Schooling for Young People with Illness or Injury: Needs have Shifted and New Solutions are Necessary

When young people are not hospitalised but "can no longer" go to school, who do we call upon to educate them?

Examples in Belgium of two organisations offering original solutions

1) ***L'Ecole à l'Hôpital et à Domicile*** [School in Hospital and at Home]

The non-profit organisation *L'Ecole à l'Hôpital et à Domicile* [School in Hospital and at Home] provides schooling for children and teenagers (of mandatory schooling age) who cannot go to school for health reasons. It picks up where the school leaves off, so that the young person can return to school without lagging behind in the curriculum while he or she is sick.

Each year, we receive more requests for home schooling for children and teenagers with psychological problems experiencing symptoms labelled as "school phobia." The concept of "school phobia" is multifaceted and includes various pathologies ranging from uneasiness to severe anxiety. These problems may be minor; adolescents may experience a bout of anxiety with symptoms that are more or less worrisome, including depression, obsessive compulsive disorder (OCD) and various types of somatisation (such as headaches, fainting or vomiting). For these young people, brief therapy can get them back in the saddle quickly. Other types of disorders will evolve into more serious pathologies such as anxiety neurosis, psychosis or schizophrenia, among others.

At the same time, family problems and/or difficulties at school can contribute to the onset of "school phobia." In cases of school phobia, *L'Ecole à l'Hôpital et à Domicile*[1] is not 'the' solution to the problem, but it is part of the solution.

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[1] Association of volunteer teachers working in close collaboration with schools, including in-hospital schools organised or subsidised by the Ministry of Education.

We refuse to label these young people and to box them into a medical diagnosis, but we will provide assistance for them only with the consent and cooperation of the therapist. Our assistance is a component of the therapy, in the sense that it must help to improve the young person's health condition.

We are therefore careful about the services we provide, making sure that they do not encourage dropping out of school but remain a means of keeping the student in the standard school system, and avoid isolating the student from the rest of society.

We want these services to be provided within a context of time and location. This young person's education must be meaningful and must have a short-, medium- and/or long-term plan. We do not accept students for an indefinite period; rather, we provide our services with a fixed-term plan, at the end of which we evaluate the benefits obtained with the various people involved. The case manager from *L'école à l'hôpital et à domicile* (EHD) works together with the therapist, a representative from the school (administrator or teacher), the *Centre PMS* [Psychological-Medical-Social Centre], and sometimes the *SAJ*[2] and the *AMOs*[3], to work with the young person and his or her parents. Each person's role must be clearly defined and understood by the family. The central role is generally held by the therapist, but usually it is the EHD manager who initiates the cooperation.

The spatial context is important. In an effort to prevent the student from withdrawing into the family cocoon and developing agoraphobia or anxiety about taking public transport, among other problems, whenever possible we hold classes at the offices of our non-profit organisation or at any other neutral location. Our objective is for the young person to be able to return to school as soon as possible. By maintaining intellectual function and educational lessons, we are keeping the student from getting behind in his studies, and with our individualised approach, we strive to re-establish the child's confidence in his or her own abilities.

The school is an important partner in addressing the problems of the child or adolescent. EHD informs the school that it is providing the student with educational assistance without violating its professional secrecy obligation. Usually it is the school that provides the educational materials

[2] *Service d'Aide à la Jeunesse* [Youth Assistance Service] (part of the Ministry of Justice)
[3] *Service d'Aide en Milieu Ouvert* [Open Environment Assistance Service] (association providing cultural activities, internships, individual follow-up and more, in daily-life environments)

and holds or allows us to hold testing; with the school, we negotiate the student's return, which is sometimes gradual or part-time.

All of these cooperative efforts, which are indispensable when the young person in is distress, must gradually give way to his or her independence.

Brigitte Beauthier, Psychologist and Vice President of *L'Ecole à l'Hôpital et à Domicile*
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2) ***L'Entre 2: Day School Centre***[4]

Introduction

Development in treatments and continuing improvements in the survival rates of children or young people with malignant or chronic illnesses have required us to rethink in-hospital education (known in Belgium as type-5 specialised education). Indeed, our students now have shorter hospitalisation periods, but longer convalescence periods and an increased risk of relapse (related to improved prognostic techniques); this has resulted in a significant increase in "forced" removal from school. Consequently, it is not uncommon to see patients absent from school for several years over the course of their schooling.

This observation has led us to rethink the concept of school during convalescence and between treatment periods. To meet this demand, some European countries send teachers to the student's home or appoint them consultants who then become the point of contact between the student's initial school, his or her home and the hospital. In Belgium, the service provided varies by hospital, and each in-hospital school seeks the solution that it deems to be most appropriate. Thus, some schools create a parallel network of in-home teachers who report administratively to the in-hospital school. Others rely on associations of volunteer teachers, and others still have increased their enrolment capacity in outpatient clinic classes.

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[4] Pascale Geubel, Educational Coordinator at *Ecole Escale - Cliniques Universitaires St-Luc*, Brussels, Teacher with a degree in psychology. Presentation made at the Congress of HOPE in Tampere, Finland – June 2008

Our aim was to propose an alternative, a day school centre known as *L'Entre 2*, which is based on two important premises:

1) In order to continue with his or her education, the child or young person needs a certain number of hours of schoolwork each week.

2) The opportunity for socialisation afforded by a group of peers is indispensable for building the student's identity.

Genesis of the Project

For several years, the teaching staff at *Ecole Escale* working at hospital units have taken into their classes a certain number of young people "from outside." All of the students have been treated at the *Cliniques Universitaires St Luc* and/or considered, for a limited period of time, to be medically incapable of returning to the traditional school system. They are enrolled in an educational institution (usually their initial school) and plan to attain a specific objective of success. We have grouped them into three categories of students for whom we felt that this project would be meaningful.

The first category is for students who, while undergoing treatment or after treatment is complete, are hospitalised on a recurring basis and are not permitted to return to regular school for medical reasons (often due to a significant decline in their immune system).

The day school centre is beneficial for this type of student for several reasons:

1. Currently these students are monitored at home by an association of volunteers, *Ecole à l'Hôpital et à Domicile* (EHD) an average of two hours per week. However, clearly this assistance is insufficient for following the "normal" curriculum, at the very least in general courses. This observation has already been made by the working group *DOMI de l'A.P.H.* (*Association des Pédagogues Hospitaliers de la Communauté Française de Belgique* – Association of In-Hospital Teachers of the French-Speaking Community of Belgium) in which representatives from EHD also participate. However, there is a legal provision that allows students who are convalescent or sick at home to receive lessons from a teacher four hours per week though a long, tedious process that is not very effective. We have also seen "private" in-home teaching services offered by health insurance or mutual insurance companies, but in our opinion the emphasis is ethically very questionable and the teachers who participate in this program are not affiliated with a specialised school.

2. Students who receive assistance through the in-hospital school structure at the time of their diagnosis and initial treatments appropriate the type-5 school as a new "vital" location for life and learning. Perpetual breaks in this work and in student-teacher relations make it difficult to maintain continuity in the lessons and methods, which is frustrating for everyone involved. In this respect, *Ecole Escale* is a safe location where the young person can remain a student and have age-appropriate experiences with other young people his or her age. The importance of peers in childhood, and even more importantly in the teenage years for building identity, has been clearly established.

3. Developments in treatment, decreased hospitalisation time and the increased risk of relapses (as stated above) lengthen the time period that patients are absent from school. It is not uncommon to see patients absent from their initial school for several years of their education.

The second category is for students with chronic illnesses (such as sickle-cell anaemia or anorexia, among others) who, due to their pathology, are experiencing major difficulties with their schooling. At a specific time or on multiple occasions, these young people require supervision in their subjects or need help studying for entrance exams or standardised exams. These young people generally require daily assistance to supplement the assistance provided by their initial school that can last from 15 days to several months, especially due to their frequent absences.

The third category is for students who are missing school due to mental difficulties, who are in a specific examination programme (often the central board of examiners of the French-speaking Community) and request assistance from *Ecole Escale* to work on correspondence courses. For a student who is alone and weakened in his or her relationship with knowledge, taking these courses is near impossible. Moreover, the role of speaking, trust and listening that can be established in a customised type of education like an in-hospital school, often results in reconciling the young person with the scholastic world. A partnership can be established within the context of providing assistance to these young people, with *l'Entreliens*, an *Ecole Escale* structure specialising in issues related to absence from school for mental reasons.

We also feel that it is important to emphasise that our hospital experience has revealed the benefits of having contact between these young people who are unable to go to school and the young people who are there for serious illnesses, as the students in the former group often gain a sense of responsibility in their daily actions, and the students in the latter group are thrilled to

be together with a little bit of the outside world, which is off limits to them, at least for the time being.

Putting the Project into Practice

Encouraged by these observations, in September 2007 we opened a day school centre (L'Entre 2) that is run by our in-hospital school but is located outside of the hospital structure. Currently, it contains a classroom with the following main characteristics:

- Children ages 6 to 18 are accommodated.
- Each student has a custom-made curriculum based on his or her needs and abilities, which can range from 1 hour of class per week to 20 hours of class per week.
- The classroom is located 500 m away from the hospital, so that it is perceived as a school and lifestyle location that is completely separate, but the students are still able to go to and from the classroom.
- Some teachers divide their time between the hospitalisation units and this classroom in order to reinforce to the continuity-based approach we have established. A managing teacher works there full time and monitors cases and coordinates this team.
- Cooperation with the initial school is supported. It is no longer a matter of receiving the teaching materials but of initiating and assisting with the reintegration process.

Overview after One Year of Operation

After one year of operation, about twenty students have benefitted from this system, which is very positive. Nevertheless, we have furthered our analysis of this assistance by paying attention to:

- The level of education of the children or young people and their geographic origin.
- The person who sent them.
- The pathology that was the cause for their exclusion from traditional school.
- The frequency and length of the assistance provided.
- The objectives of the assistance for each child and how this assistance evolves.

It seems that, regarding the level of education, there is an equal distribution between the primary school and secondary school levels, despite the fact that our structure was primarily intended for secondary school students. One possible explanation for this seems to be the

anxiety that we have observed in many children between the ages of 6 and 12 at the end of treatment when the time has come to return to school. They have anxiety about not being up to speed as well as getting to know a new group of classmates and the rules that characterise that group.

All of our students come from a 30-km radius around the hospital, but this is not necessarily true of where they are being treated. We therefore feel it is important for this type of structure to be established in other areas of the territory.

As for where they were sent from, the vast majority were sent by a hospital physician who believed that the project was appropriate for their patient. As for the physician who sent them or the pathology, the greatest number of requests comes to us from psychiatry departments, which is not what we initially anticipated. We were thinking more of a population of children or young people from the haematology-oncology department (which is very large at *Cliniques Universitaires St-Luc*). Clearly, we have not be in operation long enough to draw conclusions, but we have identified a few guidelines for analysis. Firstly, the site is located 500 m from the hospital, which is far for children who are already very weak. Secondly, establishing a programme for this type of child is closely related to their state of health. Finally, school structures within psychiatric institutions are not intended to maintain the child's level of education, but instead to participate in institutional therapy. A second phase would therefore be worth exploring.

Most of the students receive assistance for several months, frequently according to the quarterly breakdown of the school year; they often receive instruction for 20 hours per week (or in other words, every morning), which reaffirms the idea that it is important to allow for a nearly full schedule at the end of treatment. It is understood that we strive not to keep them in our programme, but to prepare them to return to their initial schools.

There are three final objectives for the assistance we provide:

- Either to enable the student to work on his subjects to fill in the information missed during treatment and to plan for the most harmonious possible reintegration;
- Or to consider redirecting the student to another type of teaching structure;
- Or to provide a reassuring approach to school for very anxious children.

Several students have already returned to their initial schools or a school that is more appropriate for their needs over the course of the school year. In an effort to evaluate the assistance provided, the managing teacher maintains regular contact with these schools, and currently everything is going well. We schedule a six-month and a one-year follow-up after reintegration.

In Conclusion

We believe that the day school centre is an advantageous solution for the changes in treatment and convalescence periods with which in-hospital education is confronted. Not only does it take into account the need to significantly increase the time spent on academics, but it also allows us to address the need for socialisation of these children or young people, in some cases following long months of isolation. It gradually makes these children full-fledged students, in every sense of the word.

For our part, we hope to be able to assist more young people, with better identification of levels (more classes) and possibly extend the concept throughout the French-speaking Community in Belgium.