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NEMO PROJECT'S OBSERVATION METHODOLOGY FOR EMBODIED INTERACTIONS AND AUTISM SPECTRUM DISORDERS¹

Claudio Paolucci

I. THE STATE OF THE ART: THREE CRITICALITIES

The prevalence of Autism Spectrum Disorders (ASD) in Europe is 12.2 per 1,000 (one in 89) children, and the diagnosis of ASD is usually provided around the age of two years and half, usually following a developmental delay in children's linguistic skills². The infant does not talk and, consequently the caregiver gets worried and asks for help: later s/he will recognize that s/he could already have seen many signs of non-typical behavior. Indeed, as our NeMo project (<https://site.unibo.it/nemoproject/en>) aims at showing, clear signs of impairments and atypicalities that can lead to ASD can be seen and read much earlier, by looking at embodied and prelinguistic interactions between infants and caregivers, when the toddler is between 9 and 18-months-old (secondary intersubjectivity)³. However, first we should examine what happens when the caregiver asks for help.

ADOS (Autism Diagnostic Observation Schedule) is a screening test that composes, with ADI-R, the Gold Standard for ASD diagnoses. These tests, more so than the others usually used for a general population screening or an already-at-risk population screening, detect ASD cases (sensitivity) and distinguish them from other pathologies that present similar symptoms (specificity). As Lebersfeld and colleagues (2020) show in a recent, systematic overview of studies administered using ADOS, this tool has an average sensitivity between .89 – .92 and an average specificity between .81 – .85. Summing up, ADOS works great though it/ arrives too late – I will come back to this – it gives a diagnosis of ASD with great accuracy and remarkable sensitivity.

However, why does ADOS work so well? Essentially for two reasons: i) *the observer is a highly competent subject*, usually a neuropsychiatrist; ii) ADOS is a *highly grammaticalized test carried out in a highly grammaticalized setting*, i. e., a controlled laboratory situation

and not «in the wild». The test takes from 40 to 60 minutes, and consists in a series of highly structured activities, throughout which examiners elicit and evaluate the presence of specific behaviours, which are natural for a neurotypical subject and that usually lack and/or are deficient in ASD subjects. This test is administered in a controlled and laboratory setting and requires a specific medical competence (differently from tests such as M-CHAT, directly compiled by the caregivers of the examined subject).

So, we have three criticalities here:

i) *28 months (or worse) is too late*, since neuroplasticity is higher during the secondary intersubjectivity window (9-18 months) and it has been shown that an early intervention is more effective if compared to a standard «post-ADOS» average one (for an overview, see Franz and Dawson 2019);

ii) *A neuropsychiatrist is a competent observer*: basically, we simply cannot use an ADOS test conducted by a neuropsychiatrist for every single baby born in this world;

iii) ADOS setting is not a real-life, in the wild test, where the infant interacts with the people he usually interacts with and does the things he usually does, so we have an «ecological validity» issue here (see Lewkowicz 2001), that has been discussed also referring to the significant increasing of ASD diagnosis in the last years.

In our NeMo project, funded by the European Commission, we have tried to deal exactly with these three criticalities.

2. THE NEMO PROJECT

Of course, the aim of the NeMo project is *not to diagnose* ASD: this must be done by neuropsychiatrists in ADOS contexts. The aim of the NeMo project is to detect non-typical interactions that can lead to a diagnosis of ASD very early, so infants can be observed and monitored. Therefore, NeMo has developed an observation methodology which is easy to follow also by non-experienced observers, like caregivers, family members and pre-primary teachers. Indeed, NeMo Methodology – developed by the University of Bologna – basically operates with three substitutions:

i) *A substitution in the age of the infant*, since it observes 9-18-month-old infants.

ii) *A substitution of the neuropsychiatrist with a less competent observer: a caregiver, a pre-primary teacher, or – ideally – a machine, like a supervised app;*

iii) *A substitution of the laboratory and highly grammaticalized ADOS setting with real-life, in the wild, home videos shot through smartphones by caregivers.*

And this is exactly what the Unibo team lead has done during the first two years of the NeMo project. Ideally, a non-competent observer, after reading a manual, can detect if an interaction is typical or non-typical, while watching homemade videos shot on smartphones by caregivers who interact with 9-18-month-old-infants. Even more ideally, a supervised app could also do that in the future, but, of course, we are not there yet (for a review on ASD and machine learning, see Rahman *et al.* 2020).

To achieve that, a huge initial problem has to be considered. Let's go back to ADOS. *ADOS-Toddler Module* (Luyster *et al.* 2009) is based on 11 activities and is focused on behaviours such as: shared actions and shared attention; competence and desire to look for the other's gaze and to respond to it; imitative competence; sensorimotor coordination competence in shared activities; absence of restricted, repetitive behaviours, interests and/or movements; requesting competence; pointing competence; social smile, pretend play, make-believe, general competence and desire to recognize and respond to and with gestures, vocalizations and emotional expressions etc.

The problem with this list of signs, skills and activities is that an Ordinary Observer (OA), like a caregiver or a pre-primary teacher, cannot really handle all that work. The first task has thus been «simplification». This took many years of work. Indeed, simplification does not mean «stupidification» and does not mean throwing away some of these signs, or, worse, all of them. Simplification means that all this must be *summed up in a small number of things to look for*, that a caregiver can easily see. Of course, Semiotics has been the main tool used in order to accomplish that (see Paolucci 2012, 2021, 2022; Fusaroli, Paolucci 2011). However, the hardest part of this work has been removing all of the semiotic technicalities and ending up with something that can be told like a love story. And the «love story» is the following: *if the infant attunes to the caregiver, he is essentially a typical-developing infant; if he does not, the infant should be monitored, since infants that do not attune to their caregivers during their interactions usually receive*

a diagnosis of ASD or a diagnosis of other neurodevelopmental impairments later.

So, what is attuning? This can also be framed in a very simple way: *attuning is adapting yourself to the other, the fact that the way you move, behave, or feel takes into account the way the other moves, behaves or feels.* This is why it is like a love story: we all loved the people that took into account the way we move, act and feel and did *not* love the people who do *not* take into account the way we move, act and feel.

The main thing, that makes the system very simple, is that you only must look at the attunement between the infant and the caregiver during their interaction. So, what can be attuned in an interaction? Three things that give rise to three dimensions: A) the bodies; B) the doing; C) the feelings, a *sensorimotor*, a *behavioural* and an *emotional* dimension.

3. SENSORIMOTOR DIMENSION:A) THE BODIES

As far as the bodies are concerned, *a typical interaction is like a good dance.* What do we usually do when we dance? In dancing, your body attunes to the body of the other in a harmonious way and your body adapts to what the other is doing. The contrary is also very easy to understand: when there is disharmony between two people – for instance when lovers are angry after struggling – each body moves with its own separate instructions. For instance, i) she is on one side of the couch with the telephone, ii) he is on the other side with the remote control (or *vice versa*). If during a doing together, the body of the infant seems to moves with its own instruction, without attuning to the body of the other, the interaction may not be typical, and this could be a sign of possible future ASD impairment. Of course, this misattunement can have a lot of causes, but in our study, we look for neither causes nor for motivations, only for meaningful signs used to detect if something is potentially worrisome. Thus, it is important to stress that the way bodies behave during an interaction is extremely revelatory and puts into discussion our ordinary distinction between the body and the mind, and the correlated idea that ASD involves mainly mindreading and communication problems (see Paolucci 2019, 2020). ASD also involves the bodies, and the way bodies behave is an extremely meaningful dimension for semioticians to fathom⁴. In order to maximise its reve-

latory power, as far as the bodies are concerned, NeMo methodology looks for four different things:

A1) *The space*. This category takes into account the distance between subjects, the moving towards/away from each other, the way the infant moves into the space and measures the typicality with which the infant approaches – or moves away from – caregivers or other infants. Research has frequently noted that infants with Autism Spectrum Disorders will often interact differently with others in regards to the other's personal space when compared with Typical Development (TD) infants. Infants with ASD will typically remain either too close to others or will retain an excessive distance from others. Moreover, infants with ASD may appear as if they fail to notice the presence of others who are nearby and may also seem to actively resist physical closeness or being touched. More, ASD infants usually prefer to interact with toys or other objects, if compared to people, so they inhabit the space accordingly.

A2) *The body of the other (Bodily Attunement)*. This category measures the extent to which the infant appears to adapt his body to caregivers or other infants during physical encounters. For example, the infant may turn his whole body to the direction that the caregiver points toward, or may physically react to the voice of a caregiver calling him (ASD infants sometimes seem deaf and do not reply to their name). In general, TD infants will adjust his/her own body to the movements of the caregiver like in a dance, in which one's own body attunes to the movements of the other body. By contrast, ASD infants typically fail to adjust their own bodily posture and movements in a way that aligns with that of another person's movements. ASD infants will often interact in a way that appears rigid, controlled, inattentive and inflexible. A sign of potential alarm could be occurring in that the infant would fail to adjust his/her own bodily posture and movements in a way that aligns with that of another person's movements, if s/he would appear more interested in coordinating their movements to play (usually alone) with their toys, and/or if s/he would avoid the other's attempts to engage with him/her in a reciprocal fashion of bodily dynamics. Such «unattuned» bodily interactions may appear as if the infant is resisting physical interaction or is anxious or unsure about his role in the situation.

A3) *The infant's own body*. This category measures the style of the infant's overall bodily posture and style of movement, including during non-interactive situations. In fact, usually infants are able to coordinate their motor movements and posture, balancing the head, trunk, hands, arms and legs movements to start or continue any kind of activity (e.g. spreading their arms while crawling as to reach a toy or the other's body). On the contrary, a sign of potential alert could be present if the infant would produce repetitive bodily motions that often manifest in the form of hand-waving/flapping, rubbing, rocking or pacing. These movements are known as "stimming" (self-stimulating). Furthermore, ASD infants will often assume a stiff and rigid posture, sometimes while also engaging in stimming behaviours. Motor disturbances such as impaired crawling, lack of integration between the upper body (which is generally looser) and the lower part (generally more rigid) may also be present. ASD infants could also present a weaker muscular tone. Please, rate with a high number here if you see some of these signs.

A4) *Degree of attention to the motor sanction of the caregiver*. A sanction should be interpreted as every kind of evaluation (positive or negative) produced by the caregiver with words, actions, sounds and gestures that are used to reinforce the infant's actions and reactions. A sanction is usually used to motivate, boost and help the infant to orient his/her performance. As far as «the bodies» are concerned, this category measures how attentive to, and anticipatory of, the infant is regarding the bodily movements of caregivers. Particular focus should be placed on the «end» of an action or where an action requires a *specific* reaction from the infant. This is most frequently observed when (but not limited to) the infant prepares for his/her own body to be picked up or hugged by the caregiver. Unlike the more general and open-ended behaviours that are measured in A2, a sanction requires a specific bodily reaction from the infant. Whereas TD infants will often naturally observe the movements of their caregivers and adjust their own bodily posture and movements in preparation, a sign of potential alert could be occurring if the infant would show a markedly reduced ability to react appropriately to the actions of others. Furthermore, TD infants often mimic the bodily actions of caregivers even outside of strictly interactive contexts, whereas these mimicking behaviours are often absent or significantly reduced with ASD infants.

4. BEHAVIORAL DIMENSION: B) THE DOING

As far as the doing is concerned, this is probably the most evident and easy to see dimension of the system. ASD infants usually carry on in their own business and look like they don't care to interact with the caregivers. Of course, we are not saying that they don't care – probably they do – but it looks like they don't, maybe because it is difficult for them to interact properly, so they prefer to quit⁵. When you are not good at something you usually do not want to do it, because it reminds you your own inadequacy. Also the «doing» dimension is divided into four items:

B1) *The doing together*. This category measures the degree to which the infant can spontaneously partake in shared activities with success. For a case of potential alert to be noticed, it is important to judge whether or not the infant can fluently partake in activities which are not strictly planned and/or structured. Therefore, this criterion measures how well the infant performs during interactive contexts, such as their ability to fulfil their role within an interactive game or task, with special attention paid to situations in which the task/game suddenly changes, or a new element is introduced and the infant must fluently adapt to it.

B2) *The mutual gaze while doing together*. This category measures the frequency and style through which the infant makes eye contact with his/her caregiver or another infant during a joint activity. These are natural behaviours used by infants for communicative and pragmatic purposes. If the infant would avoid or look for and/or respond to the other's gaze repeatedly, rarely or just sometimes, we could talk about a situation of potential alert. For instance, reduced or absent eye contact and a noticeable lack of attention to the faces of other people are both indicators of possibly alarming situations. Thus, if during a co-operative game or task the infant pays significantly more attention to objects than to other people, and/or seems to avoid making eye contact, this could be an indication of a possible ASD impairment.

B3) *Joint attention*. The category measures the extent to which the attentional focus of infant and caregiver appear to «synchronise» with one another during a game or shared task. For instance, if the caregiver elicits the infant's attention as to focus on a toy, in order

to partake in a shared activity, the infant will look at the toy and will probably invite the caregiver to play together. On the contrary, a sign of potential alert could be present if the infant would display difficulties in attuning his/her attentional focus to that of his/her caregiver's, and/or would communicate less frequently with others, both verbally and non-verbally, during shared tasks and games. In these cases, we would thus witness the infants as if they were «in their own world», which can manifest in their markedly reduced communicative, exploratory and eye-gazing behaviours. It is important to pay attention both at the springing up and the falling of something new, to exploratory behaviour of the infant and to his/her communication with the caregiver.

B4) *Degree of attention to the behavioral sanction of the caregiver.* This category measures the degree to which the infant perceives, is aware of, and can react appropriately to, context-relevant actions and/or gestures made by the caregiver. In a way similar to A4, we are here observing how the infant attends to the caregiver's behaviour as it relates to engaging in shared games and tasks and how much attention he/she pays to the reactions and evaluations of the caregiver regarding his own behaviours. For instance, during a meal, if the infant refuses to eat and the caregiver continues to insist that the infant should eat, how much does this influence the infant's behaviour? A potentially alerting situation could occur if it was the case that the infant would miss the overall meaning of an action, game or task, or fail to understand non-explicit instructions or other subtleties present in interactions, and/or fail to achieve the desired result after a series of encouragements, instructions and motivations. Furthermore, ASD or developmentally impaired infants are often less responsive to gestures that make other infants feel good and help the interaction along, such as positive words and gestures (e.g. pointing, a thumbs up or pat on the back) which can hinder their ability to learn and form social bonds.

5. EMOTIONAL DIMENSION: C) THE FEELINGS

As far as the emotions are concerned, in an ordinary interaction, behaviours and feelings change according to a change in the emotions of the others. If someone gets angry, the one that interacts with him/her takes into account that anger and maybe changes his/her beha-

viour and his/her mood accordingly. ASD children usually do not take this into account or have difficulties in doing it. Of course, we are not saying that infants must be happy when the caregiver is happy, or sad when s/he is sad. This is not an attunement at all. Attuning does not mean feeling the same emotion: it is neither empathy nor emotional contagion. It simply means taking into account the emotions of the others. For instance, a typical developing infant sees that the parent is angry and can decide to attune to that simply keeping disobeying him, because he wants to disobey. This is a choice, but it is also an attunement, because he attunes in his own way. Instead, ASD infants may simply not take any change in the caregiver's emotions into account. This can be quantified inside four different items that we have to rate.

C1) *The feeling together*. This category measures how the infant and caregiver adjust their emotional states in response to one another. Pay close attention to whether or not the infant becomes happy when the caregiver is happy and/or can then adjust this happiness if the caregiver subsequently shows subtle signs of displeasure. In fact, usually both the infant and caregiver continually adapt and adjust their emotional states in response to that shown by the other in a spontaneous, fluid and dynamic way. Keep in mind that the caregiver using so-called «infant talk» often has the power of grasping the infant's attention, so do not overestimate an infant's capacity for emotional regulation if the caregiver introduces a sudden change from «normal-talk» to attention-grabbing «infant-talk».

C2) *The emotional gaze*. This category measures the frequency with which infants and caregivers make eye contact with each other outside of task-related contexts. Infants will frequently and spontaneously make eye contact with caregivers or other infants and adults, even outside of situations related to games and tasks, in a way that seems natural and spontaneous. This eye contact usually has a communicative function and helps the overall quality of the interaction. A potentially alerting situation could be occurring if the infant would seem uninterested in meeting the gaze of another person or communicating through eye contact, and/or can even appear to avoid it. Please remain aware that, if you are rating a video recorded by a human being that does not appear in the recording, then the infant will often appear to look directly at, or just above, the camera if they make eye contact with the recorder of the video.

C3) *The facial expressions.* This category measures the extent to which the infant spontaneously imitates or reacts to the facial expressions of their caregivers. Instead of observing the overall emotional state as in C1, pay greater attention to how the facial expression of the infant (e.g., smiling, laughing, scowling, surprise) matches that expressed by the caregiver, as well as how the infant's own expression changes in direct response to that expressed by the caregiver (e.g., does the infant become sad if the caregiver appears suddenly displeased?). Usually, infants appear naturally and spontaneously predisposed to mirror the emotional expressions of their caregiver. On the contrary, a potentially alarming situation could be occurring if the infants were more likely to remain unaware of the meaning behind the caregiver's facial expression, as well as how they should emotionally react in response to it.

C4) *Degree of attention to the emotional sanction of the caregiver.* This category measures how generally attentive to the emotional «requests» of the caregiver the infant appears to be. An alerting situation would be occurring if the infant was reported to display less interest in the emotional states of others and thus fail to respond to solicitations to experience emotions when their caregivers would like them to. For instance, when interacting with infants with ASD, the caregiver may continually appear to try to elicit emotional states in the infant which are not fulfilled (i.e. attempting to make the infant feel excitement) or the caregiver may experience visible frustration when the infant does not respond contextually to their emotional state (such as anger at the infant's misbehaviour) and the infant may carry on with his own business anyway.

6. THE RATING PROCEDURE

In order to quantify the level of attunement, the 12 items presented above have to be rated on a numerical scale. Each can be rated from 1 to 8, where 1 stands for a very typical interaction (high level of attunement) and 8 stands for a very atypical interaction (low level of attunement). This schema divides the scoring possibilities into groups of two (1-2; 3-4; 5-6; 7-8) and the NeMo manual explains all the details of the rating procedure, using video examples. Depending on the

severity of the condition and on the number of anomalies detected, the schema divides each field into a range of possible concern – from 1-2, no concern, to 7-8, severe concern. This has a major advantage: it sterilizes the observer’s emotions and point of view. The observer does not make any diagnosis: s/he simply evaluate a behaviour. It will be the machine that will later tell us/him/them if that infant recorded in that particular interaction is behaving in a typical way or not. But we will come back to that.

During the first years of the NeMo project, we have collected hundreds home videos of infants-caregivers interactions, uploaded by the families and the partners of the project and stored on a encrypted database on the servers of the University of Bologna⁶. We asked for home videos of infants that were later diagnosed with ASD when they were 9-18-months-old. We also collected videos of typically developing infants, used as a control group. Later, we watched hundreds of home-videos of interactions between infants and caregivers and rated them according to our own methodology that have been built through applied semiotic analysis and through the observation of other hundreds of home videos. In the first phase (the construction of the methodology) we knew if the infant in the home video was diagnosed as ASD or not. In the second phase (the rating phase) we did not knew that. It is the difference between «testing» and «performance» in Artificial Intelligence. So which performance did we obtain?

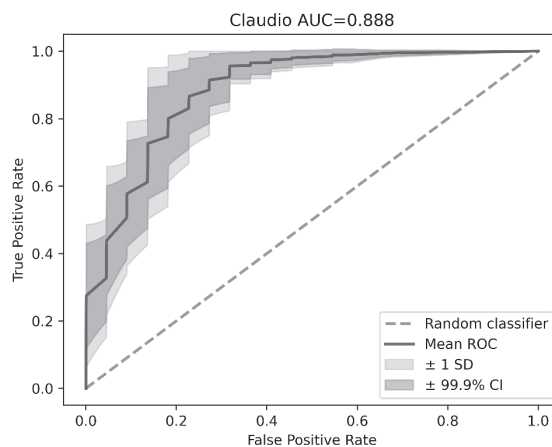


Fig. 1. *Ricercatore Claudio*.

This is the author of this paper, who also is the PI of the project. The machine learning model used is a Tree-based model called XGBoost, and is used to solve binary classification problems, in this case the diagnosis of autism (ASD group VS Control group).

The ROC (Receiver Operating Characteristic) graphs are diagrams that relate the False Positive Rate (FPR, the false positive fraction) and the True Positive Rate (TPR, the true positive fraction). Through the analysis of the ROC curves, the ability of the classifier to distinguish between a healthy and sick population set is assessed by calculating the AUC area under the curve (Area Under Curve). The higher the AUC value, the higher the model's performance. We are describing the machine learning system in its details in a forthcoming paper (see Diciotti, Paolucci 2022)

However, even if the performances of the author of this paper are quite good, this is not enough at all, since the author of this paper completely missed the substitution condition ii) described above. The PI of the project is a competent observer. Perhaps not as competent as a neuropsychiatrist, but he has studied ASD and he is the one who has built the observation methodology through semiotics. So, with the money of the grant, NeMo project has hired some PhD students in the Humanities that were not competent on ASD and that have been trained to the NeMo observation methodology and have been asked to rate the videos. These junior researchers had to rate the videos on their own, without knowing the ratings of the PI and the condition of the infant, and every Monday morning the team used to meet for hours, confronting the results, and discussing about ratings and videos.

In this situation, one major task was to build up a manual for the rating of the different items, describing each sign by concrete examples and through home-videos. Without that instrument, the rating process risked to be irreproducible by another reader. An unexperienced reader could evaluate as 8 (worst case) a situation that appears worse for him (because he has seen very few cases), while an expert might evaluate it as less than a «8». So, a sort of «manual» of ratings was necessary to standardize them and minimize individual variability. Although this procedure is standard in Artificial Intelligence, NeMo's aim is somehow ambitious for the future: ideally, everyone who reads the manual could be able to detect a non-typical interaction and distinguish it between a typical one. Of course, new data are needed for that (see below, § 7)

As far as the performances of the junior researchers trained to the observation methodology are concerned, there are mainly two groups. The first one is composed by three researchers.

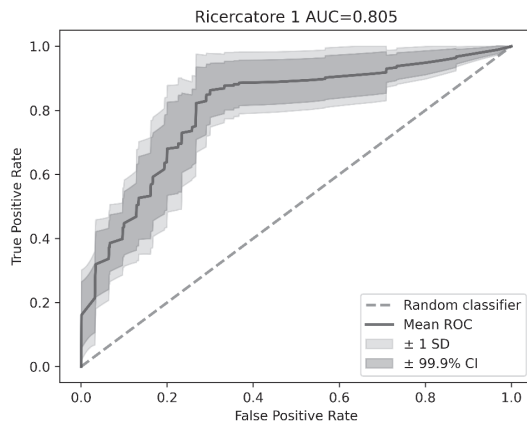


Fig. 2. Ricercatore 1.

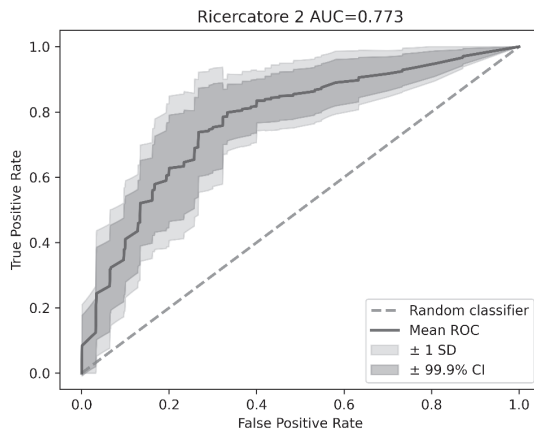


Fig. 3. Ricercatore 2.

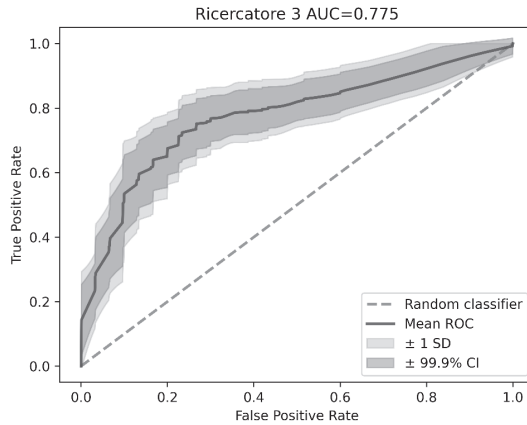


Fig. 4. Ricercatore 3.

The performances of these three unexperienced researchers are somehow very good, since they are watching home videos of real-life situations, where infants are 9-18 months-old.

On the contrary, performances by two other researchers were poorer, even if they were not bad. With these two researchers, we made a further training, and, after the first phase, they were asked to re-evaluate their own evaluations. These were their results after this second phase of training (re-evaluation). As it can be seen, they improved significantly.

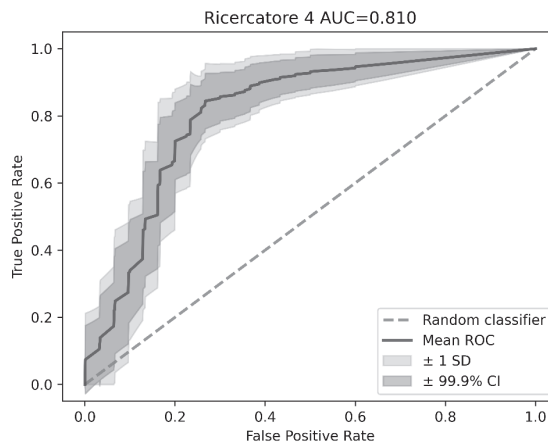


Fig. 5. Ricercatore 4.

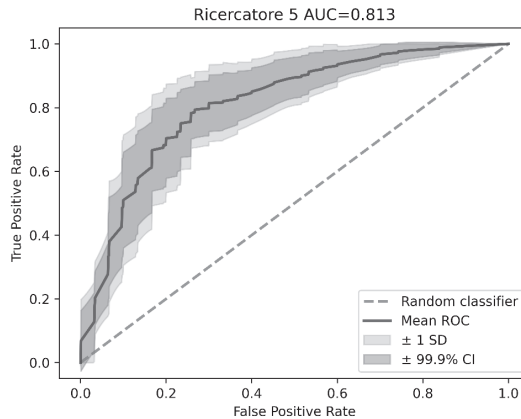


Fig. 6. Ricercatore 5.

AND NOW? SOME FINAL REMARKS

As always, there is a dark side. In the first paragraph, we saw that ADOS scored 0.89 in sensitivity, but it also scored between .81 – .85 in specificity. This means that it was perfectly capable of discriminating Autism Spectrum Disorders from other neurodevelopmental pathologies, like apraxia, attention disorders, Joubert syndrome etc., whereas the NeMo methodology does not. It discriminates quite well between typical development and not typical development, but it does not divide comparably well ASD from other similar pathologies. This looks like a downside. However, it is not. Indeed, NeMo methodology can be used for screening by the families, the teachers and by the health institutions in order to catch possible impairments in the infants that can be later taken into care by neuropsychiatrists and health centers. This is why, in the Joint Staff Training Event of the project that took place in Nicosia, Cyprus, from 27 to 30 September 2021, the Unibo team trained the other teams of the project in the NeMo observation methodology. Indeed, for the last year and half of the NeMo project, pre-primary teachers will use the methodology we have presented here in their schools in Slovenia, Sweden, Spain, Italy and Cyprus. This will permit our team to collect performance evaluations and new data in order to improve the system, making it more robust, and, making the methodology more effective.

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ENDNOTES

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² However, in their paper of 2021, van't Hof et al. performed a systematic review and meta-analysis (statistical analysis that combines the results of multiple scientific studies) for studies published between 2012 and 2019 to evaluate the current age at autism spectrum disorder diagnosis. They included 56 studies that reported the age at diagnosis for 40 countries (containing 120,540 individuals with autism spectrum disorder). Results showed the current mean age at diagnosis to be 60.48 months (range: 30.90-234.57 months) and 43.18 months (range: 30.90-74.70 months) for studies that only included children aged ≤ 10 years.

³ See Gallagher, Hutto 2007; Threvarthen, Hubley 1978, Paolucci 2020.

⁴ See Fontanille 2004, Pennisi 2021.

⁵ For a discussion on this topic, connected to Social Motivation of ASD, see Paolucci 2021.

⁶ For how we handle privacy aspects of our work, please see: <https://site.unibo.it/nemoproject/en/support-the-project>.

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