Paris, July, 2-3, 2015

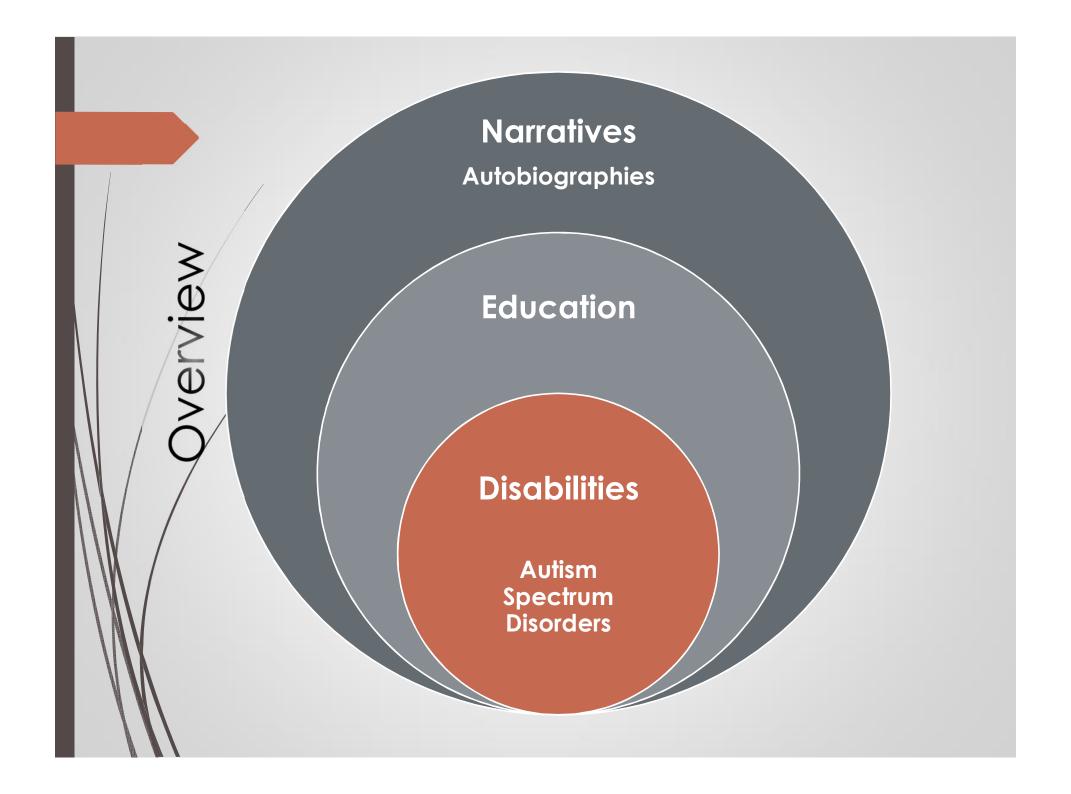
IV Alter Conference

"Questioning contemporary societies through the lens of disability"

Autobiography and disability: educational perspectives

Marzia Mazzer

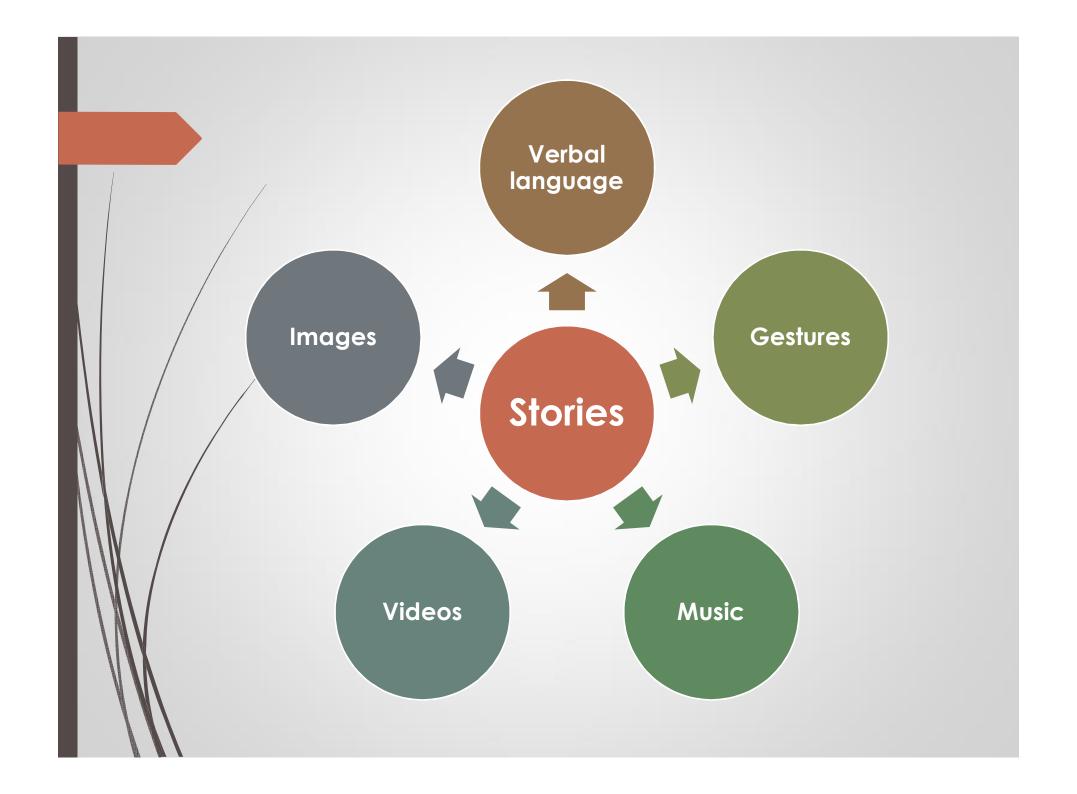
University of Rome «Foro Italico» marzia.mazzer@uniroma4.it



Telling stories

- WA man is always a teller of stories, he lives surrounded by his own stories and those of other people, he sees everything that happens to him in terms of these stories and he tries to live his life as if he were recounting it» (Sartre, 1964).
- «For humans, story is like gravity: a field of force that surrounds us and influences all of our movements. But, like gravity, story is so omnipresent that we are hardly aware of how it shapes our lives» (Gottshall, 2013).





Why stories?



To **organize** and **share** experiences (Smorti, 1994; Bruner, 1983)

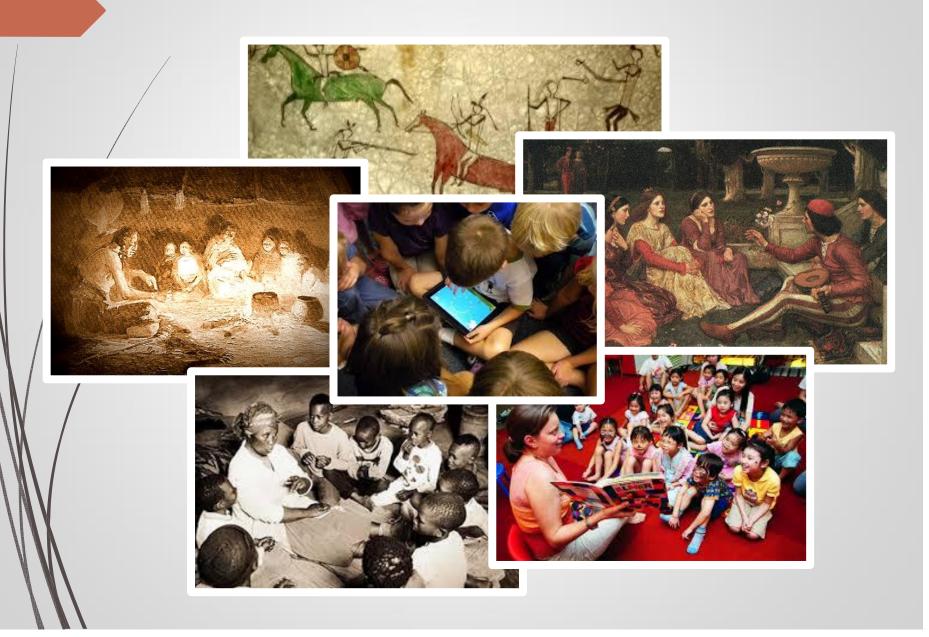


To anticipate the **future** (Demetrio, 2012)



To **navigate** and **orientate** oneself in the world (Bruner, 1989)

Homo narrans



First-person narratives as a tool for...



Self knowledge and self analysis (Cambi, 2007)



Representing and reconstructing past experiences = **creative act** (Ricoeur, 1994; Gusdorf, 1956)



Metacognition (Demetrio, 2012) and resilience (Cyrulnik, Malaguti, 2005)

From individual to collective

Stories are a direct social exchange of experiences (Benjamin, 1936)

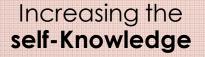
SPACE OF DIALOGUE AND CHANGE

Other's stories can make us better understand our story

Self narratives and disabilities

Self narratives

 Autobiographies written by people with disabilities



- Metacognition
- Resilience

Increasing the community's knowledge about «lived disability»

 Overcoming prejudices/ stereotypes

Talking about autism...

Autism as an "object of inspection"

"...right for the start, from the time someone came up with the word 'autism', the condition has been judged from the **outside**, by its appearances, and not from the **inside** according to how it is experienced" (Williams, 1996, p.14).

Changing perspective...

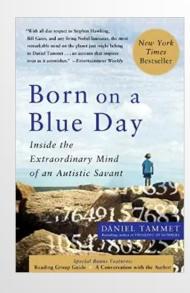
- Self advocacy movement (e.g. ASAN, AFF)
- Engagement of academically trained autistic in research
- Autistic autobiographies

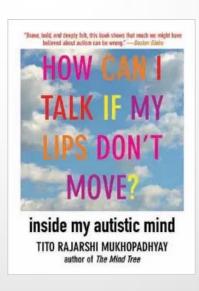
Only the top of a book mountain...

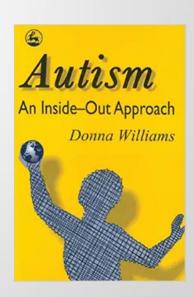
- Grandin T. (1986). Emergence: labeled autistic.
- Sinclair J. (1989). Bridging the gap.
- Williams D. (1992). Nobody nowhere: the extraordinary biography of an autistic.
- Mukhopadhyay T. R. (2000). Beyond the silence: my life, the world, the autism.
- Sainsbury C. (2000). Martian in the Playground: Understanding the Schoolchild with Asperger's Syndrome.
- Nickson T. (2002). Autism experience.
- **Tammet D.** (2006). Born on a blue day: inside the extraordinary mind of an autistic savant.
- **Higashida N.** (2013). The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism

Autism from the «inside»

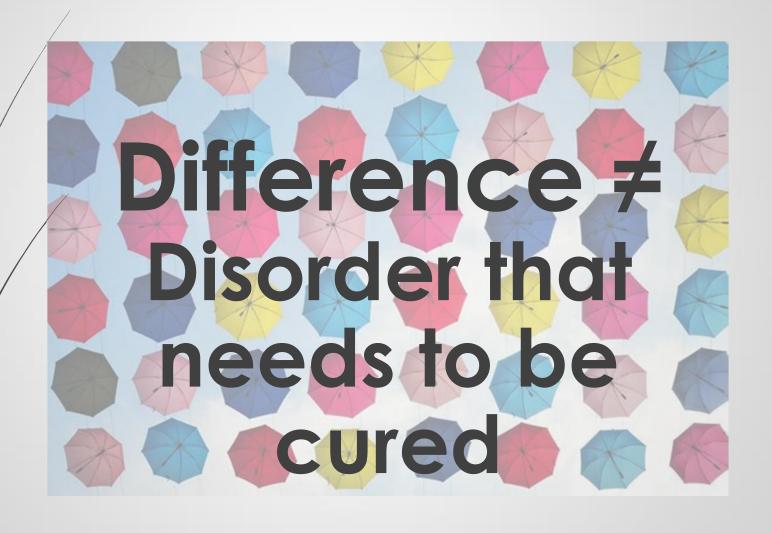
«Autism narratives are not just stories or histories, describing a given reality. They are creating the **language** in which to describe the experience of autism, and hence helping to forge the **concepts** in which to think **autism** » (Hacking, 2009)







Autism from the «inside»



A different sensory world

- Different sensory and perceptual experiences = different quality and/or intensity of what is experienced
- Hyper/ hypo sensitivities to stimuli (light levels, sounds, smells, colors, textures, tastes)



«Every time I am touched it hurts; it feels like fire running through my body» (Gillingham, 1995)

«Strange» and «bizarre» behaviours

«Autistic people will instinctively reach for **order** and **symmetry**: they arrange the spoons on the table, they line up matchsticks or they rock back and forth (...). **Rocking movements** are deeply calming, suggesting the body itself can be used to soothe the effects of over stimulation through smooth, repetitive, predictable behaviors» (Prince-Hughes, 2004)



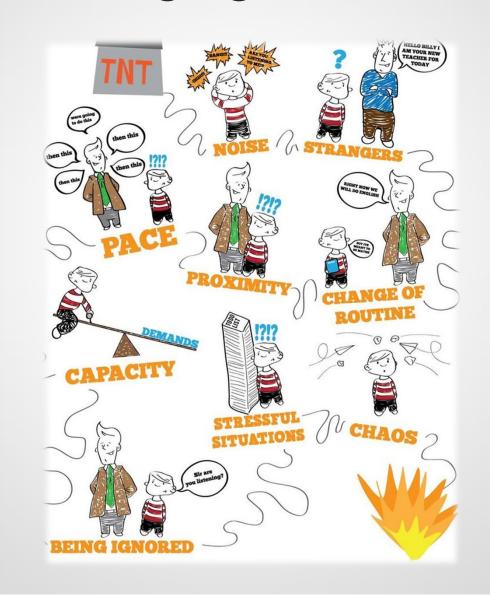
Communication



«Autistic people are "foreigners" in any society. You're going to have to give up your assumptions about shared meanings. You're going to have to learn to back up to levels more basic than you've probably thought about before, to translate, and to check to make sure your translations are understood. You're going to have to give up the certainty that comes of being on your own familiar territory, of knowing you're in charge, and let your child teach you a little of her language, guide you a little way into his world».

(Sinclair, 1993)

Challenging behaviours



Conclusions

Medical literature

Simplification
Diagnostic labels
Categorization



Self narratives

Complexity
People
Critical thinking



Through which lens we see the disability?

Being a person before being on the spectrum

actor of my being (but having a healthy acknowledgement of it) that it's there but also thinking about other qualities I have such as being a writer, poet and artist. I do have disability, I do have autism and I have a "mild" learning disability that is true but I am a human being first and foremost. And for someone to be seen as person equal to everyone else is a basic human right»

Paul Isaacs (2012), Living Through the Haze

Donna Williams, «TO DARE»

Thank you for your Merci de votre

