

INCLUSIVE SCIENCE EDUCATION AND ROBOTICS

STUDIES AND EXPERIENCES

Edited by
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Introductory essay. Disability at School: The inclusion is not ambient music

by *Matteo Schianchi*

Inclusion is by now an ordinary term when talking about schools and disabilities and, naturally, it must be declined in a broader perspective aimed at all pupils and all diversities. Remaining on the subject of disability, it has been said that this concept is now assuming a rhetorical function: it is ambient music because alongside its continuous proclamation no radical, widespread and significant changes are produced (Gardou, 2015).

Inclusion, in fact, is a complex horizon to be reached in a short time, it risks becoming a consolatory chimera if we do not return to focus, beyond the normative dimension, beyond the didactic technique, on cultural, social, pedagogical processes and on the very conditions that produce inclusion. Pupils with disabilities continue to be considered inferior individuals in everyday practice, in the eyes of adults and classmates, and in ordinary pedagogical approaches. In this context, obviously, no kind of inclusion is possible.

The Italian way of the school “for all” has long been the subject of analysis around its lights and shadows (Canevaro, 2007; Canevaro & Ianes 2016). There is also a lack of evaluation on the methodological procedures implemented (Cottini & Morganti, 2015). Certainly, despite significant experiences, there is still a lack of a well-established and organic system of inclusion in all schools: pupils with disabilities are mainly taken care of by support teachers. With the exception of primary schools, where teachers must now be trained in “special education” as part of their university course, the preparation of teachers is very poor. In many situations, pupils with disabilities have good individualized courses: their schooling proceeds on a parallel track that never meets that of the rest of the class, except on spontaneous occasions or in small projects. We have exceptional tools at our disposal to design and evaluate inclusion (Booth & Ainscow, 2011). Universal design

for learning, based on reshaping didactic approaches and tools on individual learning modalities, but according to logics attentive to the involvement of all students are still far away. Personalization is best done. The levels of social exclusion of young people with disabilities when they finish school, i.e. when the forced coexistence with their peers is over, are very high: from the age of 18 onwards they attend services, social situations, professional conditions “for the disabled” (Schianchi, 2021a).

In these pages I intend to focus on some aspects that are sand in the gears for inclusive schools. In other words, it is a question of considering, in synthesis, some dimensions that seem to me to be scarcely addressed not only in the school debate and academic reflection, but also in the same training courses for teachers, both support and curricular.

The origins of school inclusion

In 1977, the Italian school, with an unprecedented measure, adopted a decisive change in terms of teaching and management of disability situations: the establishment of a single school pathway for all pupils put an end to the separation based on the system of differentiated classes and special schools. This officially ended the era of separation of pupils with disabilities, of medicalization (Ascenzi & Sani, 2020). In reality, the measure was not unanimously welcomed. It is enough to reread the news of the following year to see how many pupils were physically removed from state schools for being “too handicapped”. In order to support the new law and try to counteract the prejudices that were strongly held by public opinion, an advertising campaign was launched to raise awareness, made up of commercials and posters supported by slogans such as: «Let’s stop being afraid of those who look different»; «Let’s help handicapped children fit in at school».

Looking at the posters and commercials of that campaign on the web brings us face to face with messages, linguistic and social codes that may seem very distant today. Yet, some issues such as the fear of the different with disabilities evoked by those slogans have not yet been deeply elaborated. To better understand the cultural climate of those years, and the scope of the legislative measure, another example is sufficient. A few years earlier, one of the first experiences of families with children with disabilities organized in Versilia (Tuscany) and narrated by a documentary (“L’estate più bella”, 2018) had been strongly opposed (Alimena, 2021). In fact, such

ordinary issues as accessible schools and holidays for people with disabilities continue to pose problems even today. After all, special schools, both public and private, continue to exist (Merlo, 2015); meeting disabled people in a holiday center continues to be a nuisance (Onnis, 2021). Moreover, the refutation of school inclusion of pupils with disabilities is beginning to have a certain scientific credentials (Ianes & Augello, 2019).

School inclusion was actually popularized with the UNESCO Conference in Salamanca (1994). The history of special education also distinguishes between the years after 1977, defined as the phase of inclusion, the 1990s, based on the concept of integration, and today's, which began with the new millennium, centered on the notion of inclusion. The latter, in the school context, is defined as a process oriented by cultural, political and ethical choices made by school models aimed at building an educational environment capable of welcoming everyone, focusing on participation and without excluding: everyone's differences (disability in our case) must be addressed in everyone's classes, according to specific strategies and methods that address those conditions, not according to a logic that excludes on the basis of criteria of normality.

More generally, the concept of inclusion linked to disability stems from a set of instances that redefine the very nature and essence of the issue, the participation and social roles of people. From the 1990s onwards, the social model of disability was definitively discussed, with the first formulations among disability activists and scholars dating back to the 1970s. According to this approach, it is not impairments as such that lead to a specific social condition of disabled people under the sign of exclusion. On the contrary, it is a social issue: in order to avoid the social exclusion or imprisonment of people with disabilities within specific institutions, the focus of the issue must be shifted from the deficits (which exist and are not to be denied) to the ways in which the political, social and educational contexts respond to the specificities of those individuals. Some commonly used tools or regulatory guidelines have supported this social definition of disability. For example: the bio-psycho-social classification of functioning and disability (ICF, 2001) adopted, as a rule in Italy, as one of the tools on which to base the school inclusion of pupils with disabilities; the UN Convention on the Rights of Persons with Disabilities (2006 and Italian law since 2009) which reasons in terms of the human rights already inherent in persons with disabilities, pointing the finger at forms of discrimination. Reasoning in terms of inclusion therefore means shifting the focus from deficits to the system of contexts,

relationships and supports that favour the participation, self-expression and learning of people with disabilities.

Certainly, the cultural and conceptual instances, the necessary tools and the radical individual and collective changes to achieve inclusion are not assimilated by decree. The idea of disability as a deficit, as an objective obstacle that prevents people from doing things normally, remains widespread; in this condition people must be assisted so that they can satisfy their basic needs. This is the belittling and interiorizing idea that remains of disability: nothing to do with inclusion.

Discomfort in the face of disability

The long presence of pupils with disabilities in ordinary school life, their management by specific figures such as support teachers, educators, assistants, educational processes and everyday school life that unfold through tools, methods, relational contexts that we know to be articulated, complex and contradictory have made us forget something that is constantly present: disability poses a problem. Basically, the handling of these now ordinary presences in the school world has led us to ignore the psychological, social and relational discomfort that assails us when we are faced with disability, all the more so if it is of a complex type. Non-ordinary functions, languages, ways of relating, communicating and learning, difficult and painful situations, which we sometimes have few tools to decipher, pose problems for us and, in the end, disturb us. Even if we do not say so openly.

This uneasiness is an implicit deflagration on which research and teacher training should focus (Schianchi, 2021b).

The dynamics and sacrosanct principles of inclusion based on the idea that through daily attendance, the sharing of places, relationships, educational processes between “able-bodied” and “disabled” people are often left to spontaneous dimensions, to purely emotional approaches and rarely the subject of reflection. The sharing of places and experiences between different people is necessary and unavoidable, but it does not spontaneously and magically erase either the subjective discomfort in the face of disability or the dynamics of interiorization of the people who have it. On the contrary, the social and psychological literature has for some time been reminding us that the psychological discomfort caused by disability is continually present, deep-seated and cannot be neutralized even by greater knowledge (Braud,

2003). Forms of stigmatization and contempt towards those with a disability do not necessarily reduce with familiarity (Goffman, 2003). Some attitudes of positive acceptance of diversity at an explicit level are contradicted by implicit forms of rejection (Volpato, 2019). The processes of interiorization of people with disabilities are culturally and socially deeply rooted, to the point of being natural, and continually subject to renewal (Schianchi, 2019). The origins of this discomfort are, at the same time, psychological, social and cultural.

For some time now, a concept coined by Freud in 1919, the uncanny, has been introduced into the field of disability (Sausse, 2006). According to the father of psychoanalysis, when faced with different types of impairment we are disquieted, a sensation that lies in the sphere of what is frightening to us, causing anguish and horror. It is our unconscious that drives the mechanisms of this feeling, that weaves its threads. Uncanny is not what is unknown to us (and of which we can be afraid), but what should have remained hidden, secret, but instead, has re-emerged. It is something that had become extraneous through the process of removal and instead suddenly resurfaced. In addition to death, disturbing situations include epilepsy and madness, as well as infirmities of the body: mutilations and non-ordinary bodily manifestations (Freud, 1969).

Since it is always unforeseen, unpredictable, and undesirable, disability has a traumatic effect that imposes itself on our psyches: it prevents them from thinking about and harmoniously integrating the elements of the external world. In the face of disability, our gaze is placed in front of an absurd dimension that we cannot understand. It is impossible to make sense of this situation. The difficulty in relating to disability is not only in our unconscious, but in our way of thinking about and experiencing the body. Here another interpretation comes into play that is useful to consider.

We know, in fact, intimately and in the very materiality of our lives, the importance that our body has in the construction of our biological, psychic and social world. Don't we always find it difficult to relate to the complicated evolutions of the body, with its explosions, hesitations and decay? We sink into our bodies. That is why when its agreement with the world breaks down, our existence feels the ground beneath its feet missing and falls into uncertainty (Binswanger, 2007).

It is here that we all share the issue of disability as an attack on the body and its integrity. For some (the person with a disability) it is an experience. For some others (the person without a disability) it is a fear, a possibility

never escaped forever. The person with a disability in front of us, and the person with a disability in front of him/herself both when he/she has lost his/her own bodily integrity in the course of his/her life and when he/she has never had it, refers to a possible aspect of our being in the world. It reminds us of our difficulty in thinking we can live with a disability, but also of the inevitable decline in life. The encounter with disability calls into question the existential alternatives, continually based on the body, between life and death, between ideal and real. According to this further interpretation, the uncanny, unlike Freud's thought, is not linked to the unconscious. That is, it does not bring out what was hidden and should have remained hidden but is precisely the becoming visible of the original existential anguish that characterizes our being in the world.

The socio-cultural origins of discomfort

These purely psychic dimensions originate in the body: the only common denominator among humans, the only way of grasping what we call the individual, the basis of our being in the world, of our existence, of our identity, of our relationships. In fact, disability is not a matter for some individuals, their families and the professions and services that deal with it: it is a matter intrinsically linked to the very nature of human beings. What we now call disability is a biological and social condition that characterizes the history of humanity. The whole body and the disabled body have always existed. There is no human history without impairment. However, this condition is considered abnormal, deviating from normality. On the contrary, human biological-social nature is made up both of integrity and of congenital or acquired bodily impairments caused by diseases, genetic errors, infections, accidents, incidents of various kinds, clashes, war-military events, accidents at work, forms of punishment and torture, self-damaging behavior, poor hygiene and food conditions. This non-unique biological nature, but made up of both bodily dimensions, is continuously removed, denied in all social and cultural dimensions and in our own psyche.

All types of disability (physical, intellectual, psychic, sensory) always involve, first and foremost, functions and uses of the body. It is precisely because it involves the body that disability is a universal anthropological issue. The body is not simply a biological envelope: there is never a division between body and soul, between soma and psyche, between sensibility and

intellect, between instinct and spirit. The body, the relationships we build on it and the image we have of it are part of our interiority. In the body, on the body, our psychic sphere and our social sphere intersect, intertwine seamlessly, it is a precondition. For these reasons, psychic and social, psychic because social and vice versa, disability always concerns us, all of us, individually and collectively, and continually poses a problem. It is a theme that questions the idea that the human being has of his own nature. It raises questions about the ways and means of being in the world, about the boundary between human and non-human, between normal and abnormal, between life and death. It raises questions about the reasons why impairments develop that lead to deviations from what is considered normal, about their meaning, about the possibility of treating them, healing them, managing them, normalizing them. In other words, the disabled body highlights something that concerns all bodies. The social cannot be abstracted from the body. Bodies are, always and since always, in practice, subjected to social and cultural readings and constructions. This is true in living bodies and in thinking about them. The body, including the body with disabilities, is always, continuously and immediately invested with social values and meanings.

In our daily lives, we unconsciously classify bodies and people. Bodies are always classified in relation to gender, age and performance (Mauss, 2017). Disability casts doubt on the fact that we can fully fill the social roles that compete, at all ages and as they evolve, for women and men. The presence of impairments calls into question the reality and the sense attributed to the things of the world, for which those who, through their bodies, are able to guarantee the production and reproduction of the social order have social value: «Since the classificatory schemes through which the body is perceived and practically evaluated are always doubly founded, in the social division and in the sexual division of work, the relationship with the body is specified according to the sexes and according to the form assumed by the division of work between the sexes according to the position occupied in the social division of work» (Bourdieu, 2005, pp. 111-112).

Under the aegis of this whole series of relationships we have with the body, the person with a disability, because of that body and its compromised functions, seems to us, intuitively, not very suitable (in-able, dis-able, in-valid) to be in the world: his existence is problematic. The ordinary individual for us is the one who acts to produce value and increases his value through relationships, work, exchange. The psychic, social and cultural reasons for which disability has always posed a problem contribute to fearing

this intrinsic dimension of humanity, to considering it as abnormal, unnatural and undesirable. The status of inferiority that we attribute to individuals of any age with any kind of impairment is therefore pure and unconscious automatism. Stigmatization, discrimination, more or less unconscious pietism, forms of welfare, reduction to inferior individuals and citizens, as is well known, are clear consequences of these dynamics.

The persistence of stigma

The concept of stigma is well known and was coined by Goffman in 1963 precisely because of disability issues. Stigma is not a characteristic of the individual, a mark stamped on his or her body, but a social relationship: it is a point of view, a way of considering individuals with certain characteristics. This form of classification, which establishes a hierarchy of people, occurs and is reproduced in relationships: «one must not lose sight of the fact that what counts is the language of relationships and not that of attributes» (Goffman, 2003, p. 161).

The presence of stigmatization mechanisms continues to be present even in the social and professional environments in which disability is routinely present. Moreover, familiarity does not necessarily reduce contempt (Goffman, 2003). It is no coincidence that a more recent interpretation of stigma calls into question precisely situations in which there is disability (communities, social and health services) and professional figures related to them (Kleinman, 2002). In this meaning, stigma is not linked to a denial of the other and his or her non-ordinariness: it is the expression of a specific moral sense and a series of emotions and feelings that demand to be affirmed. It is the moral sense of discomfort in the face of non-ordinary functioning that continuously invokes the need for ordinariness, the normal course of things. Stigma is thus an element through which the members of a local community, a microcosm, express and defend their adherence to certain values: this can lead to the adoption of stigmatizing, if not violent and discriminatory criteria towards those who are considered responsible, with their anomalous presence and functioning, for challenging them.

Stigma becomes the unconscious and easy escape route, a form of survival, of the teaching and educational figures who work with disabilities. It is indeed difficult to enter into a relationship with non-ordinary functioning: the relationship involves a long work of mutual understanding and adaptation

that also needs to be understood, supported. It is complex to deal with families who bring weariness, experiences, uncertainties and radical problems. It is difficult to disentangle a parent's illusory hopes, dreams, lack of awareness or partial awareness of the difficulties of a child with disabilities and the fact that professionals and services themselves may not see certain possibilities and potentialities. All these dynamics, when they do not find relevant ways to be understood and processed (and it must be the prerogative of every socio-educational service to provide this), easily find their solution in stigma. They concretely return to the idea that it is those behaviors, those deficits that represent the real problem. On the contrary, the crux of the matter, without denying the difficulties, is the individual and collective inabilities of the same service to deal with those complexities. Stigma is triggered in this inverted dynamic. That is, it is triggered in every possible context, in defense of values, dictates, conventions of norm and normality. The diversity of disability challenges them. So, instead of allowing oneself to be questioned by finding ways, strategies, behaviors, relationships that favour respect for each body and functioning, i.e. for each individual, it is much easier to point the finger at the anomaly and normality of the other.

Each person's beliefs about disability are based on prejudices, stereotypes, and experiences, but these last two steps are often lacking. However, the inclusive perspective, in order to take shape, needs a cultural substratum that must become a specific object of reflection and construction: the messages implicitly conveyed by teachers with respect to disability contribute to forming this culture in learners.

At the root of all these highly articulated dynamics is the general persistence (although there is no lack of significant experiences) of stigma. Not stigma in its basic, easily identifiable and censurable dimension, but stigma as an anchor of everyday life, as a means of defending ordinary values and functioning. Of course, all this happens without intending it, nor planning it, nor openly desiring it, but it happens. It continues to produce forms of interiorization of people with disabilities. And it will continue to happen until these dynamics become the object of analysis, confrontation, discussion, shared debate, throughout the school world and academic research itself. Let us look at some of them.

Let us start with words that seem innocent (to you this check to others another), with gestures that seem trivial (the positioning of desks in a classroom and the reasons behind them). We think of the time spent by pupils with disabilities outside the classroom, of their being looked after by figures

(specialized teachers, educators) whose status is devalued. Is this not enough to tell us that this necessarily produces a devaluation in these pupils, in their peers, in the whole school world?

Let us add the use of diagnostic categories, not to mention acronyms, with which these pupils are commonly identified (the BES, a DVA, ADHD, etc.). Their accumulation in current and administrative language ends up making them effectively “specific and inferior subjects”, as well as becoming categories of school spirit. The very naming of specific tools that are certainly necessary (diagnosis, PDP, PDF), the idea that they have to carry out “minimal” school programs with dispensations, compensations, alternative tools that trigger like an unconditional reflex. All this, in everyday language and practices, produce a stigma linked to the difficulty of coming to terms with diversity is motivated by a school moral sense that defends its own values, its own procedures, its own hierarchies of knowledge and individuals.

It is not yet common sense that schools are no longer governed by the imperative of national programs, but by specific educational objectives (law 59/1997): it is the school programs that must educate by adapting to the needs and specificities of children (including the presence of disabilities) and not vice versa. The student must be placed within the educational project, recognizing the potential and specific needs of each one. On the contrary, one continues, by instinct, to reason and act with educational-didactic ways based on the average normal pupil. Disability is not considered as a characteristic that must be taken into account in order for that specific pupil to reach the maximum of his or her potential and possibilities (and there are many in each pupil, even the most impaired), but continues to be thought of and experienced as a negative characteristic, which prevents pupils from doing as others do, that is, from being normal. It is always thought of as an inferior form of schooling, i.e. of life. The conceptual basis with which we view disability is always that and continues to produce stigma and inferiorisation. All these everyday dimensions are part of the labelling processes inherent in stigma.

The certifications, diagnoses, all the medical, administrative and bureaucratic procedures and processes to access services and benefits, specific to one’s condition (and to which one is entitled), and which motivate and justify the professional figures, devices and money that go together, enter the school in a whole circuit of thoughts, practices, perceptions and relations that are, in fact, a continuous occasion for the production of stigma.

Facing us, on a daily basis, are

the myth that the integration and teaching of pupils with disabilities must be based on medical and bio-structural knowledge [... the] need for the medical “piece of paper” to activate additional resources and teachers often still believe that a functional diagnosis from the ASL is needed in order to be able to construct meaningful individualized programming [...] an individual-medical legal culture [that] weakens the pedagogical one and the work of the school, delegitimizes curricular teachers and delegates special ones, gives breath to specialist and hyper therapeutic sirens (Ianes & Augello, 2019, pp. 44-45).

The presence of new tools for the construction of school paths suitable for pupils with disabilities (the ICF-based individualized plan), even when it becomes fully operational and if it works over time, will not be sufficient to produce inclusion, to erase the stigma if cultures, people, contexts and relationships are not changed. We are still faced with a school that confirms inequalities even in the face of disability, despite egalitarian and inclusive principles.

Inclusion and liminality

Another concept is particularly interesting for interrogating inclusive practices, that of liminality. The concept was introduced in disability studies by taking up some classics of anthropological thought. Adopting some concepts related to rites of passage, Murphy (2017) states that people with disabilities are always, constantly, by their essence in an intermediate condition, of liminality, a social and cultural mechanism whereby they are considered neither sick nor healthy, neither dead nor fully alive, neither outside society nor fully participating. This is why people with disabilities live constantly, in a state of social suspension: they are neither flesh nor fish, they exist in partial isolation from society as persons, undefined.

This concept has been used to analyze how some people with intellectual disabilities had left an institution to go and live, in co-housing, in a city neighborhood: their everyday life had been built halfway between the institution and the neighborhoods community, which does not recognize them as its members by constantly thinking of them as those in the institution (Calvez, 1994). The school life of a pupil with disabilities who attends an ordinary school but is often, if not continuously, separated from his or her peers, only with the support teacher or in a special classroom, is also liminal.

Equally liminal is the everyday life of young people who attend schools, specific recreational and rehabilitation services and who end up in a world of their own (of relationships, of reference figures, of friendships) even if these services are “mixed”, i.e. involving contact with facilities and people not related to the disability.

In this sense, liminality as a tool allows one to consider, in practice, the relationships experienced by persons with disabilities in order to interrogate the socio-cultural assumptions and repercussions of educational actions and processes. It is therefore useful to grasp, to explore, a series of aspects of the social experience of persons with disabilities and to move away from static and often oversimplifying readings, generally based on antithetical categories such as inclusion-exclusion. It also makes it possible to measure and evaluate what it means to be, eventually, included by focusing attention on the fact that being “within society” (i.e. not in separate places or situations) does not at all mean being included, participating. This presence may not be full, authentic, resulting in liminality. The fact of participating in a social gathering says nothing about the quality and characteristics of that belonging. The experience of pupils in state schools, for example, tells us this. Not only in everyday life conducted in the famous support classrooms, but at the end of the school day or cycle, when these children and young people often remain separated from the relationships and sociality of their classmates. In other words, it is the nature of belonging (or non-belonging) that concretely imprints a mark and a meaning on the experience of a person with disabilities.

Liminality, also, is a concept that, like that of stigma, questions us deeply and allows us to understand, in a different light, the assumptions with which we think and consider people with disabilities and how they experience these dynamics. Even with liminality, and despite certain criticisms that continue to start from a heuristic deficit that does not consider the whole prism of the components of disabilities and all the cultural, social and symbolic aspects that precede the socioeconomic mechanisms themselves, the very definition of disability and the social position that people are given are always at stake. The condition of liminality is the result and consequence of dynamics (thoughts, words, actions) that affect persons with disabilities and from which they can hardly escape. More precisely, it is constructed through a twofold movement: 1. persons with disabilities are given specific attention, treatment and services; 2. persons with disabilities and those who deal with

them know that these collective and individual actions can never guarantee social inclusion.

Murphy affirms that this condition of liminality leads one to be in a situation between two antithetical experiences, highlighting the lacking, deficient, half-hearted character of the experience, without a precise identity, neither flesh nor fish. But this position between one thing and another is continuous, in everyday life and throughout existence: between inclusion and exclusion, between normality and abnormality, between difference and homologation, between ordinary services and specialized institutions, between discourses of inclusion and practices of exclusion, between being an ordinary citizen and a person with special needs, between being noticed and going unnoticed, between access and inaccessibility, between ability and deficit, between compensation and overcoming the limit, between autonomy and dependence, between family and external relations, between rights and assistance, between aspirations and needs.

Conclusions

The inclusion of disability, also in schools, is not a dynamic that is produced neither by decree, nor by guidelines, nor by educational technique, nor by good feelings. For this reason, teachers, but also the university and research world, cannot be content to move in normative or ideological circles. A reflection from a few years ago still applies:

Acknowledging “different” therefore means not being under the illusion that it does not constitute a real problem of intervention, that it can be calmly assimilated to its term of diversity with the wishful thinking of socializing rhetoric, political apostolate, private philanthropy and false bourgeois consciousness. But to truly recognize diversity is to re-appropriate it to social living. Its “re-appropriation” is in fact required by the fact that the “diversity” of the handicapped can be recognized in its real meaning not as danger or extraneousness, but as a differentiated mode of the “being” of every human person (Massa, 1986, p. 178).

The condition of disability has always been the object of practices and cultures that have their core in inferiorisation. The more complex the impairment, the stronger the dynamics of inferiorisation. No educational process can be said to be inclusive if it does not succeed in producing, in the everyday

life of people with and without disabilities, concrete experiences that combat, and do something different from, those forms of inferiorisation.

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