RAREDUCANDO DIGITAL EDUCATION

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E- Course -LESSON 2

Rare diseases at school -Italy

In lesson 2 we will discuss some fundamental knowledge principles for teachers, summarized in the three main questions received, in presence, by phone and online, from Italian teachers when they have to address in class the topic of rare diseases or deepen some of their curiosities. (reference email:

centroservizimalattierare@gmail.com (a service p63 E.E.C Syndrome International)
Website: www.csmr-centroservizimalattierare.eu

- ***In class I have a child with rare disease, it is very closed in itself, I would like to know something more about the topic to help him include himself in the class and find new friends and serenity.***
- ***In class I have a child with rare illness but the family does not accept his condition, how can I help him?***
- ***I would like to know something about rare diseases, what it is and how they are classified, to talk with my pupils on the social issue and maybe give some courses of Reducating for children and parents***.

Below is the analysis divided according to the priority suggestions we want to provide in order to give adequate answers to teachers.

- Rare diseases can be treated with an emotional and cognitive impact in many ways, especially outside the family. They constitute a social emergency given the growing number, both because science proceeds in cataloguing and because environmental changes also have important effects on human health from conception. Genetic or metabolic mutations can be many, but they do not affect the basic consideration of the right of the fragile child to have access, thanks to the right supports and awareness, to a good quality of social and school life. Within the course, you will find many simple and important steps to learn about

rare diseases in school and the management of children who carry them. In addition, the advice is always to assess the case as an opportunity for social and cultural growth also for all classmates of the fragile child, so that they understand the value of resilience in the face of health and social difficulties, the inclusion of the fragile person in the daily context and time; because often a child with rare disease does not enjoy a long life time like all his peers. The rare disease can be bad and deeply disabling over the years; but this must not interfere with the human relationship that can sprout within a cohesive class thanks to the wise guidance of teachers, trained and positive to the values of life, especially if supported by the family and educational sharing. Finally, the very important value of the relationship between parents and teachers, which can change the role of the child in the classroom and its inclusion. It happens a lot

often that the parent has to provide exact explanations about the specificity of the child's disease, even more involved in discomfort when there are neurological impairments. The times of reception, learning, management of the fragile child, often require a support/support teacher, who must have the same training as we are proposing and live in symbiosis with the child who follows, in order to increase all the remote potentialities in it. Learning method agreed with teachers and parents and use of aids, will therefore make the difference for the fragile child, exponentially increasing his/her self-esteem and ability to autonomy where present. An excellent guide to the approach to rare disease for primary school teachers, is provided by the publication of the Italian Higher Institute of Health, below

ANNEX FREELY DRAWN FROM:
https://www.salute.gov.it/imgs/C_17_pubblicazioni_2111_allegato.pdfWe propose the very current and important as yet innovative course titled Training course on the use of the video story "With your eyes. A story of love and friendship" with Methods and materials to talk about rare diseases in primary school.

- If the child has a family that does not accept his situation as a rare patient, how can the school and the teacher intervene? Let's start from the beginning: Parents are confronted with the shock of birth, with the urgency of diagnosing and finding information about the disease and treatment if any. It is also necessary for them to worry about a continuous care often characterized by crises and worsenings and are frequently placed by

faced with the suffering of one's own child. The risk that the chronicity also affect the relationship of the couple is high, often there is also a concern for the other children who inevitably end up suffering the concentration of the parents on the sick child. Parents begin a long and delicate work, a path of processing and integration of the disease into the image they have of the child. It is therefore essential that they be oriented as soon as possible towards a path of information and knowledge of the problem as far as possible, as far as possible.

with their cultural and character resources, to have the perception of being able to somehow cope with it, managing it thus enhancing their levels of empowerment. In the event that the rare disease manifests itself in childhood, not neonatal age, for parents, at every age of development of their children, to deal with the disease implies difficulty in expressing and managing thoughts and feelings. The appearance of the disease alters a previous balance, a normal life that suddenly gets wiped out. To relate to the diversity of the rare disease requires the ability to approach it, to process it, to seek adaptation and a new balance. Entering a crisis is part of the natural reaction to such a shocking event; a "crisis" is a moment in life characterized by the rupture of the previously acquired balance and the

needto transform the usual patterns of behaviour, which have proved to be no longer adequate to cope with the present situation. The opening of a state of crisis can pave the way for the search for renewed resources or the rediscovery of strategies already available and that the trauma had only silenced; people who are managing a rare disease often face many critical events accumulated over the same time and repeatedly, resulting in a high level of tension and emotional, psychological and organizational overload. The risk is that this reactive behavior will crystallize and that people feel crushed with the risk of entering the vortex of suffering that ends up in cut off from affective networks, relationships and sociality. The change proposed by the critical events is influenced by the resources of the ego and the personality structure of the subjects involved, the resources of the family, the parenting couple and environmental support. It is not unusual that in the parent couple of children with a rare disease there is a clear division of roles: there is a total absorption of one of the parents — usually the mother — that if it is excessive leads her to forget herself and who she's around her, feeling she can't share responsibility, managing her child's care exclusively or almost. She tends to maintain a fusion or symbiosis relationship giving the feeling of living in place of the child and for the child, without a plan for the future and without being able to imagine it adult and autonomous, or at least partially such. The other parent — more frequently the father whose classical role is to preserve the right distance — becomes essential for rebalancing the situation. This is generally outward facing and may tend more frequently to passive acceptance, denial or emotional distance behaviors. This scheme is of course not rigid, the opposite can also occur, while one of the parents devotes himself completely to the child, the other feels excluded, envys the attentions, proximity and/or role subtracted of parent. It seems to me necessary to emphasize that a rare disease can generate a deficit, or a consequent incapacity, but it is only the encounter with a socio-cultural environment and a non-facilitating collective imaginary that generates the handicap. It is the relational experiences that underline the diversity, the social environment but also the family environment with the same parents, it may not understand and not welcome. If the disease is genetic in nature, it could mean that one or both parents have transmitted the disease to the child. This puts the tightness of torque, A it may be that the 'responsible' parent of the transmission may feel that the other parent is mad at him, whether or not substantiated by facts. The ability to react and tolerate the proposed frustration depends on the quality of the pre-existing relationship, the influence of the environment, the personality structure of the individual parents, but above all the ability to adapt to the couple.

*Very often it is easier to talk about the positive feelings that are reinforced and accepted by parents**, it is much more difficult to talk about the negative feelings for which it is more it is common that there is no room within the family**. Feelings like anger, sadness, shame, frustration, from the brothers and for whom great senses of guilt are felt.

*We do not underestimate the economic frustration that the family lives about access to expensive and continuous care suitable for the health care of the sick/fragile child, especially when the rare and certain disease but not recognised

***It is very useful to be able to accept these difficult emotions by confronting them in an open and spontaneous way in order to channel them in the right way and to identify within the family more useful and functional management strategies.**

So what tools does the teacher have to interact with the family and consequently complete her work as a school educator in an efficient and positive way?

Here are some simple and useful tips:
First you always ask the family if the diagnosis of the rare disease is certain.

It is the family doctor or pediatrician of free choice or the specialist doctor of the national health service who, by formulating a diagnostic suspicion of a rare disease, directs the citizen to a specialized center of the network, in order to validate or not the diagnostic suspicion.
The citizen, therefore, must go to one of the *Reference Centres* indicated by his/her region.

WARNING: Throughout Italy, tests for the diagnosis of rare diseases, including genetic examinations, are exempt (D.M.. 279/2001).

If the diagnosis is confirmed to the small patient, if it is a rare genetic disease, investigations of the patient's relatives are also exempt (this applies to every patient of all ages) The **regional reference center** (or the center of diagnosis and treatment, always keep in mind that in Italy each region has its own REFERENCE CENTER FOR MALACTS RARE) is required to:

3. Through the website of the Higher Institute of Health www.iss.it and clicking on the entry "National Center for Rare Diseases" located on the right, in the "Departments and Centers" bar 4. typing www.iss.it/cnmr/

With regard to the psychological aspect of the pathology, urges the parent and the family to request information from the center where the child is being treated; a psychological support service is very likely to be active. Alternatively, it is useful to know that patient associations often offer psychological assistance and listening to people with rare diseases and their family members.
Identify the association that represents you, or invite the family to contact the National Centre for Rare Diseases (CNMR) at 800.89.69.49 which can give you an orientation with respect to the services on the territory that offer psychological support.
For any doubt contact the Service Center Rare Disease Services CSMR, a service of the ass.
p63 Syndrome E.E.C International net work word communication APS- Padova-Italy
+ 39 3333063353

- **School problems of children with chronic diseases:** Children with chronic diseases attend school with a very heavy burden of medical and psychological problems that need to be addressed and solved. **To understand the world of rare diseases, what it is and how they are classified, to talk with pupils on the social and health issues but also educational and**
  to include meetings of RAREDUCANDO in presence and online for children and parents and to propose it to other teachers, it is enough to be curious about this world, both selective and priority for people's quality of life and positive thinking.

CURIOSITY
If you are looking for:

1. information on rare diseases go to link
2. the list of rare diseases
3. Centres for the treatment and monitoring of rare diseases

4. Information on orphan drugs
5. Italian and European rare diseases associations If you are looking for:

1. School problems of children with chronic diseases, freely taken from: https://www.ospedalebambinogesu.it/problemi-scolastici-dei-bambini-con-malattie 90599/

2.**If you are looking for DIGITAL EDUCATION,** the information starts from the school:

3.RED website: https://erasmusredproject.wixsite.com/red-project

4.https://drive.google.com/file/d/1Be86KaNBbZLw1mK4dtZnJnSrM0fO4huR/ view

5. https://e-learning.alteravita.eu/course/view.php?id=86

5. http://www.sindrome-eec.it/it/ — https://alteravita.eu

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