

# **THE RING CHILD – A FAIRY TALE NOT TO FEEL SO LONELY**

## **SCHOOL INTEGRATION PATH OF DISABLED CHILDREN**

### **RING 14 ASSOCIATION**

**2011**

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#### **Profile of the Association**

The Association cares for rare neurogenetic diseases affecting children.

Ring 14 (ring shaped chromosome 14) is a rare disease whose most steady symptoms are on the central nervous system.

The Association started in May 2002 and it first grouped three families.

Now it represents a lot of families all over the world and it is the only both Italian and foreign board to deal with chromosome 14 abnormalities.

#### **Mission**

- To spread knowledge of these syndromes among doctors (geneticists, paediatricians) so that families can get a diagnosis and put in touch with the Association.
- To spur scientific research in the clinical, genetic, pharmacologic and rehabilitative fields by supporting research projects and enriching our biologic and clinical data banks, the only ones in the world.
- To offer support to the families with members affected by serious disabilities: to assist them at the hard diagnose time, in their relations to educators, speech therapist, teachers, doctors by planning actions aimed to the whole family welfare.

#### **Introduction and reference contest**

In the last 20 years compulsory school has witnessed a regular growth of disabled children attendance. In 2009/2010 school year they are more than 130 thousand; among these about 73 thousand are primary school pupils and about 59 thousand attend Junior High School.

School integration of disabled students is gaining a more and more prominent role and becoming both stimulus and enhancement to the didactics as synonym for School Quality.

In order to cope with a growing and diverse need, new working groups are being shaped, which will steadily draw new programmes, and will reform and renew the inclusion plans of disabled or difficult students.

By now Quality school integration is positively expected to involve the whole community of teachers and pupils: it is impossible to carry on integration only relying on the learning support teacher, moreover front teaching is known not to be a good opportunity for integration since it does not care for diversities and individualities, more and more frequent in classes.

People are increasingly aware that school integration is not a “vertical” process but a “horizontal” one instead, reticular and widespread, which is supposed to stir and organize the resources from numerous other significant subjects: other teachers, staff of the school, class fellows, social workers, family and community.

It is basic to foresee new didactic strategies to link handicapped students to their class, making their presence significant and to join ordinary teachers and support ones.

These didactic strategies must involve all students (not only the disabled one) and spark off teaching informal resources in the class in order to evaluate differences.

A note from the Education and University Ministry of 30<sup>th</sup> Nov. 2001 reads that school basic assistance is connected to the educational and didactic activity: all of these three interventions contribute to the disabled person integration; an only project shared by all members (headmasters, teachers, staff, parents, rehabilitative workers, etc) which law defines as Individual Educational Plan (IEP). On turn IEP is part of the more general plan of independent schools which by law (DPR 275/99) are bound to draw up a Formative Offer Plan (FOP), where they state the criteria and means of the whole education system they intend to carry out, in relation with the diverse needs of pupils and families.

Since these needs are extremely diversified, The Child of the Ring wants to offer an answer to the particular need which arouses when disability comes from a rare genetic disease, difficult both to explain and to understand, and which often scares people, not well informed. In fact in schools inclusion policies are often made up without a real knowledge of the problem dealt with: this may cause serious consequences to the disabled ones. The Convention of the United Nations on the rights of disabled people, ratified by Italy with Act No 18 of 3<sup>rd</sup> March, 2009, describes disabled people as “the ones with long term physical, mental, intellectual or sensorial handicap which might prevent them from taking part in the society on the basis of equality due to numerous barriers”. The causes of disability are not legally relevant but they might be on practical terms, because integration and social inclusion imply the knowledge of the disabled person condition, the only way to knock down fear and taboos which often go with children and teachers.

## **Project description**

Special integration pedagogy says there is a basic and radical difference between insertion and integration of disabled people in the school system. While insertion might mean just the physical presence of a disabled pupil in a school without any change at all, integration implies a project and a mutual adaptability process which is a change in itself.

The Child with the Ring is a tale which wants to be means towards change, through an easy explanation of this disability and its causes so as to face the fears, curiosities and doubts around rare diseases. The Child with a Ring is organized as a fairy tale which simply faces the subtle problems of the disease and its difficulties, concerning the affections and the people who care for the disabled one. Through archetypes and symbols, the tale offers the reader the opportunity to identify themselves with the main character and arouses emotions suitable to understand directly the uneasiness and the limitations affecting the disabled person.

Thanks to The Child with the Ring pupils may build up their skills and actively make up their knowledge. Teachers and educators can take advantage of The Child with the Ring as a support to their role as leaders of children looking for skills and awareness as well, in fact they can draw hints to enrich the pupils' stories and former spontaneous knowledge so to offer useful tools to grow up.

The Child with the Ring supplies didactic files which suggest different approaches to debate and which can be adapted to any different group need. It offers different didactic paths ready to be used and activities to develop in class, suitable to be diversified with regard both to the topic and the age of students involved.

It gives scientific information about genetic diseases and chromosome 14 syndrome, furthermore it has been written in two languages, which make it suitable to various didactic contests even at Junior High School.

The book was born mainly to explain the Ring 14 syndrome, but it copes with various themes shared by other disabilities, both from pathologies and acquired defects. The tale wants to be a versatile education tool to help teachers and families as well in their hard path towards school and social integration of the handicapped.

The project aims to make the book introduced at those Primary and Junior High Schools attended by a disabled student, in order to openly face the theme of disability through debates and reflections – all this might make students closer to one another, on the one side favouring the awareness of their disabled mate condition and on the other hand removing fears and awe towards them.

### **General aim**

To implement available tools to integrate disabled children at school and make school itself better.

### **Specific aims**

- make it easier to express one's own fears, doubts and feelings
- make pupils aware of the disabled person's uneasy position
- stimulate a larger empathy
- improve the support to the disabled one in everyday activities
- increase cooperation among teachers
- inform families and make them more aware about it.

| <b>TABLE 1 AIMS AND WAYS</b> |   |
|------------------------------|---|
| <b>AIM 1</b>                 | <b>Make it easier to express one's own fears, doubts and feelings</b>   |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Narration, explanation of the syndrome and elaboration of the tale through acting and graphic or painting art</li> <li>- Debate with children</li> </ul>   |
| <b>AIM 2</b>                 | <b>Make pupils aware of the disabled person's uneasy position</b>   |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Tale reworking</li> <li>- Debate with children</li> <li>- Make up of a questionnaire to hand out in the classes involved to check the awareness gained even concerning the themes suggested by teachers and the emotions aroused</li> </ul>  |
| <b>AIM 3</b>                 | <b>Stimulate a larger empathy</b>   |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Tale reworking, graphic-painting activity and/or role plays</li> <li>- Identify three main themes and group work to make pupils debate about them</li> <li>- Debate</li> <li>- Make up of a questionnaire to hand out in the classes involved to check the awareness gained even concerning the themes suggested by teachers and the emotions aroused</li> </ul> |
| <b>AIM 4</b>                 | <b>Improve the support to the disabled one in everyday activities</b>   |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Identify the main problems of the disabled pupil and make their school mates experience the same difficulties and limitations</li> <li>- Debate</li> </ul>   |
| <b>AIM 5</b>                 | <b>Increase cooperation among teachers</b>  |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Meeting between teachers and other educators to define the best pedagogic path to follow</li> </ul>  |
| <b>AIM 6</b>                 | <b>Inform families and make them more aware about it.</b>   |
| <b>ACTIVITIES</b>            | <ul style="list-style-type: none"> <li>- Involvement of all the class families through a meeting to show the project and its aims</li> <li>- Final meeting to hand out to parents the results of the work made and possible problems</li> </ul>   |

## Foreseen results

- Expression of fears, doubts and feelings made easier
- Fears and diffidence removed
- Awareness of the disabled person's uneasy position acquired
- Relational skills improved
- Larger empathy acquired
- Availability to support the disabled pupil in everyday activities induced
- Families more informed and aware
- Cooperation among pupils improved
- Atmosphere of greater trust and serenity in the class
- **Elements contributing to the Project sustainability**
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- **Political sustainability**
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- The handicapped children's right to integration, even in serious cases, is guaranteed by law No 104/92, art.12. Possible ways to favour the integration of the disabled in schools foresees a series of measures involving various people, parents among them, and aiming to the complete fulfilment of school integration.
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- **Social sustainability**
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- The Program agreement requests the participation of different organizations and the Individual Educative Plan implies the involvement of other components of the civil society. Since the school integration of the disabled child is a project which aims to the human wellness and which is shared by a lot of subjects, both public and private, The Child with the Ring represents a further dialogue tool, to encourage the capacity to work together effectively and to promote both an institutional and social level plan.
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- **Economical sustainability**
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- This Project has been enthusiastically welcomed by families tied to the Ring14 association and has been supported by private donations. We mean to start a cooperation with other organizations, both public and private, together with a wider involvement of more and more families and schools so that The Child with the Ring can be adopted as an educational device of the Individual Educative Plan and economically supported not only through donations from the families involved, but also from the special school financing.
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- Cooperation among teachers increased