LESSION 9

FOR TEACHERS-GENERAL SUGGESTIONS

Students suffering from Rare Disease are usually very affectionate, sensitive/resilient and diligent. They strongly want to be able to have friends and be part of their school community. Although they face some

particular challenges, with proper support and understanding, “our pupils-rare” play, learn, study, and live successfully in our communities.

Useful tips for school integration of pupils with rare genetic syndrome

The school integration of children and adolescents with rare genetic disease **must be addressed by all those working in the school (school** manager, teachers, school workers) bearing in mind some elements that permanently affect the lives of those affected by these syndromes, that is why we make a presentation of cases in storytelling.

SCHOOL INTEGRATION INTO INTELLECTUAL DISABILITY, GENERAL ADVICE.

The school integration of children and adolescents with rare genetic diseases should be addressed by all those working in the school (school manager, teachers, school workers) bearing in mind some elements that permanently affect the lives of those affected by these syndromes according to the priorities of the pathology, including serious and intellectual, e.g.:

• the intellectual deficit, which is normally medium serious and varies from subject to subject; • behavioral problems arising from emotional fragility and from the difficulty of self-control in the presence of relational difficulties and which do not rarely result in manifestations of a psychiatric nature (disruptive behavior, obsessive and compulsive attitudes, even if not serious forms of self-harm (skin Pikin), psychotic manifestations, stubbornness, etc.;

These elements affect the ability to follow the lessons with the rhythm of the other classmates and determine a discontinuous commitment that compromises school performance. The objectives must therefore be calibrated from time to time through **flexible individual projects,** attentive to the evolution of the student’s receptive capacity with regard to the contents of individual subjects and behaviors within the class.

The support **of the teacher is essential,**which must be as trained as possible, but **must not de-responsible professors in the** implementation of individual projects and in the pursuit of objectives.

Both professors and support teachers must pay the utmost attention and **caution in calling the rare sick pupil,** when he commits mistakes or misconducts with his/her companions or adults, so that the call is useful and does not provoke reactions difficult to manage, it must be accompanied by forms of psychological support (e.g. praising some gestures or some good initiative that the child/boy has done earlier). Moreover, the misplaced call can also become a mockery and mockery of some other members of the class and give rise to forms of bullying even submerged.
You should **never use food, game, other dear to the rare child as an incentive/pattern for a greater**

commitment, to achieve better goals, or to try to correct misbehavior (e.g. saying: if you do not, do this do not eat, do not play etc.), the child could connect him to his situations of discomfort and isolation from other companions and peers.

In the presence of **disruptive behaviors the pupil must be accompanied out of the class** until he has reassured or has ceased to have self-harmful or aggressive attitudes.

It is essential that **teachers, and school workers know, through parents and psychologists and doctors** who have good experience with the characteristics of syndromes, especially the most difficult, the description of the child, his character, his weaknesses and his illness. Under this

with regional/national associations with the Italian UNIAMO Federation, on whose site you can find news and knowledge tools.

When behaviors of a psychiatric nature appear, in general the problems must be addressed through a proper relationship with **the ALUNNO/INSEGNANTE/FAMIGLIA.** Through the ability of teachers to grasp situations of anxiety and emotional difficulty, to support him in these moments, to reassure him, great results can be achieved, while the clinical decisions will be defined by the attending physician and the family.

Every pupil must be reassured; a pupil with rare illness when he is reassured becomes more permeable to the things he has to learn at school and can manifest aspects also relational, in the relationship with his companions and with adults, surprisingly positive.

Teachers have to work a lot on the increase in the self-esteem of the child/boy, because the comparison with classmates is unfavorable to him. It is therefore important the ability of teachers to understand the moments of difficulty of the student, to be able to prevent emotional or behavioural or health crises and to manage them, supported by the family, when they occur.

Where the achievement of certain objectives is too difficult or results in inadequate behavioural reactions, it is necessary to be able to reduce and lower the targets so that they can actually be achieved. It is necessary to know how to grasp the moments of rupture of the pupil's psychological strength and know how to reverse, change strategy and change the paths set.

A teacher who **has a pupil with a rare intellectual or similar illness** in the classroom does not put himself in the condition, including through appropriate training, to properly manage the inclusion in the context of the child/boy's class, compromises not only the possibility of developing to an at least an acceptable extent the aptitude of the disabled person, but also the educational performance of all other pupils.

On the problem of **crisis management depending on rare genetic/metabolic pathology e.g. hunger,** the only remedy is to avoid, even that in the school there are machines distributing snacks and sweet drinks.

Problems arise especially in lower secondary school, when the child feels more inadequate than his/her companions and when adolescence begins, and becomes particularly challenging in school

In this regard, parents should be advised to choose the most suitable school paths for the child and their future.

Of great importance is the construction of a relationship between the pupil with disabilities and classmates. The problem does not arise so much in kindergarten, where it is easier to accept a child with disabilities in the group by other children.
But at the beginning of the next school cycles, in the first grade, first grade and first grade, it is essential to find the most appropriate way to make known to classmates the problems presented by the child/boy with rare illness, provided that he knows it.

It can be done through parents, when they hear it and when they are able to speak appropriately to the class, or through a figure who knows the syndrome (e.g. a psychologist or a social worker), with a meeting with all

the pupils in the class, in the presence of a teacher. **For this reason it is also advisable a cycle of meetings of RED in presence** where the children bring direct solutions to their peers in the social and school field.

Almost always, when this happens, the comrades no longer look with wonder, with suspicion and with distrust the companion other than them, who perhaps exhibits strange and uncomprehensible behaviors. They change attitudes and become very careful to build a relationship of sympathy and help. In this regard it is useful **to participate in the ErasmusKa210 RED project,** which will be very useful in suggesting through lived experiences (storytelling) strategies that can facilitate the construction within the class of a relationship of empathy and integration of a companion "different" from others.

Another fundamental aspect of educational strategies is the problem of rules. Children and adolescents with cognitive disabilities and rare disease, have poor ability to understand and assimilate the rules. This is all the more important the intellectual deficit is. **It is therefore necessary to focus on the acquisition of good habits.** The sedimentation of correct habits allows the disabled person to assimilate appropriate behaviors and to find that balance in daily life that helps him to better relationship with others and in the life of relationship in the various contexts he will face.

One last comment: teachers should not think about the inclusion of pupils with behavioural problems with standardized criteria acquired once and for all.
They must be able to question themselves and be available to training courses which it is not always easy to find, but which in some cases the same regional associations of rare patients make available by their own means and which have always been evaluated, by the teachers who have participated, of great value for the management of the classes where these young people are included; perhaps in some cases it can also be of use for "normised" children and teenagers.

ASSISTANCE TO THE HYGIENE OF THE FUN AT SCHOOL

Basic care for disabled pupils is a key part of the **school integration** process and its practical implementation contributes to the realization of the constitutionally guaranteed right to study.

However, the requirements relating to basic care for pupils with disabilities, and in particular those relating to personal hygiene and diaper change, continue to be the subject of debate and controversy between pupils' parents, **who claim their children's right** to hygiene care, and the school staff who should provide them. In particular, for many, there is still a doubt as to whether or not it is up to school workers or the assistant to autonomy and communication.

On this subject, the Miur intervened in letter No 3390 of 30 November 2001 which, in accordance with the contractual provisions in force at the time, requires school staff to provide care and hygiene assistance to pupils with disabilities, identifying them as a significant part of the process of integrating disabled pupils, participants in the **individual educational project of the pupil** and collaborating with teachers and the family in order to facilitate their school integration.
Currently, Table A of the current CCNL reads verbatim about the tasks of school workers: '**provides material assistance to disabled pupils... in the** useof toilets and in the care of personal hygiene, including with regard to the activities provided for in Article 47'. "Care for personal hygiene" must obviously also mean the change of the diaper and its cleaning, as also pointed out by the Court of Cassation, Section. VI Penale, by judgment No 22786 filed on 30 May 201, also refers to the question of the assignment, in the context of ATA staff, of

school staff in the state school also for the performance of the assistance tasks provided for by the professional profile, taking into account the gender of girls and boys, pupils and students, within the framework of the **human resources available** and allocated to each school institution.

In essence, the above rules merely reiterate that the lack of hygiene care, including the change of diaper, is **not the responsibility of the support teacher.**

Finally, we would reiterate that Articles 47 and 48 of the CCNL 2006/09 for Area A (school collaborations) provide for the performance of the tasks linked to personal assistance, assistance to disabled pupils and first aid.

EMERGENCY MEDICAL CARD

A document that should always be carried with you, the child and the rare sick boy, describing the possible medical complications of the syndrome, the main health problems, allergies and therapies in place in the individual case, as well as the personal information and contacts to be contacted in case of need

CURIOSITY: DID YOU KNOW THAT?
THE RIGHTS OF THE PATIENT
In June 2009, the National Rare Disease Centre of the ISS (Director Dott.ssa Domenica Taruscio), started a collaboration between the Association Crescere — Bologna (with the Avv. Ernesto Stasi) and the Association Prader Willi — Calabria (with Prof. Domenico Posterino) for the updating and extension of the "Guide From Constitutional Rights to Receivable Rights", prepared by the latter association and published in PDF format on the CNMR website.

The result of this project, to which the CNMR has joined, is the present hypertext characterized precisely by an intense use of hyperlinks and intended, as such, to provide an easy tool of documentation to those dealing with the world of rare diseases: we are convinced, as Professor Fulco Lanchester said during the presentation of the proceedings of the conference "Rare Diseases: research between ethics and law" (Rome, La Sapienza University, 14 February 2006), that legal instruments are also essential to combat Rare Diseases.

FROM CONSTITUTIONAL RIGHTS TO ENFORCEABLE RIGHTS

The Civil Invalidity Guide and Law 104 all the rights of rare patients — ENTRATE AGENCY
https://www.agenziaentrate.gov.it/portale/documents/20143/233439/Guida_alle_agevolazioni_fiscali_per_le_persone_with_disableta.pdf/e2d707df-58cf-2ac5-e1e8-c49829f55f6d

The FISCAL AGVELATIONS FOR PERSONS WITH DISABILITY (February 2022)

EUROPEAN DISABILITY CARD

HTTPS://WWW.DISABILITYCARD.IT
How to request it: The European Disability Card **may be requested on the INPS website via an online procedure**. Then, once the request is completed, the Card is sent to the citizen's home. Circular Inps 853 of 22.02.2022 lays down the procedures
a European Disability Card is the document in card format that allows people with disabilities to access goods and services, public or private, free of charge or at preferential rates.

The European Disability Card is part of the European project "EU Disability Card" which has as its objective

the mutual recognition of disability status among the acceding countries.

The European Disability Card replaces to all intents and purposes paper certificates and records of disability status.

ENTITLEMENTS PLAN 2022

Adopted the first UN Resolution on Rare Diseases

Last December, the **resolution** recognising the **rights of persons with rare disease, presented by Qatar, Brazil and Spainand promoted by RDI (Rare Diseases International), in partnership with Eurordis(Rare Disease Europe) and NGO Committee for Rare Diseases, was adopted by consensus by the 193 Member States during the seventy-sixth session of the United Nations General Assembly**. Italy is among the 54 countries co-sponsor of the initiative thanks to the action of **UNIAMO-FIMR**, the Italian Federation of Rare Diseases. We join in agreement with Eurordis and RDI, asked the Italian Government to support the adoption of the UN Resolution in favour of people with rare disease, to ensure greater integration and social inclusion for **300 million people** with rare disease in the world. The Resolution is a tool to include rare diseases within the United Nations system, to strengthen the global community of people living with a rare disease, and to **promote and encourage national strategies and international collaboration**. The implementation of the key elements contained in the Resolution in the various countries will also be monitored and verified by the Secretary-General of the United Nations.

This resolution also represents a **milestone for the inclusiveness of women**, who most of all experience barriers to access to care, a greater stigma and often find themselves unique caregivers of the family".

The UN Resolution promotes the achievement **of the Sustainable Development Goals** of the**UN 2030 Agenda**, to which both the European Union and the individual Member States have committed themselves. In Europe this will result in the development of a European Action Plan for Rare Diseases for the attention of the European Commission. The Resolution is therefore a fundamental part of the overall reclassification of current and future rare disease policies to address the unmet needs of even the 30 million people living in Europe with a rare disease.The **Permanent Mission of Italy to the United Nations**, which, as already stated, supported the adoption of the Resolution in question, noted: "The protection of the rights of persons living with a rare disease is an essential condition for the full recognition of their dignity and that of their families and for the realisation of their full and effective integration into the social and economic fabric".

"The UN resolution on rare diseases is a fundamental step forward to decline **the universal right to health** in the widest and fairest possible way, taking care of the overall well-being of patients and their caregivers and giving resonance to their voice with a global echo — said **Pierpaolo Sileri, Under** -Secretary for Health -. Italy has a strong commitment to the implementation of national and international strategies to promote clinical research, access to the most appropriate and innovative treatments for rare patients, proper training and information, as evidenced by the recent approval by the Parliament of the **Consolidated Text on Rare Diseases** [*Law 175/2021, N.d.R.*]. In this sense, the drive and ability to make a system that patient associations can offer is absolutely precious and irreplaceable.

"From amyotrophic lateral sclerosis (ALS) to spinal muscular atrophy (SMA), through mitochondrial pathologies, leukodystrophies, Ehlers-Danlos syndromes, Duchenne and Becker muscular dystrophy to facial-scapular-humeral muscular dystrophy. There are many rare diseases that are often accompanied by **serious physical, intellectual and neurodevelopment disabilities** and therefore with complex needs to be protected. I am pleased to say that we have already begun to build on what is recommended in this first resolution.

UN dedicated to the challenges of people with rare diseases, with policies starting from the law **delegating to the Government on disability** [*Law 227/2021, N.d.R.*], provided for by the National Recovery and Resilience Plan, which received full support and recognition from the President of the Council **Mario Draghi** and was voted unanimously by the Parliament. Our commitment to this is part of the "ambitious goal of **modernizing**

and making our welfare system more inclusive, so that no one is left alone," concluded **Erika Stefani**, Minister for Disabilities. Source: press release of UNIAMO-FIMR.