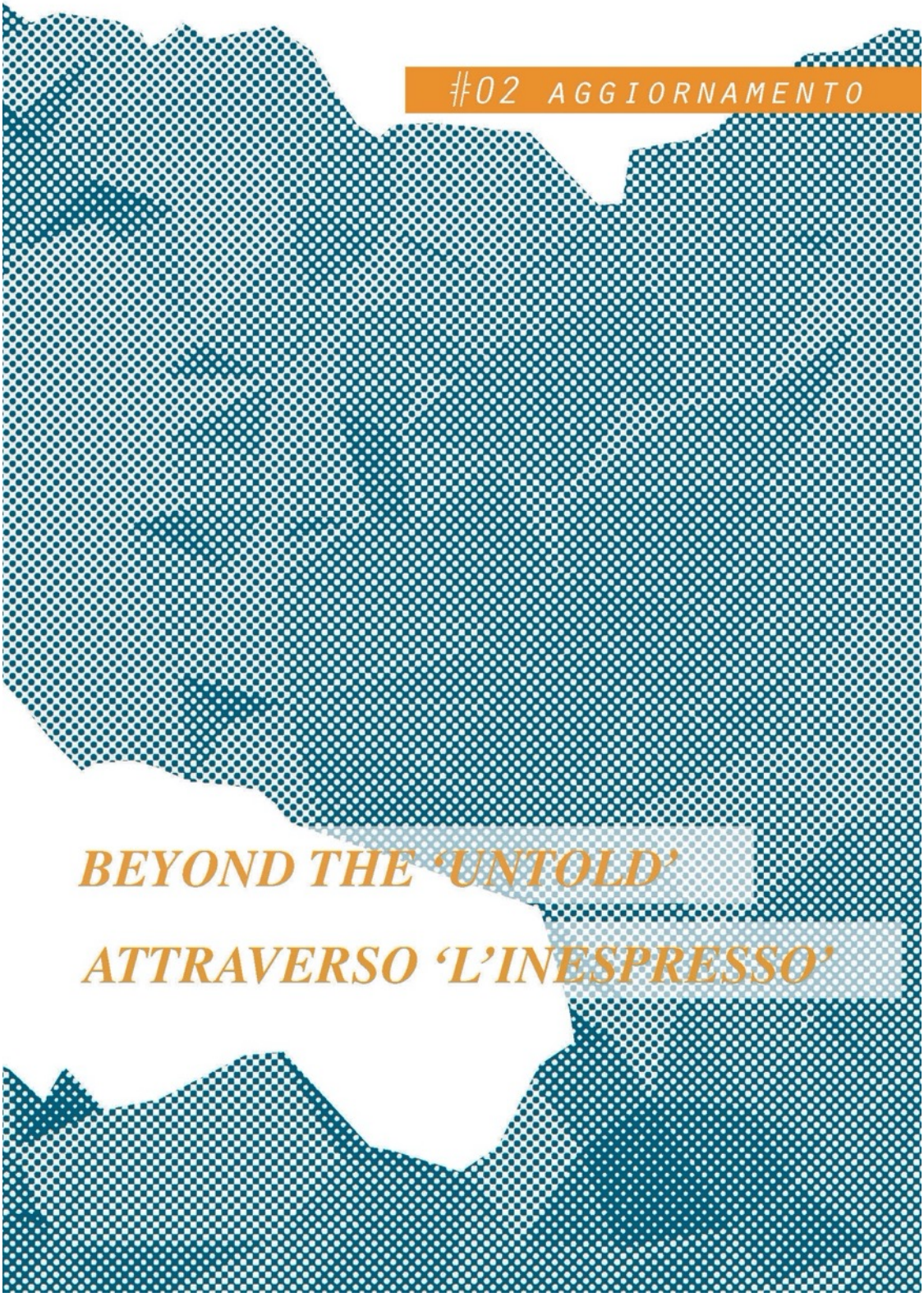


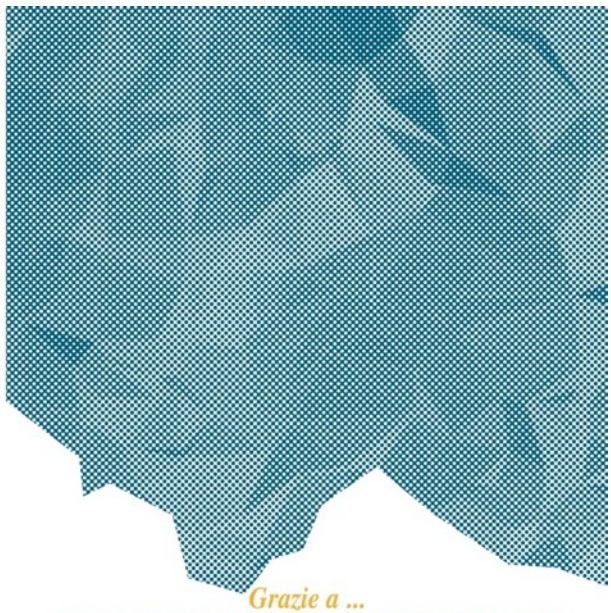
"Che avventura comincia quando si traccia la prima linea quando si stende il primo colore! Quanti rischi vi aspettano! In quali trappole si cadrà o meglio ci si bloccherà? Churchill, che era un cattivo pittore, diceva che dipingere un buon quadro era difficile come vincere una battaglia..." Sono le parole di Jonesco, grande autore di teatro che tardivamente cominciò a dipingere, prima in modo occasionale e poi via via sempre più intenso, accompagnando il proprio lavoro con un'attenta riflessione sul modo e le forme del dipingere.

Questo progetto è stato supportato e reso possibile da:

Grazie a Open University (UK) e alle supervisors Rachael Luck e Katerina Alexiou.
Grazie a Design Star per aver supportato e reso possibile questo dottorato di ricerca

Appendix 6.2. (Booklet 2)


#02 AGGIORNAMENTO
BEYOND THE 'UNTOLD'
ATTRAVERSO 'L'INESPRESSO'



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Benvenuto in questa ricerca

Per proteggere l'identità del partecipante a questa ricerca, anche in questa piccola pubblicazione il suo nome verrà sostituito con A.

Il titolo di questa tesi di dottorato è:

BEYOND THE 'UNTOLD': An exploration of the possibilities for inclusive design with adult on the autistic spectrum and limited speech abilities.

ATTRAVERSO 'L'INESPRESSO': Un'esplorazione delle possibilità di progettazione inclusiva con giovani adulti nello spettro autistico e capacità limitate di parola.

La Ricerca Azione Partecipata (in inglese PAR Partecipatory Action Research) "è un'indagine sistematica svolta in collaborazione con i soggetti coinvolti in un problema a scopi educativi o per un'azione volta al cambiamento" (Tilakaratna, 1990). La Ricerca Azione Partecipata è impiegata in diverse pratiche sociali finalizzate al cambiamento, soprattutto nell'ambito del lavoro di comunità. Obiettivi e funzioni della ricerca azione partecipata sono la conoscenza, l'apprendimento e, in particolare, il cambiamento. Si tratta di un tipo di indagine qualitativa propria delle scienze umane che può essere svolta in qualsiasi contesto ma che privilegia aree di intervento locali considerate marginali o svantaggiate (Orefice, 2006). La Ricerca Azione Partecipata può essere considerata come un momento fondamentale di un processo di cambiamento. Coincide con il processo di "presa di coscienza" da parte dei soggetti, protagonisti della comunità, delle loro condizioni, delle loro necessità, delle loro potenzialità, delle loro risorse, dei loro limiti, dei loro valori e dei loro desideri (Arcidiacono & Marta, 2008).
In questo processo chi è l'ideatore e il coordinatore dell'azione sociale non si considera esterno o distanziato dall'oggetto di ricerca, anzi, partecipa come gli altri e contribuisce anche attraverso la propria esperienza alla costruzione di un processo di narrazione dei vissuti ad un interlocutore (storytelling) (Cicognani, 2012) La Ricerca Azione Partecipata può essere considerata quindi un processo o un approccio più che un metodo: cerca di comprendere e migliorare il mondo per cambiarlo.Il suo obiettivo principale è l'interesse a un cambiamento sociale progressivo o una maggiore giustizia sociale. I partecipanti sono i primi beneficiari della conoscenza prodotta.

riduzione delle distanze

Occorre fornire stimoli culturali e concettuali in modo da riattivare interessi e motivazioni nei confronti della cultura cinematografica per approfondire in maniera creativa la reale importanza del dialogo, dell'analisi, del confronto, nonché della documentazione dei fatti e delle storie personali. Inoltre, la coscienza della forza dell'immagine come atto di conoscenza e di rappresentazione del mondo, può diventare uno strumento fondamentale nel processo di riappropriazione del territorio in cui si vive. L'atto di filmare offre la possibilità di elaborare un percorso alternativo a quello imposto dall'ambiente esterno.

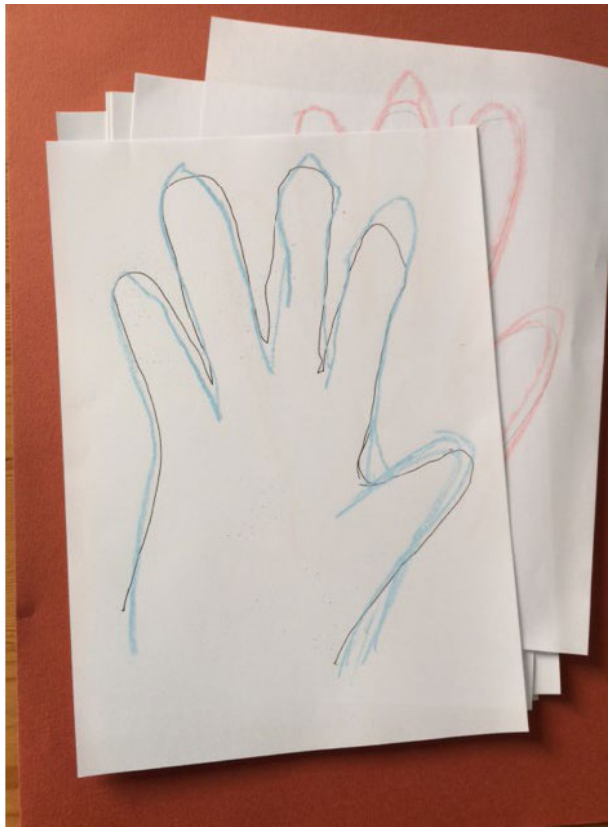
Per conoscere A. e per capire come creare una cooperazione positiva con lui sono stati applicati dei metodi di ricerca che appartengono all'antropologia ed etnografia che vengono da tempo utilizzati anche da ricercatori nell'ambito del design. Questi metodi di ricerca conoscitivi ed esplorativi comprendono l'osservazione del partecipante alla ricerca nella sua quotidianità, allo scopo di conoscerlo. Queste osservazioni sono state annotate tramite l'utilizzo di diari. Nei diari sono state trascritte le attività svolte quotidianamente, i comportamenti osservati e le osservazioni riguardo l'interazione con il partecipante. In questo caso la designer ha seguito le attività quotidiane di A. con i terapisti ABA, il lavoro in ufficio, le attività di arte terapia, le attività di scrittura.
Durante questa osservazione durata due mesi molte informazioni utili al progetto sono state comprese:

- Come comunicare con A.
- Attitudini e abilità di A.
- Le attività preferite e rituali di A.
- Come organizzare le attività di Design Partecipativo

Tipo di attivita' selezionate

Le attivita' che sono emerse essere particolarmete amate da A. sono l'arte terapia, quindi disegnare, dipingere. A. ha dimostrato di essere una persona creativa. Un'altra attivita' emersa e' la propensione e il piacere che A. prova nel strappare piccoli pezzettini di carta, foglie, e piccoli rametti di legno. A. utilizza molto le sue mani, sembra siano molto sensibili e utilizzate come sonde esplorative:

- Attivita' che richiedono di desegnare.
- Attivita' che richiedono di utilizzare la sensibilita' tattile.
- Le attività preferite e rituali di A.



Repetitive Behavior Scale-Revised RBS-R
Il Questionario RBS-R (Bodfish e al., 1999, 2000) permette di rilevare la frequenza e l'entità dei comportamenti ripetitivi nel bambino ASD. È composto da 43 item, valutati su una scala Likert a 4 punti che va da "comportamento assente = 0" a "comportamento sempre presente", per cui punteggi alti sono indicativi di comportamenti disfunzionali frequenti.

Gli item del RBS-R sono raggruppati in 6 sottoscale, che sono:

(a) Comportamento Stereotipato (movimenti senza scopo evidente che si ripetono sempre nello stesso modo);

(b) Comportamento
Autolesivo (azioni che causano o hanno il potenziale di causare arrossamenti, ecchimosi, o altre lesioni al corpo);

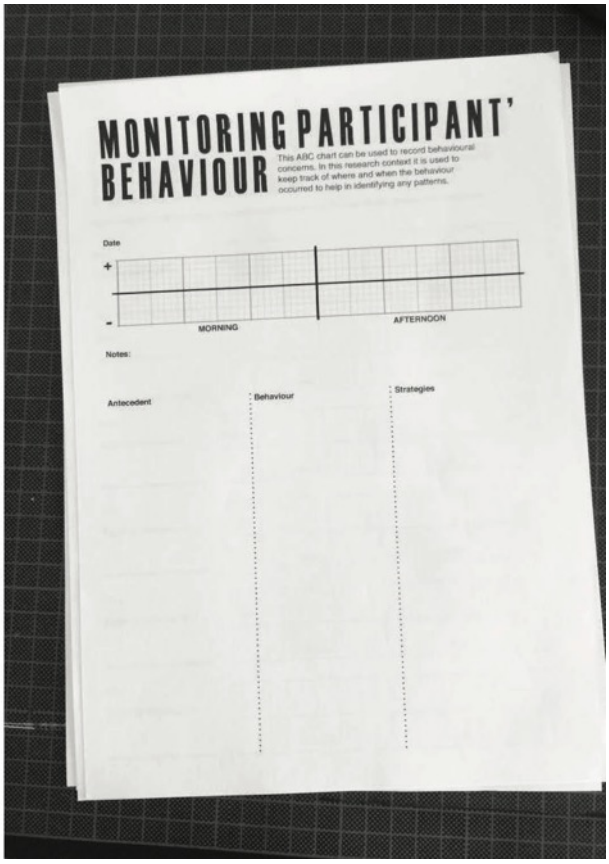
(c) Comportamento Compulsivo (comportamento che si ripete ed eseguito in maniera irrefrenabile);

(d) Comportamento Rituale (esecuzione di attività della vita quotidiana in maniera rigida e sempre uguale); (

e) Comportamento Monotono (comportamenti che evidenziano la resistenza al cambiamento); (f) Comportamento ristretto (interesse limitato a una ristretta gamma di attività).

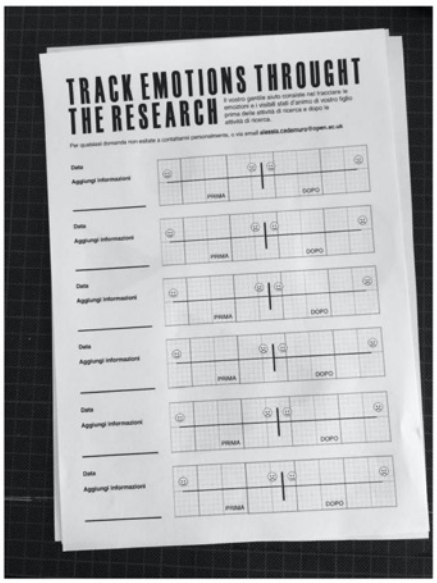
Le ultime due cose che voglio dirti di me

Questo schema e' stato rielaborato da me e si basa sul ABA chart sviluppato ed utilizzato dalla Ntional Autistic Society.
Questo schema e' stato utilizzato da me durante tutto il corso della ricerca ed e' stato di molto aiuto. Specialmente per capire se c'erano momenti della giornata in cui A. e' piu' nervoso e in quali e' piu' dispostoalla collaborazione.



Monitoraggio dei comportamenti di A.

Traching participant's emotions



Per tracciare le emozioni di A. e controllare il suo benessere durante la ricerca sono stati utilizzati questi grafici che hanno facilitato la comprensione e l'andamento delle attivita' e se esse influissero negativamente o positivamente all'umore del partecipante alla ricerca, per capire cosa potrebbe stimolare emozioni negative e quali quelle positive.

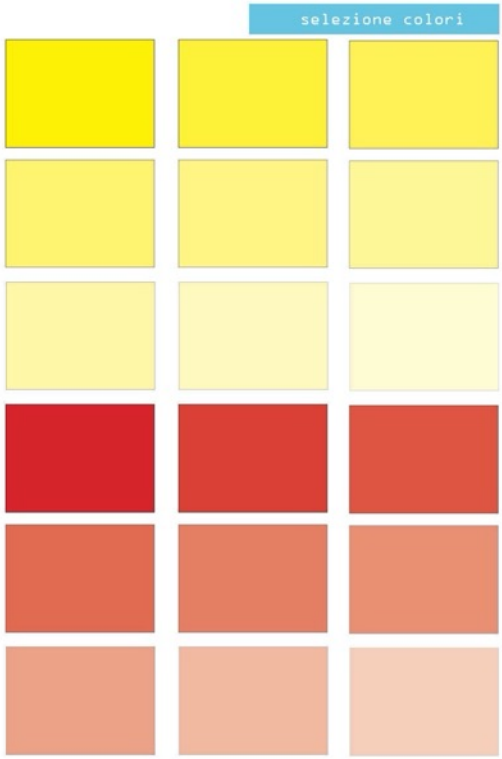
Le prime attivita' non hanno dato molti risultati, sembra che non ci sia stata molta comprensione reciproca tra me ed A. Durante la prima attivita' di ricerca A. sembrava preoccupato e spaventato . Inoltre sembra che lui dipinga solo con pennelli e spatola e l'utilizzo delle penne per lui ha forse una connotazione molto personale. Gli piace smontarle, prendere l'inchiostro, metterselo sul dito e poi dipingere. Le attivita' future devono tenere conto di queste difficolta' ch stiamo incontrando. Anche l'utilizzo di pasta modellabile e costruzioni tridimensionali non sono attivita' molto amate da A.

Ho iniziato ad osservare A.A nelle sue attivita' giornaliere, la terapia comportamentale ABA e le varie attivita' che essa prevede.
Ho visto come si fa la spesa utilizzando una lista visiva dove foto che si possono cambiare a seconda delle esignenze, vengono attaccate con un velcro. Per tenere conto di quali bene sono stati gia' presi durante la spesa e messi nel carrello A. deve fare una croce rosso sui riquadri sotto alle foto degli oggetti.
Una volta segnate tutte le crocette A. sa che deve andare alla cassa, disporre i beni in modo tale che sia conteggiato il prezzo complessivo, pagare ed inserire i beni acquistati all'interno di una sacchetto. Per A tutta questa sequenza di azioni non e' semplice, ma sta imparando in fretta. Attualmente va a fare la spesa con un suo terapista ABA che lo accomplagna al supermercato, entrano insieme e poi aspetta A. vicino alle casse. A. sa che in qualsiasi momento di bisogno sa che puo' chiedere aiuto al suo terapeuta che lo aspetta in un posto preventivamente concordato con A. e che e' sempre lo stesso.

Attivita' che coinvolge la selezione di colori

In una delle attivita' svolte con A. abbiamo utilizzato la ruota dei colori. E' emerso cha A. ama molti colari e che li ama di tonalita' molto forti. Questa attivita' e'stata effettuata chiedendo a A. di indicare dopo alcune mie domande quale colore preferiva.
Le domande erano: Preferisci il giallo in alto o quello in basso. A seconda della risposta potevocapire se cio' che chiedevo veniva compreso da A.

Che cosa e' la ruota deicolori?
La ruota dei colori o cerchio di colore è uno strumento fondamentale per la combinazione dei colori. Il primo schema di colore circolare è stato progettato da Sir Isaac Newton nel 1666. Lo schema e' concepito in maniera tale che tutti i colori presenti stiano bene se abbinati tra loro. Nel corso degli anni sono state fatte numerose varianti, ma la versione piu' comune e' una ruota di 12 colori. Tradizionalmente, ci sono una serie di combinazioni di colori che sono considerati particolarmente gradevoli. Queste sono chiamati armonie di colori o accordi di colore e sono composte da due o più colori, con un rapporto fisso nella ruota dei colori. La ruota dei colori e' semplicemente una guida su come i colori si relazionano tra loro, non una formula scientifica per creare opere d'arte di successo.
Bisogna anche tenere presente che la miscelazione dei colori richiede uno sforzo maggiore rispetto la semplice aggiunta di blu al rosso per ottenere viola.



Le attivita' di riverca con A. devono essere molto situte alle sue abilita' e ai suoi interseei anche momentanei. Questo richiede di modificare anche molto in fretta le attivita' programmate ed essere molto rapidi e flessibili nel riadattare le nuove attivita'.

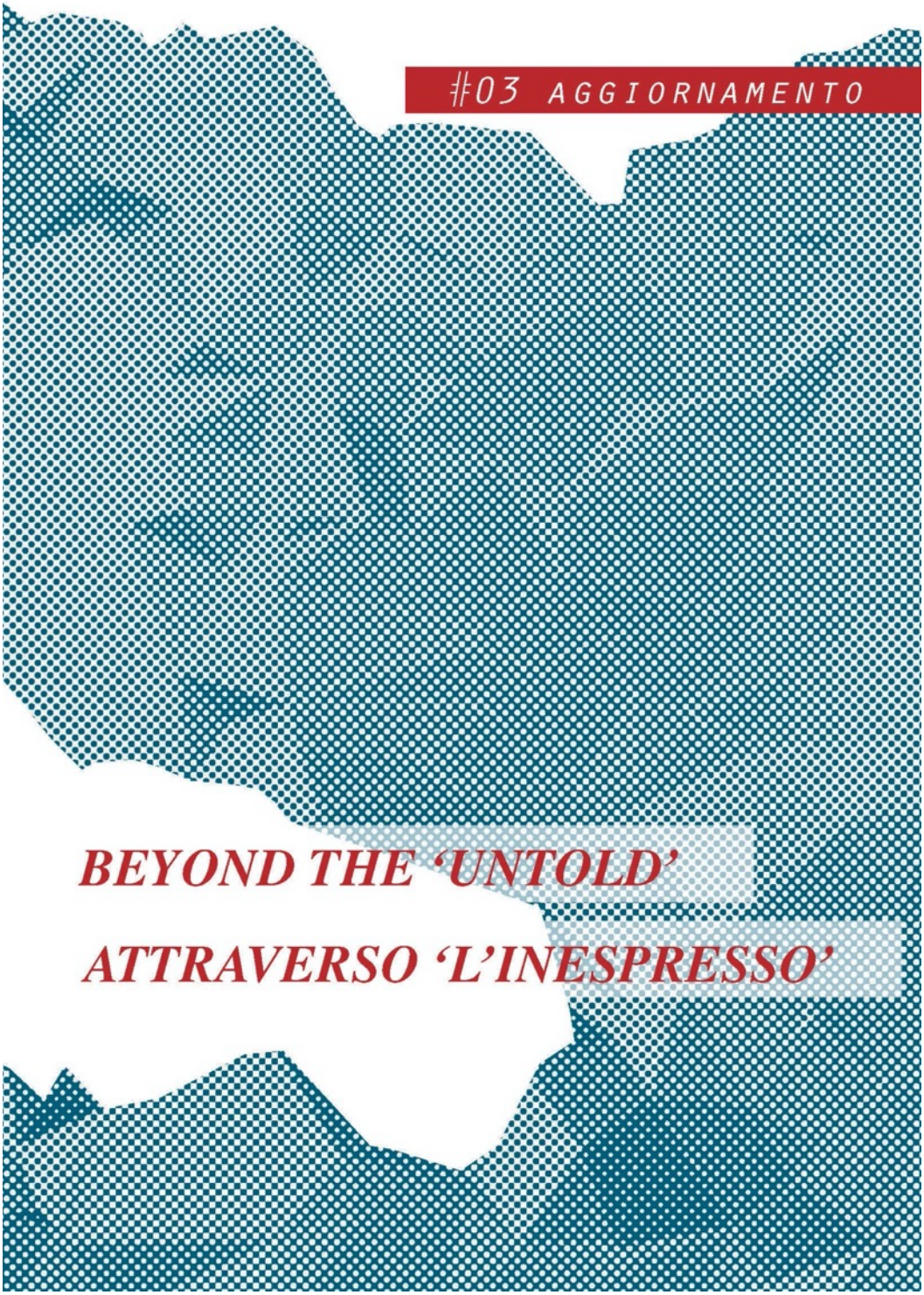
Questo progetto è stato supportato e reso possibile da:

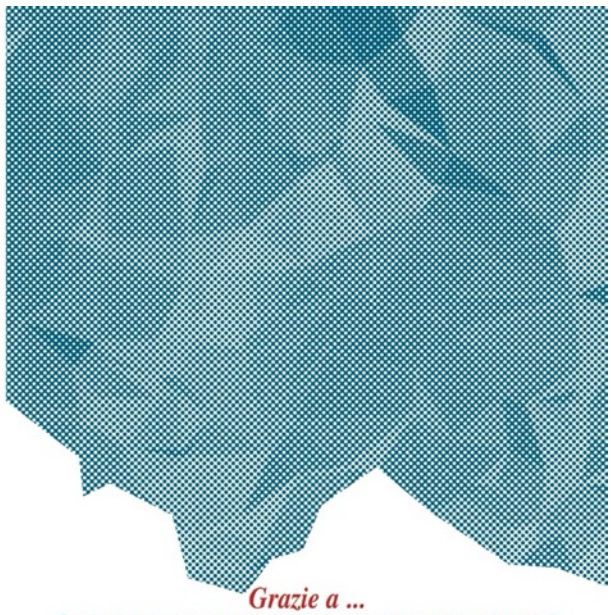
Grazie a Open University (UK) e alle supervisors Rachael Luck e Katerina Alexiou.
Grazie a Design Star per aver supportato e reso possibile questo dottorato di ricerca

The Open University

Arts & Humanities Research Council
design star
Centre for Doctoral Training

Appendix 6.3. (Booklet 3)


#03 AGGIORNAMENTO
BEYOND THE 'UNTOLD'
ATTRAVERSO 'L'INESPRESSO'



Grazie a ...

Grazie al partecipante a questa ricerca un giovane adulto che con il sorriso mi ha guidato a conoscere il suo autismo e a conoscere lui come persona. Si, sto ringraziando proprio te A., senza il tuo prezioso aiuto questa ricerca non sarebbe stata possibile, te ne sono grata. Grazie ai tuoi genitori per la loro grande disponibilità, gentilezza, apertura e per avermi permesso di lavorare con te. Grazie ai tuoi terapeuti ABA, la tua arte terapeuta, logopedista e psicologa che sono stati gentilissimi e molto disponibili. Tramite loro ho imparato tantissimo, grazie per aver sempre risposto a tutte le mie domande e grazie per avermi permesso di prendere parte alle vostre attività.
Un grande grazie anche a tutte le persone che tramite te ho conosciuto dai tuoi familiari a tutte le persone che lavorano in fondazione, per aver accolto la mia presenza con generosità e disponibilità.

-Alessia Cadamuro-

Con questa breve nota si vuole dare un aggiornamento riguardo al lavoro svolto durante la ricerca. Il materiale realizzato durante l'investigazione verrà valutato e presentato all'interno della tesi, inclusa la rilevanza che questa ricerca coprirà nella disciplina legata al design partecipativo in relazione all'autismo.

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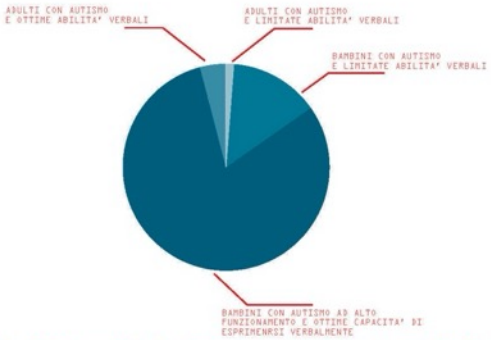
Questo progetto nasce dalla volontà di comprendere se è possibile includere attivamente giovani adulti con autismo e limitate capacità verbali nel ruolo di esperti delle loro esperienze di vita in ricerche e progetti nell'ambito del Design. Attualmente ci sono a disposizione poche conoscenze nel campo del Design Partecipativo volto all'inclusione attiva riguardo ad adulti con autismo. Questo sta determinando l'esclusione di un importante parte della comunità composta da persone che vivranno la maggior parte della loro vita da adulti. Questo porta come conseguenze l'insufficienza di servizi, progetti e conoscenze dedicate alla vita adulta legata allo spettro autistico.

Al contrario ci sono molti progetti di Design che coinvolgono bambini con Autismo ad alto funzionamento con ottime capacità di verbalizzazione. Questi progetti sviluppati con bambini, hanno fornito moltissime informazioni riguardo alle dinamiche di collaborazione utili per i ricercatori e designer. Questo ha aiutato la comprensione riguardo all'utilità e necessità di alcuni progetti quali i supporti tecnologici per la scrittura e la comunicazione facilitata, robot da compagnia, stanze gioco con stimolazioni sensoriali, guide linea per la progettazione di spazi pubblici e privati "autism friendly".

I progetti sopra menzionati sono un importante tassello per il mondo del Design, ma molto spesso sono realizzati con forme, colori ed utilizzi che sono molto apprezzati dai bambini, ma che non sono rivolti ad adulti e alle loro esigenze, abilità e pertanto con un'estetica che può essere percepita inadeguata. Inoltre, molto spesso le persone con autismo non vengono coinvolte nella fase di ricerca e produzione delle idee ma subentrano nella fase di collaudo di prodotti e servizi che vengono pensati da progettisti e ricercatori così detti "neuro-tipici".

* con il termine neuro-tipico si fa riferimento a persone che non sono nello spettro autistico.



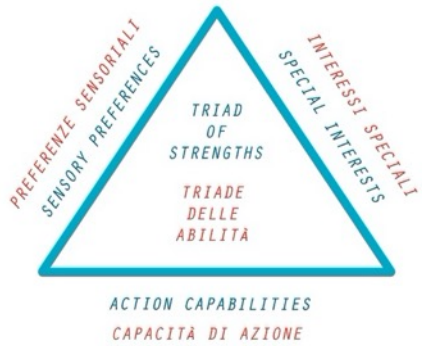
1. schema progetti di ricerca nel campo del design dedicati alle persone con autismo

Questa ricerca al contrario ha come scopo di includere fino dalle primissime fasi di ricerca la persona adulta e di introdurla nell'investigazione nel ruolo di esperto dello spettro autistico. Con la comprensione della soggettività con cui l'autismo viene vissuto da ogni persona che ne è affetta, come afferma L. Wing: *"once you've met one person with autism, you've met one person with autism"*. Wing infatti sottolinea che ogni persona affetta da autismo è differente e che se si incontra una persona con autismo si è incontrato solo una persona con autismo. Seguendo questo importante assunto, la ricerca si fonda su casi studio, ovvero la conoscenza approfondita di un numero limitato di partecipanti in questo caso specifico con A. e la sua soggettiva esperienza di persona con autismo. Questo tipo di approccio è considerato fondamentale in questo preciso contesto progettuale riguardo al design partecipativo, nel quale non sono ancora state studiate e testate metodologie inclusive che coinvolgono adulti nello spettro autistico e limitata capacità verbale.

Questo non ha come solo scopo la riduzione delle "distanze" oggigiorno esistenti tra persone con autismo e persone senza autismo, ma guarda alle potenzialità di inclusione all'interno delle quali l'adulto con autismo non è l'oggetto passivo di decisioni altrui, ma un uomo/donna con esperienze di vita, competenze, abilità, aspirazioni e pensieri talvolta complessi. Queste abilità e competenze anche se espresse in modi atipici e non convenzionali hanno ugualmente il diritto di essere presi in considerazione, studiati, compresi ed utilizzati al fine di contribuire all'implemento dell'inclusione sociale, del design e della divulgazione del sapere.

Fasi di ricerca e metodologia utilizzata

Approccio Etnografico, Triangolo delle abilità, Participatory Design o Design Partecipativo, Empathic Design o Design Empatico sono le principali metodologie utilizzate
L'approccio di ricerca è un approccio basato sulle abilità del partecipante e non sulle sue limitazioni. Questo approccio si basa sul triangolo delle abilità già sperimentato con adulti con autismo e limitata capacità verbale nel progetto di Gaudion (2015)



2. schema Triad of Strengths - Triade delle Abilità. Creato da Gaudion nel 2015

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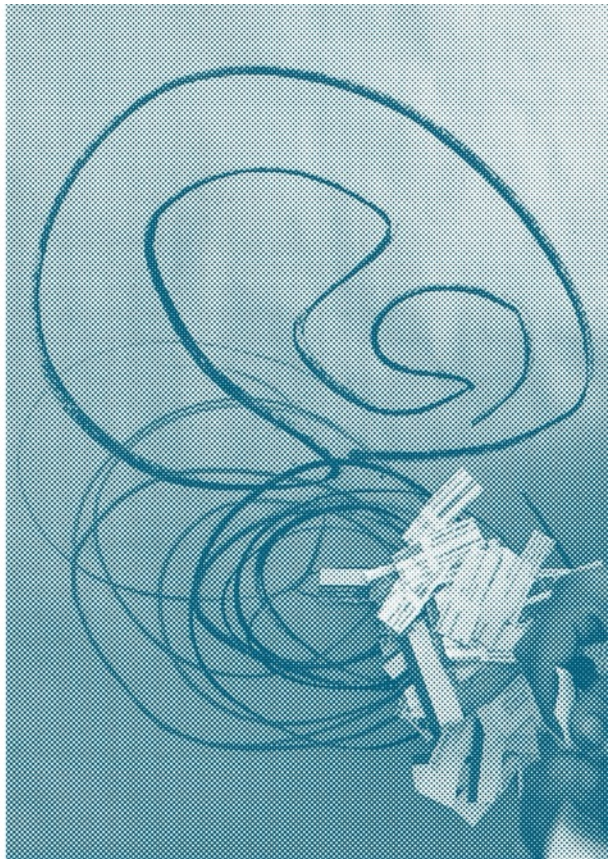
- Come comunicare con A.
- Attitudini e abilità di A.
- Le attività preferite e rituali di A.
- Come organizzare le attività di Design Partecipativo

Durante l'osservazione si è notato come A. sia aperto a conoscere ed includere con felicità nuove persone nella sua vita. Per esempio, durante il primo incontro la designer non sapendo come interagire con lui si è avvicinata in silenzio e A. prendendo l'iniziativa ha mostarto due foto dove era ritratto da piccolo con altri bambini. Questo atteggiamento di apertura e socialità è stato presente in tutto il progetto.

Tra le molte attitudini di A. si nota una spiccata passione per la pittura astratta dove i colori vengono abbinati con straordinaria abilità. Durante l'attività di pittura e arte terapia A. prende decisioni quasi sempre autonomamente sull'utilizzo dei colori e gli attrezzi da utilizzare - pennelli e spatola.

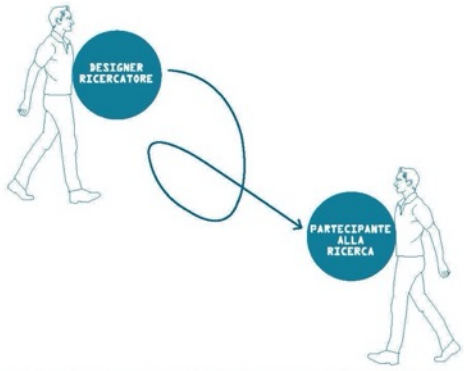
Inoltre durante la fase di osservazione si è evidenziata la propensione di A. nel dipingersi le mani e dipingere con le mani utilizzando i materiali più diversi; dal colore al cibo alle bibite. Questo tipo di atteggiamento è stato valutato di grande interesse in quanto molto probabilmente A. ha una spiccata sensibilità visiva ma anche probabilmente sensoriale sulle mani ed in particolare sulle dita.



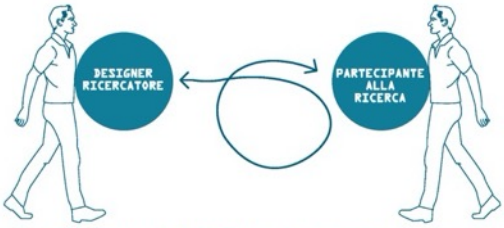
Design di partecipazione con la designer

A partire da questa osservazione la designer ha creato attività e oggetti di ricerca che avevano lo scopo di attirare l'attenzione di A. e permettergli di instaurare una comunicazione non-verbale con la designer svolgendo un'attività da lui apprezzata.
Queste attività si ispirano ed hanno come riferimento metodologico in Design Partecipativo ed Inclusivo, meglio noto come Participatory Design, e Participatory Action Research.
Alcune note per comprendere la metodologia utilizzata; Participatory Design è nato negli anni settanta nei paesi scandinavi con lo scopo di coinvolgere i lavoratori e le loro competenze acquisite da anni nel processo di informatizzazione ed evoluzione tecnologica all'interno del loro lavoro, processo mediato da designers. Questo processo è stato estremamente importante perché ha offerto la possibilità di innestare un processo democratico come valore, che ha reso legittima l'inclusione da parte degli utilizzatori finali ovvero gli operai e non come scelta imposta dai datori di lavoro e passivamente subita. Inoltre tramite questo tipo di approccio estremamente rispettoso e democratico è stato possibile comprendere conoscenze tacite che i lavoratori possedevano grazie alla loro diretta esperienza lavorativa, ma che non venivano direttamente espresse. Dagli anni 70 del 900 ad ora il Partcipatory design è stato applicato in diversi contesti socio-culturali con successo. Oggigiorno è particolarmente utilizzato da molti designer e ricercatori che lavorano con persone portatrici di disabilità, ma non solo, anche in contesti lavorativi pubblici e privati o comunità, per co-creare idee all'interno di conferenze o workshops , etc.
In questo caso specifico si vogliono comprendere se è possibile instaurare una collaborazione di tipo inclusivo e partecipativo con A., e se è possibile comprendere anche le conoscenze tacite e non di A. in quanto esperto della sua condizione di persona con autismo.

Inoltre è importante sottolineare che un approccio empatico è stato seguito, ovvero la ricercatrice ha sempre cercato di comprendere umanamente, senza giudicare, ma cercando mettersi nei panni di A. a volte imitando gesti ed azioni di A. per immergersi nella sua prospettiva per quanto possibile
Una citazione ritenuta fondamentale in questo progetto che descrive l'approccio empatico è:
Rogers (1975), "it is impossible accurately to sense the perceptual world of another person unless you value that person and his world – unless you in some sense care" (pag. 7)
Tradotto: "è impossibile sentire e percepire accuratamente il mondo percettivo di un'altra persona, almeno che non si dia valore a quella persona e al suo mondo – almeno che in qualche modo tu te ne prenda cura".



3. schema Approccio verticale - Il designer ha un ruolo centrale all'interno del progetto e il partecipante viene incluso marginalmente - SCHEMA NON ADOTTATO IN QUESTA RICERCA

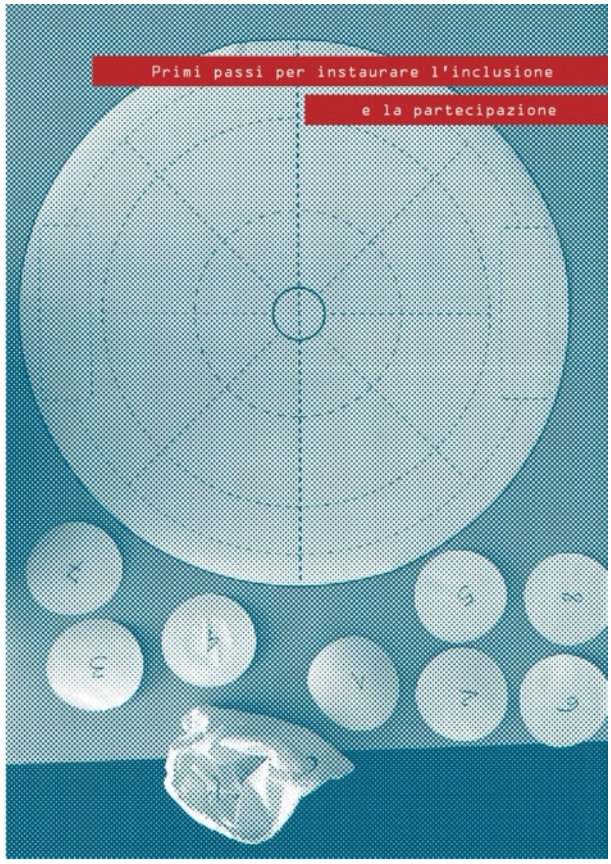


4. schema Approccio ORIZZONTALE - Il designer ha un ruolo di coordinatore e facilitatore all'interno del progetto e il partecipante viene incluso in modo il più possibile democratico e paritario come esperto della propria vita- SCHEMA ADOTTATO IN QUESTA RICERCA

Elementi di collaborazione

alcuni esempi del lavoro svolto

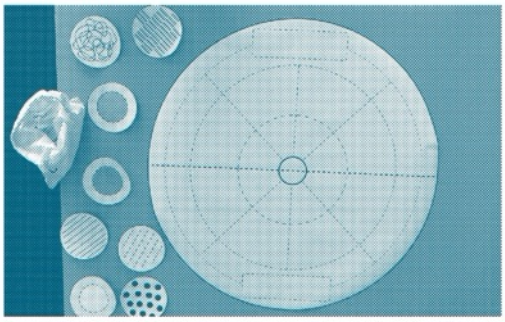
Durante il lavoro con la designer A. si è dimostrato disponibile ed interessato.
Per scelta etica durante il lavoro A. poteva smettere di collaborare in ogni momento se non era interessato o se non trovava l'attività di suo gradimento. Durante le sessioni di lavoro con la ricercatrice, sono state effettuate due pause in ogni sessione per permettere ad A. di riposare. Inoltre ogni qual volta che il partecipante ha mostrato segni di stanchezza o semplicemente insofferenza, il lavoro è sempre stato completamente sospeso dalla ricercatrice stessa e rimandato ad un altro giorno. Questo approccio è stato deciso a tutela della libertà di scelta del partecipante, e a tutela del suo benessere e nel pieno rispetto della sua volontà, anche quella non manifestata verbalmente, ma supportata da atteggiamenti ed azioni.

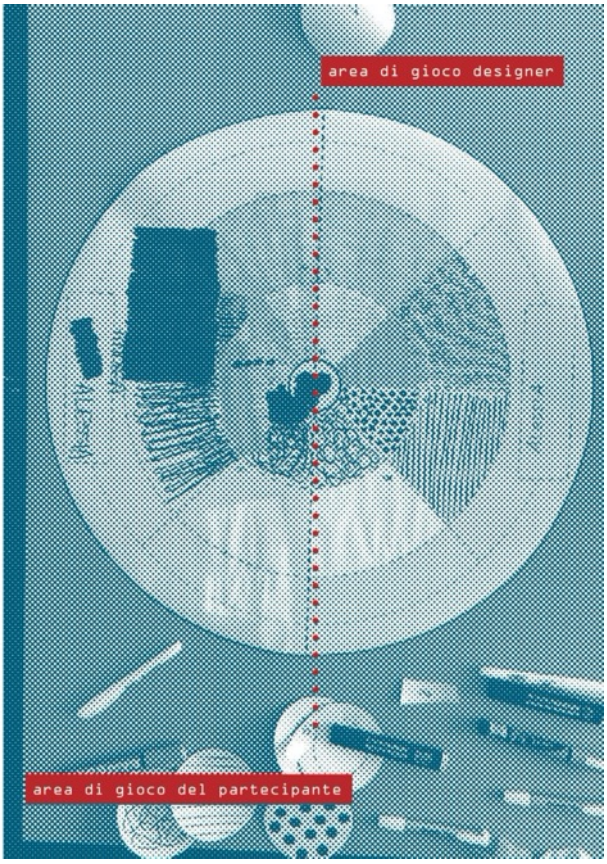


Prima attività svolta con A.

Attività progettata sottoforma di gioco dove il partecipante alla ricerca e la ricercatrice condividevano due parti uguali della superficie di gioco. Con questa attività esplorativa, la designer ha cercato di comprendere se il partecipante alla ricerca, accettava di collaborare e condividere parte dell'area di gioco e se manifestava curiosità o prendeva iniziative.

Breve Analisi:
Il partecipante ha accettato volentieri di prendere parte al gioco e ha portato a termine l'attività senza interruzioni. Al principio A. ha copiato le azioni della ricercatrice ma con il procedere del gioco ha preso più iniziative, talvolta anche reinterpretando forme e segni. Ad ogni modo si osservano poche importanti diversità tra l'area di gioco della ricercatrice e quella del partecipante, segno che una potenziale partecipazione paritaria è possibile, utilizzando segni grafici. Si osserva la comparsa di un pattern (rettangolo nero) applicato dal partecipante anche durante arte terapia ed in generale quando dipinge. Tuttavia, il partecipante è riuscito a contenere questo automatismo.

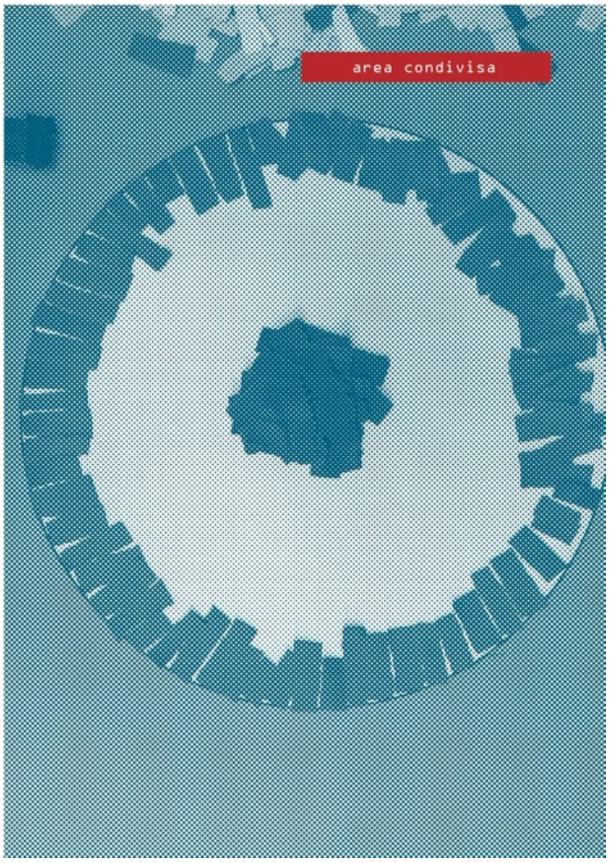




Seconda attività svolta con A.

Attività progettata sottoforma di gioco/mandala dove il partecipante alla ricerca e la designer hanno condiviso interamente la superficie di gioco.
Con questa attività esplorativa la designer ha cercato di comprendere se il partecipante alla ricerca accettava di collaborare e condividere tutta la superficie di gioco e se l'utilizzo dei molti pezzetti di carta continuamente strappati dal partecipante (attività molto amata da A.) potevano diventare risorsa per una attività

Breve Analisi:
Il partecipante ha accettato volentieri di prendere parte al gioco, specilamente nella fase preparatoria, dove A. ha strappato differenti pezzi colorati di carta utile per la realizzazione del mandala. Durante la realizzazione del mandala A. ha partecipato e aiutato la designer; con il procedere dell'attività il partecipante ha iniziato a ritagliare ulteriormente i pezzi di carta disponendoli con apparente casualità sul mandala. Il re-utilizzo di alcuni pattern comportamentali quali la passione per ritagliare piccoli pezzi di carta ha reso il partecipante parte attiva dell'attività, che per la prima volta ha preso iniziative senza aspettare le azioni della ricercatrice.



Terza attività svolta con A.

Oggetti di ricerca progettati prendendo spunto da un' attività molto amata da A. quale la pittura, ma al contempo si sono inseriti degli elementi come l'utilizzo diretto delle dita per stimolare e parzialmente provocare una reazione da parte del partecipante alla ricerca. A. utilizza molto le dita quando dipinge sia con i colori, sia con il cibo, acqua e altri materiali, ed è interessante capire quale reazione questi oggetti possono provocare nel partecipante e se possono diventare strumenti per una comunicazione espressiva non verbale.

Breve Analisi:
Il partecipante alla ricerca ha accolto con curiosità gli oggetti di ricerca. Questi oggetti sono dei ditali con differenti strumenti espressivi posti in una delle due estremità. I ditali hanno differenti funzioni quali: spatola, pennello, spugna, pastelli, etc.. Gli oggetti sono stati testati approfonditamente dal partecipante e in alcuni casi ha staccato il supporto dalle estermità, testando successivamente le estremità singolarmente. Questa attività è la più complessa da interpretare e una comprensione ulteriore è ricercata e supportata da domande scritte che vengono poste al partecipante e al test di questi strumenti durante arte terapia.

Possibile lavoro futuro

Questa breve pubblicazione ha lo scopo di informare anche se solo brevemente riguardo al lavoro svolto con il partecipante alla ricerca. La tesi finale di dottorato sarà più esplicativa e verrà resa disponibile per A. e la sua famiglia, compresi tutti i terapeuti.
Le informazioni ricavate da questa ricerca sono molteplici e avranno un impatto nel mondo accademico, nel campo del design partecipativo e di inclusione. Inoltre con le conoscenze ricavate dall'investigazione si vuole promuovere in modo empatico, la comprensione dello spettro autistico. Per promuovere questa conoscenza ad un pubblico vasto ed in modo empatico, la designer sta pensando di progettare un'esperienza da vivere attraverso la realtà virtuale. In questa esperienza lo spettatore verrà immerso nella realtà di una persona autistica, sperimentandone limiti e abilità, anche attraverso l'uso di sensori e oggetti che hanno lo scopo di stimolare differenti sensi durante l'esperienza virtuale. Anche se per breve tempo, le persone che non sono nello spettro autistico potranno vivere e sentire quale impatto nella vita viene creato da questa condizione e forse tramite questa esperienza si potranno sentire incuriositi o spinti a comprendere, includere e conoscere persone che vivono costantemente con lo spettro autistico.

Sperando di poter realizzare questo ambizioso progetto e di terminare il dottorato di ricerca vi saluto e vi ringrazio ancora per tutta la disponibilità con cui avete accolto la mia ricerca e presenza.

Alessia Cadamuro

- to be continued -

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