

DIFFERENZE

DIDATTICHE INCLUSIVE

9

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# DIFFERENZE

## DIDATTICHE INCLUSIVE



La différence est la légère, l'aérienne, l'affirmative

GILLES DELEUZE

La collana intende costituire un luogo di incontro tra riflessioni, esperienze e sperimentazioni che rappresentino le diverse declinazioni del concetto di inclusione nella scuola italiana e nel panorama nazionale ed internazionale della ricerca scientifica sulla Didattica Speciale. Il recente cambio di paradigma dall'integrazione all'inclusione, recepito anche a livello istituzionale, si configura come ulteriore tappa di una storia innovativa della didattica italiana e offre l'opportunità per un ripensamento della Didattica Speciale, a partire dall'idea di differenza come *singularità positiva* cara a Deleuze e dal riconoscimento del processo di insegnamento-apprendimento come sistema complesso adattivo, in grado di cambiare in seguito all'esperienza, composto da un numero elevato di parti interagenti in modo non lineare che danno luogo a comportamenti globali. Da questa prospettiva, la differenza appare non più come una *condizione liminare*, rispetto alla quale esclusione o integrazione si pongono come estremi di un unico *continuum*, ma come sintesi risolutiva della complessità, come complessità accessoria, "semplice" perché relativa alla situazione locale, come luogo di nascita di una singolarità che si stabilizza definitivamente attraverso la variazione. In questo quadro, il *focus* della collana sulla dimensione educativa e didattica rappresenta un *trait d'union*, una lente attraverso cui leggere ed interpretare una serie di interventi che, nel tentativo di rendere la complessità del fenomeno osservato, spaziano dall'ambito clinico e terapeutico alla riabilitazione, dall'aspetto politico-istituzionale alla dimensione sociale e antropologica della *differenza* in educazione.

La collana è *peer reviewed*.



*Vai al contenuto multimediale*

Felice Corona

**L'X fragile e la gestione  
didattica inclusiva**

*prefazione di*  
José Guzmán





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## Foreword

José Guzmán\*

The text entitled *L’X fragile e la gestione didattica inclusiva* is well-structured and clearly explains the research-related aspects on the etiology and epidemiology in terms of research, also on an international level.

Educating a child with Fragile X Syndrome challenges the professional knowledge and practice of teachers. Every child is unique in their needs and abilities and all good teachers consequently differentiate their practice: but the child with exceptional needs requires something “exceptional” from the teacher.

Diagnostic elements and psycho-therapeutic interventions are highlighted with precision and attention. The potential and limitations commonly associated with children with the Fragile X Syndrome is widely investigated. The three areas taken into consideration are the communicative, socio-behavioral and cognitive dimensions.

\* President of the Spanish Federation of Fragile X Syndrome

The analysis carried out on the aspects characterizing the Fragile X Syndrome is particularly interesting, both related to the language connected to emotional feedback, and to behavioral characterizations, which can be placed between hypoactivity and hyperactivity, as well as cognitive functions.

The easy and practical applicability of educational strategies proposed as cultural artefacts are valid inputs on which to reflect to start planning ecological and inclusive contexts as educating communities.

In particular, a stimulating socio-psycho-educational investment is proposed which, through forms of experiential learning and pedagogical-didactic examples, intends to acquire concrete ways to deal with even the small daily difficulties.

The paper, in its aim to provide a general view of the problem, investigates the teaching strategies and methods to develop higher-order skills and prosocial behavioral skills, taking into account the intrinsic needs and difficulties related to Fragile X.

Every educator, teacher or professional who intends to take care of the development and training of the individual must pose this challenge as the ultimate goal.

It is clear that the challenge becomes even more difficult when a child has a disability as that of the fragile X syndrome, which, because of its patholo-

gy, struggles to understand the meaning of what is happening around him or her.

The following work focuses precisely on this challenge and attempts to provide a general overview of the situation and, subsequently, to investigate how, through teaching, it is possible to help these individuals, especially children, to develop educational, social and behavioral skills with strategies and methods appropriate to their specific needs.

An appreciation is due to the author Prof. Corona, for having provided an interesting and exhaustive text to the scientific community and to the many international organizations involved in the care and education of children with Fragile X Syndrome.

The Spanish Federation of Fragile X Syndrome (FESXF) is a non-profit organization, consisting of fourteen associations of families from different communities in Spain with the aim of guiding, facilitating, advising, promoting research, collaborating in educational and scientific areas, people, centers, entities or professionals dedicated to the study and care of fragile X syndrome. The Federation is a member of the Spanish Federation of Rare Diseases (FEDER), EURORDIS and the European Network of Fragile X Syndrome.

Article 22 of the Spanish Constitution recognizes the fundamental right of associations based on the principle of associative freedom. Currently, the Organic Law 1/2002 March regulates the right of association of the FESXF and develops its work relying on that law.

Fragile X Syndrome is the most common hereditary form of mental retardation. It is estimated that in the general population 1 out of every 4000 males and 1 in every 6000 women are mentally retarded due to this syndrome, and 1 in 250 women are healthy carriers, thus becoming the second pathology of intellectual disability in frequency after Down Syndrome and the first hereditary dysfunction in mental retardation.

Despite the prevalence data, the characteristics and complications generated by SXF is not sufficiently known in professional groups, as in different administrations or in society at large. Throughout the twelve years of existence of the FESXF, the associative movement on the Fragile X Syndrome has been mobilized and committed to respond to this ignorance. During these years, it has tried to alleviate this lack of information, firstly with families who receive the diagnosis with intervention programs aimed at the proper dissemination of these characteristics in order to the correct intervention of those affected and their families.

In this sense, each organization of the associative movement on the Fragile X Syndrome has developed activities in its area of influence, collaborating at times with other entities or organizations. This work has been an important effort and has been marked by a palpable lack of necessary economic resources.

Despite the work done, today we continue to find that the deficiencies detected that led to the Constitution of the different associations and the Federation, are not sufficiently served. Important steps have been taken, but not sufficient to cover those gaps.

There are still different aspects that deserve further attention:

- it is not ensured that the genetic test of the indicated diagnosis carried out provides complete reliability and that the results are provided in a reasonable period of time for the interests and future of the people;
- health care is not appropriate on many occasions;
- the maximum potential in educational interventions is not given;
- there is no real inclusion in society;
- the inclusion into the working world is rare;
- there is not enough funding for the research.

With the desire to implement this coordinated commitment and joint interventions, the Spanish Federation of Fragile X syndrome was born. The work developed so far has been possible thanks to professionals who collaborate selflessly with our entity, and the support received from official bodies such as the Royal Board on Disability, the Ministry of Health and Social Policy, the Ministry of Education and Social policy and some private entities.

The FESXF is constituted as a group of associations and is motivated by the conviction that the union between the different associations will allow to exert the necessary force to achieve the common objectives, which are the following:

- early diagnosis;
- use of reliable diagnostic techniques in accredited reference centres;
- prevention;
- prenatal diagnosis in accredited reference centers;
- genetic counseling by accredited personnel;
- creation of a census of affected, carriers and families;
- carrying out the Fragile X Syndrome test in newborn infants;
- medical follow-up;
- early care;

- educational intervention that allows to obtain the maximum potential of these people;
- social integration;
- opportunities in the working world;
- attention to families;
- preimplantation diagnosis covered by public health and carried out by accredited centers for genetics and reproduction;
- reducing the cost of drugs: matching with the prescriptions for pensioners;
- research funds.

Special attention is also given to people affected by spectrum X fragile, such as those suffering from Tremor Ataxia syndrome (FXTAS) and early ovarian failure associated with premutation. Both will be part of the claims of our entities in order to give adequate attention and devote the necessary means for the investigation that should tend to alleviate the effects and the search for its cure.

The priority objectives of the FESXF are as follows:

- a) maintain and promote the role of FESXF as a state benchmark;
- b) participation of the associative movement in order to promote the development of the objectives raised;

- c) coordination with other State entities of wide representation such as AS FEAPS, FEDER or CERMI;
- d) establish contact with other entities of international scope; relaunch and enhance communication tools, such as the web and the e-newsletter;
- e) encourage and promote research papers and studies that are relevant to the organizations and the fulfilment of the objectives of the FESXF;
- f) develop useful projects for the associative movement: training, awareness-raising, dissemination ecc.;
- g) define common and general projects, avoiding duplication, such as informative or dissemination campaigns; creation of work commissions;
- h) develop quality projects and continuously monitor their practical impact;
- i) prioritize and specialize in activities that are aligned with the aims of the FESXF;
- j) create strategies for competitive improvement: to create networks, to carry out joint actions with other similar entities, ecc.;
- k) decide collaboration in clinical studies that are proposed by the professionals who usually collaborate with our entities and by other professionals who address us, provid-



ed they are governed by the current ethical norms.

However, it is not effective for each organization to challenge this problem in isolation. An effective response requires a joint, well-articulated and coordinated interventions, capable of promoting health, education and social policies as well as in all other areas which are influenced by the Fragile X Syndrome. In short, we need a joint effort, where our actions are complemented and empowered and from where we can take concrete measures that increase our capacity and efficiency to meet the challenge of achieving the highest goals for the issues related to the Fragile X Syndrome.

This contribution of Prof. Felice Corona adds on to the scientific literature representing a useful and necessary tool to be explored and to stimulate new ideas for reflection and research that can eventually be carried out with our FESXF (Spanish Federation of Fragile X Syndrome).



## Prefazione

JOSÉ GUZMÁN\*

Il testo dal titolo *L'X fragile e la gestione didattica inclusiva* si presenta ben strutturato ed esplicativo negli aspetti inerenti l'eziologia e l'epidemiologia, sul piano della ricerca anche a livello internazionale.

Educare un discente con la sindrome dell'X Fragile sfida la conoscenza professionale e la pratica dei docenti; ogni bambino possiede bisogni e abilità specifiche, e tutti i buoni insegnanti di conseguenza personalizzano la loro pratica educativa: ma il bambino con esigenze speciali richiede all'insegnante qualcosa di "eccezionale".

Nel testo vengono evidenziati con precisione ed attenzione elementi diagnostici e d'intervento psico-terapeutico. Si indaga sulle potenzialità e i limiti comunemente associati ai bambini con la sindrome FXS, in tre aree di interesse: comunicativa, socio-comportamentale e cognitiva.

Risulta particolarmente interessante l'approfondimento effettuato sugli aspetti caratterizzanti

\* Presidente della federazione spagnola dell'X Fragile.

l'X fragile, relativi sia al linguaggio connesso ai feedback emotivi, sia alle caratterizzazioni comportamentali, collocabili tra ipoattività ed iperattività, nonché alle funzionalità cognitive.

La facile e concreta applicabilità delle strategie didattiche proposte come artefatti culturali costituiscono dei validi input su cui riflettere per avviare progettazioni di contesti ecologici ed inclusivi come comunità educanti.

In particolare, viene proposto uno stimolante investimento socio-psico-educativo che, attraverso forme di apprendimento esperienziale ed esempi pedagogico-didattici, intende puntare all'acquisizione di modalità concrete per affrontare anche le più piccole difficoltà quotidiane.

Il testo, nell'intento di fornire una visione generale della problematica, prova ad investigare strategie e metodi di insegnamento per lo sviluppo di abilità di ordine elevato e competenze comportamentali prosociali, tenendo conto dei bisogni e delle difficoltà intrinseche connesse all'X Fragile.

Ogni educatore, insegnante, professionista che intenda occuparsi di sviluppo e formazione dell'uomo, deve porsi questa sfida come obiettivo ultimo.

È chiaro che il compito diventa ancora più arduo con un bambino affetto da X Fragile, il quale, proprio per la natura della patologia, fatica ad organizzare il senso di ciò che accade attorno a sé.