ORIGINAL PAPER DOI: 10.7401/visions.04.05

Sustainable education for children who are ill: Promoting wellbeing in hospital learning environments

Francesca Andreatta¹, Caterina Robol¹, Chiara Bolognani¹, Martin Dodman²

¹Graduate in Education, Free University of Bozen, Italy; ²Interdisciplinary Research Institute on Sustainability, Italy

Abstract. In this paper we look at the provision of schooling in hospital for children who are ill and consider it as an example of sustainable education. Since illness is a potential cause of exclusion, we start from the perspective of promoting learning in hospital as a form of inclusive educational policy. We than consider wellbeing as an integral part of a human sustainability paradigm and examine both the characteristics of the hospital as a learning environment and psychological and social factors involved in fostering the resilience and the transformability necessary for a healing process in which learning can play a vital role.

ISSN 2384-8677 **DOI:** 10.7401/visions.04.05

Published online: December 21st, 2015.

Citation: Andreatta, F., Robol, C., Bolognani, C., Dodman, M. (2015) Sustainable education for children who are ill: Promoting wellbeing in hospital learning environments. Visions for Sustainability 4: 43-54

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Competing Interests: The author has declared that no competing interests exist.

Corresponding Author: Martin Dodman, Interdisciplinary Research Institute on Sustainability, Italy.

E.mail: martindodman@libero.it

Perspective: Educational vision

Fields: Social processes and structures

Issues: Educational processes

1. Introduction

Devising and implementing educational policy is one fundamental way in which a society invests in its own future. Current educational paradigms generally assert that policy should promote educational systems that enable all of a society's members to develop their learning potential to the maximum possible extent, to be able to build personal life projects and to make a full contribution to society itself. Through education a society shapes the future of both its individual members and its collective self. Education must therefore be sustainable in order for society to be sustainable. As Sterling puts it, sustainable education is "an educational culture [...] which develops and embodies the theory and practice of sustainability in a way which is critically aware. It is therefore a transformative paradigm which values, sustains and realizes human potential in relation to the need to attain and sustain social, economic and ecological wellbeing, recognizing that they must be part of the same dynamic" (Sterling, 2001:22).

In recent decades educational paradigms have also increasingly emphasized the need for policies designed to promote integration for those who risk segregation, inclusion for those who risk exclusion. Integration and inclusion are not just questions of equity and justice for individuals but also of the integrity, wellbeing. vitality therefore and sustainability of society itself. Illness is one of a number of potential causes of segregation and exclusion. Yet all children have a right to education regardless of their health. In this paper we look at one particular feature of educational policy and practice - the provision of schooling in hospital for children who are ill - that is designed to guarantee that right.

Concern about the effects of hospitalization and studies of ill children in hospital and their needs begin with the work of Robertson

(1958) and Platt (1959). Subsequently organizations such as the European Association of Children's Hospitals (EACH) and the Hospital Organization of Pedagogues in Europe (HOPE) have stated that "children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs" (EACH, 1988) At the same time there has been a gradual recognition of how this provision for education must also be considered an integral part of caring for children, curing illness and bolstering the healing process itself (Filipazzi, 2004).

We consider wellbeing as a key aspect of such provision and relate it to two terms that are recurrent in sustainability literature: resilience and transformability (Clark, 2001; Raskin et al., 2002; Walker et al., 2004; Chapin et al., 2010; Folke et al., 2010, 2011; Westley et al., 2011). If resilience is seen as the capacity to reorganize and maintain integrity in the face of perturbations while undergoing change and transformability as the capacity to develop new ways of being in order to make change sustainable, then the challenge of building learning environments in hospitals able to promote wellbeing, resilience and transformability is a clear example of an important goal of sustainable education. Resilience is reacting to illness, living with it and treating it, managing to sustain the effort and maintaining occasions for learning even in adverse conditions. Transformability is getting better, helping to get better, improving efforts and abilities to do so, learning in and through situations of adversity.

Many documents have long underlined how the complex question of the health of a person cannot be addressed from a uniquely biological point of view but is rather to be seen an integration of numerous physiological, psychological and social factors (WHO, 1946). A parallel, more recent, development concerns the emergence of the idea of "human functioning" based on the idea of the wholeness of the person (WHO-ICF, 2001) and consequent approaches to creating environments that facilitate that functioning, thereby promoting wellbeing. If a sustainable educational process requires schooling in hospital, what factors are particularly important in creating the wellbeing necessary to render schooling in hospital sustainable? In the first part of our paper we examine the features of the hospital as a sustainable learning environment and in the second part we consider some particularly significant psychological and social factors.

We base our analysis and conclusions primarily on participant observation, an approach designed to grasp the essence of the daily existence of the people who live in an environment, their perceptions and their relationships (Bogdewic, 1992, Kawulich, 2005). As Douglas affirms: 'When one's concern is the experience of people, the way that they think, feel and act, the most truthful, reliable, complete and simple way of getting that information is to share their experience' (1976: p.112). The observation conducted in children's hospitals or pediatric units in hospitals in the area of Trento and Bozen in Italy, near Zagreb in Croatia and in Akron, Ohio, USA. The overall period of observation was from the summer of 2013 to the autumn of 2014 and comprised periods of observation that varied in length from hospital to hospital, ranging from intensive observations of specific children for a few days or weeks (with both mild and serious illnesses and short-term and long-term hospital stays) to longer and more extensive observations focusing on various aspects of the functioning of the hospital environment and the interaction between children. parents, teachers, other educational and social services figures and hospital staff over a period of months. The age range of the children was from 3 to 15 years old. The more intensive observation involved in particular 8 children, their parents and 6 teachers.

Our objective is in no way to make general comparisons of an evaluative nature between different environments, but rather to gather qualitative data that can inform such a study and reflection on problematic aspects. Alongside the field notes taken during observation while participating in the learning activities conducted together with teachers and children, other instruments used for data gathering included questionnaire for the medical and nursing staff and interviews conducted with teachers, parents and children (alone in their own child patient rooms). In this paper we have used the data to obtain general perspectives and not elaborate a formal triangulation of points of view. In particular our concern was to involve the children directly in expressing on their own subjective feelings and experiences and not base our considerations only on our observation or adult input. The right and the need of children to express themselves and their views is clearly stated in the UN's Convention on the Rights of the Child (1989). Educational research has at times been accused of being more concerned with validity and reliability of data rather than with children themselves (Greene, 2007, 2008) and of not adequately taking account of children as active agents within their environments (Hood, Kelley, & Mayall, 1996). In the following discussion of our findings we have thus incorporated some examples of what children told us, as well as examples of what teachers and parents said.

2. A sustainable hospital learning environment

In attempting to offer some answers to our initial question about factors that create wellbeing, we modify one key word in Kurt Lewin's (1936) assertion that human behavior can be analyzed as a function of the relationship between a person and his/her environment and propose the following equation: Wellbeing = f (Person, Environment). Maintaining schooling while in hospital is of vital importance in terms both

of ensuring that educational opportunities are not lost and of promoting wellbeing as an essential component of the healing process. If wellbeing is a function of the relationship between people and their environments, then a hospital environment is clearly particularly problematic from this point of view, since the very fact of being there is a traumatic experience both because of the reasons why the child is there and the characteristics of the place itself. Being in hospital produces a profound trauma for children primarily because they can experience great difficulty in understanding and elaborating the reasons for being placed in such an environment. As one teacher put it: "The most important thing is to listen to the children and try to help them understand with simple words". These psychological and emotional difficulties combine with others concerning the sphere of interpersonal relationships (the child is still basically dependent on the family from which s/he is "taken away") and the cognitive dimension (a child in hospital may lack many of the normal surroundings and stimuli present in daily family and school life. A number of children expressed discomfort in terms such as, "I miss my bedroom and my toys", "I haven't got my toys and I can't run in the garden", "At home I always played at being an explorer and I've explored everywhere, but here no". This determines the need to create special conditions that promote wellbeing for the child. As one child put it: "Thank goodness there's school here. I always ask my teacher to give me different things to do and she does it because she knows I like exploring".

The peculiarity of school in hospital is determined by two main characteristics: the children suffer from different types of illness and attend this school for a period of time that is both very variable and unpredictable. As a result, the teacher in particular must endeavor to create a learning environment as much as possible capable of responding to the particular needs of each child. Such an environment can be considered in terms of

four variables present in any environment of whatever kind - space, time, people and activities - each of which provided the basic focus for our participant observation and other forms of data gathering.

Space is a variable that exerts a considerable influence on a child's life and learning experience. The way space is structured reflects the pedagogical idea underlying a learning environment and particularly significant is the way a teacher organizes space in terms of furniture, materials and instruments, flexibility and functionality, accessibility and usability, in order to render each of these components of the environment welcoming, accessible and usable by all of the children present. In hospital, provision for dedicated to educational rooms recreational activities is of great importance. "Where possible, the hospital learning environment must have a clear spatial collocation that is different from the child's hospital room. In this way, the child can recognize it as having the characteristics of a school, a place that is welcoming and reassuring in which habitual activities take place" (Benini, 2004, p.74). However, some teachers report that this is not always respected. One teacher said that "the space allocated to the school is sometimes too small and not sufficiently respected by hospital staff" and others echoed her words.

Time is also an important variable for the child's wellbeing and learning in terms of the relationship between linearity and cyclicality, duration, rhythm and flexibility. In particular the cyclical unfolding permits the prediction of events and the perception of reassuring points of reference. A learning environment in hospital therefore requires a daily routine that takes account of the necessary timetable of hospital staff, the planning and conducting of learning activities and, above all, the life rhythms of a child who is at one and the same time in hospital and at school.

The people present in the hospital as a learning environment are clearly a variable of vital importance in terms of relationships and communication, roles and actions. They constitute a group that is highly heterogeneous in terms of roles and functions, formed by individuals with competences that are as diversified as they are interdependent in terms of working together toward a common goal - that of providing a complete care for the child. Particularly important is their awareness of the importance of working as a team in order to realize the synergies necessary for creating wellbeing both for the child who is ill and for themselves as professionals working in highly stressful conditions. The activities planned and conducted are clearly an equally significant variable, in terms of the areas of the hospital in which they take place, the people who participate, the rules or conventions that govern them, what types of activities are proposed, how they are structured and what kinds of experiences they permit children to have, how they contribute to the building and the putting into practice of an educational approach, a learning curriculum and particular methodological choices by teachers. Each one of these aspects involves providing learning experiences with particular attention to psychological (in particular, affective) and social particular. interpersonal (in relationships) factors.

3. Psychological and social factors

There is a clear relationship between various forms of wellness: welcoming, wellbeing, getting well, and also doing well in terms of roles that are played and achieving well in terms of outcomes produced. As a fundamental point of departure, the provision of schooling in hospital highlights the importance of creating a welcoming learning environment in terms of sustaining children in respect of their affective needs. The affective dimension is an indispensable component of all learning (Corao & Meazzini,

1978) and the relationship between affectivity, welcoming and wellbeing is central to every aspect of the learning environment and the activities and experiences that are a vital part of it.

In any educational context, for a child a welcoming learning environment is much more than being given a place at school, being shown how everything is organized and being helped in getting to know the other children. Nor is welcoming only a question of the first few days or the beginning of the morning at school. Welcoming is a key concept in early years education (Staccioli, 2009), a complex methodology of working, a way of being and acting, the ability of the adult to create opportunities whereby children can build a sense of personal identity, become the protagonist of their own learning, feel they are valued, given support and comfortable in the school surroundings. Welcoming means encouraging the gradual development of positive states of being and promoting personal and social competences. Whereas at school the activities are often principally designed to create a sense of membership of and participation in a group, in hospital the need is to counterbalance the destabilizing effects of that environment (Loiodice, 2002) and render it welcoming. Much depends on being able to create positive interpersonal relationships. For the teacher, the difference between teaching in hospital and "normal" school-based situations consists of having to face "often in massive doses, situations characterized by extreme discomfort" and having to draw on "existing knowledge and a capacity for personal introspection, in order to build relationships, all within environment that is often disorienting and destabilizing" (Benini, 2004, p.75). The question of relationships is thus of paramount importance. As Sterling affirms: ecological view implies putting relationship back into education and learning" (2008, p.66, emphasis in original).

In a large body of multidisciplinary literature, ranging from relationship science to systems thinking, relationship is seen as a primary vector for evolutionary development ontogenetic human and emphasis is placed on the influence of interpersonal relationships on individual human development (Berscheid, 1999, Reis et. al. 2000, Andersen & Chen, 2002). The individual exists by being in relationship (Galimberti, 1991) and "interpersonal relationships are the foundation and theme of human life" (Reis et. al. 2000, p.884). Within a hospital the challenge is that of how to promote healthy relationships between all the actors in the face of illness and stress. maintaining a dynamic equilibrium between providing for and satisfying diverse needs and promoting wellbeing and learning (both personal and professional) for all the actors involved. In formal educational agencies such as schools the principal actors can be identified as the child as learner, the teacher or educator, the family and the peer group. Within the pediatric unit of a hospital these actors become the ill child, the medical and nursing team, the teachers and the family.

The ill child has to face a situation that has various complex aspects: the illness itself, the distance from home and personal possessions, the need to adapt to a new environment, undergo often painful treatment and maintain a relationship with parents who are very likely to be stressed and anxious. Habitual interpersonal relationships undergo a sudden change and the trust hitherto placed in particular people as stable points of reference can vacillate (Mangini & Rocca, 1996). Being admitted to hospital is almost inevitably a sudden and traumatic event in which relationships change, parents are no longer in charge of or able to take control of any situation, and moreover various forms of autonomy, often only recently acquired, are severely reduced. In such a critical situation it is necessary to rebuild a network of relationships within a structure whereby the child interacts with medical staff, parents and teachers within the overall context of a hospital in order to render the stay in hospital sustainable for all involved.

In this context, the wellbeing of the child will depend on the ability of the hospital staff - the new and strange adults with whom the child must enter into relationship, each one specific role and particular with competences within a multidisciplinary team - to adopt a global approach in order to take care of as well as cure. Relationships between all the actors as well as between the actors and the patient are of paramount importance for the wellbeing of the child. Each actor must possess competences within the spheres of interpersonal dynamics and affective needs that are related to the concept of the composite professionalism necessary in order to both care and cure, so as to avoid concentrating on solely sectorial or specialist interventions and maintain a focus on the wholeness and the bio-psycho-physical unity of the child. Communicative competences, based on the ability to use a plurality of different types of language in order to mix body, visual, sound and human language (Dodman, 2014a) in an appropriate way, are also essential both for the creation of good working relationships within the team and for interacting with the child. The entire care and cure project must be seen as a network operation based on the principle of social solidarity and mutual sustaining recognized and considered by every member as vital for achieving a common goal.

In this respect, our participant observation focused on the relationships between highly trained and specialized professionals and ill children and their parents. The underlying question posed is that of how ways of behaving towards and relating with the child in hospital can influence positively or negatively the patient's wellbeing. For example, "a doctor should make the effort to shed the austere presence that is often imposed by the professional role s/he plays

and enter into the world of the patient, a world full of fears, ugly monsters and pain" (Dato, 2002, p. 39). What emerges is how the various actors (teachers, parents, nurses and doctors) work together to satisfy in the best possible way the varying needs of each child, giving however priority to the aspects concerned with medical care. In this respect, not all are fully convinced of the need for schooling in hospital: In the words of one parent: "Personally what interests me is that my son gets better. [...] The teacher is very kind and willing [...] but I don't think the children should overdo it and get tired doing all the activities she proposes. After all, they are ill and they need rest!". At the same time there is a clear recognition on the part of teachers of how caring for and curing the child requires dealing with both physical and psychological needs since together they constitute interdependent aspects of hospital treatment, in particular because the latter will already have been inevitably damaged by illness and by being taken to hospital. As one teacher put it: "Here with children who are ill and frightened the most important thing is to create a positive relationship based on trust". And in the words of another teacher: "There can never be too many smiles in hospital".

The child needs to be surrounded by people who encourage positive attitudes and promote positive experiences. In the words of the title of the project of one of the hospitals: "Like this, I'll get better more quickly!". Above all, the emotions of the child play a determining role as factors that can facilitate or impede reaching a state of wellbeing. The observation conducted shows how the burden of responsibility for helping the child understand and cope with his/her emotional states often rests on the shoulders of the teacher. As one child put it: "This morning I had a pain here, here and here. And feeling sick gave me a tummy ache too. Then I went to my teacher and she made me laugh. I didn't feel sick any more but I still had a tummy ache because I laughed so much!".

The various actors necessarily tend to perceive the child in particular ways. For the doctor the child is the child-patient, for the parent, the ill son/daughter, for the teacher, the learner-patient. The challenge for all is that of how to integrate these perspectives in a holistic view and approach. The resilience of children, parents, medical staff and teachers are interdependent. For example, even children can show understanding of parents' excessive preoccupation and how the teacher can counteract this. As one child put it: "My teacher sent my mum to have a cup of coffee so we could get on with working together!". At the same time, new forms of relationship between children and parents can emerge. In the words of one child: "Here I can play with my mum too. At home she never plays with me and she goes away as soon as we arrive at the village school".

While suffering and stress clearly afflict primarily the children in hospital, the adult professionals who care for them may also suffer considerably and have great difficulty in maintaining resilience and transformability while facing situations that are constantly problematic and stressful, dealing with and treating risks of burnout.

Burnout is a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who do 'people - work' of some kind. It is a response to the chronic emotional strain of dealing extensively with other human beings, particularly when they are troubled or having problems. (Maslach, 2003, p. 2).

The emotional burden and the stress factor that a teacher must be able to manage when working in a hospital can sometimes become excessive and potentially uncontrollable. In many hospitals the figure of the psychologist has a vital role to play in situations where their support is necessary to help medical personnel, parents and teachers cope with the pain and the chronic emotional strain of

the complex relationships in which they are frequently directly involved or to which they constantly exposed. The burnout syndrome can be a particular risk for hospital teachers for two main reasons: their close involvement in terms of the suffering and loneliness that often characterizes this profession together with a lack of recognition and support both from medical staff and other school-based colleagues (Kanizsa & Luciano, 2006). The teacher in the hospital, in fact, because of the peculiarities that characterize such a work environment, is sometimes considered as a teacher apart and different from those who work in a "normal" school and can suffer considerably from a sense of isolation.

Maintaining contact between the hospitalbased school and the school usually attended by children who are ill is important for teachers in both institutions, as it is for children in hospital and their classmates. A child writing to his friends describes the experience of a visit to his hospital by Spiderman and the games played together and then finishes: "I want to come back to school to be with you all". At the same time, as one teacher affirms: "It's very important also to work with the classmates and help their teacher explain their friend's illness to them [...] helping children to come to terms with illness itself [...] as well as delivering letters and gifts to keep them in touch".

4. Learning in hospital

The attempt to provide significant learning experiences in such a difficult environment is clearly a challenge for the teacher working in hospital.

For the teacher, taking account of the length of the stay, the type and load of the treatment needed, the multiple and diverse interventions on the part of the hospital staff, the variable levels of presence of the parents, all requires a considerable flexibility in daily organizing time, space and activities in terms

of the differing needs of the children s/he works with. The task is very difficult, but it represents an intriguing challenge for the teacher who is thus forced to go beyond safe and unchanging methodological choices and assume a position of constant research for new strategies and ways of working (Kanizsa & Luciano, 2006, p. 47).

If the basic goal of schooling has always been that of promoting an optimal relationship between teaching and learning processes and the outcomes of these processes have always been and will necessarily continue to be redefined, such redefinition is particularly within hospital complex a learning environment. Within infants and primary education. recent decades have increasing emphasis on building constructive relationships and promoting cooperative learning practices via authentic challenging learning activities in which children are led to experiment and reflect on their experience and through which values such as inclusivity and mutual respect are cultivated, in which they discover and build ways of knowing, doing and being, activities which foster proximal development, based on the importance of diversity and equity, where perceptions and cognitions meet and are compared.

Building such characteristics in a hospital learning environment is particularly difficult because the participants in the teaching learning process are subject to constant change, both in terms of number and age, and each one has particular medical needs that are subject to change during the period spent in hospital (Perricone, Polizzi, & Morales, 2005). The teacher is the same person but the members of "the class" vary from day to day. At the same time, emotional aspects such as fear of the unknown on the part of children who undergo experiences that are invasive, often physically, and at times painful and repetitive, can be very difficult to confront. One particular aspect of the role of the teacher is to create a protective and intimate

space based on mutual respect and trust and on familiar activities such as play and story reading in which the child can feel reassured (Michelon, 2007). As one child put it: "I prefer the room where we go to school because the teacher shuts the door and keeps other people out. In my bedroom there are always people coming and going!" In this way the teacher offers both occasions for learning and for expressing and overcoming personal disease. As another child expressed her feelings, "My teacher is really good and is always there when I want her". In the words of a mother: "What the teacher does is help my son to let off steam and not think about his illness".

The school in hospital becomes a kind of workplace constantly reconstructed and where learning can take place through various forms of free expression in activities that are capable of temporarily transporting the child out of the hospital, a place almost inevitably felt to be restriction or even a kind of prison. In the words of one child: "My teacher has always got lots of things for us to do". The principle of learning by doing becomes particularly significant (Edwards, Gandini, & Forman, 1995), through which the child builds relationships with the teacher as an adult and with other children with whom he is also able to share his experiences as a patient. Story reading, conversation, play and creative workshops (Kanizsa & Luciano, 2006) are thus a significant part of all learning experiences. Group work necessarily organized with the children present in any given moment and inevitably involves children of different ages working together. This kind of work creates conditions whereby older children can help those that are younger, sharing information and building knowledge together, negotiating levels of investigation and areas of interest, careful attention to individual dispositions and abilities in assigning tasks, collaborating and cooperating, with particular benefits for the development of personal and social competences.

Particularly beneficial are workshops based on pictorial or manufacturing activities in which children can participate in diverse and individual ways on the basis of their different ages and types of illness. Such activities can channel energies in positive directions and be therapeutic in that they offer varying forms of safety valves for externalizing dis-ease at a physical level (offloading negative energy caused by being ill and confined in hospital) and at an expressive level (through the activity of creating something, the child can free himself of or share with others experiences, pain and needs of various kinds). Within the learning experiences what children seek is often not so much the learning activity typical of school but rather the opportunity to interact and converse with other children and with adults. As time passes the teacher is increasingly able to calibrate the learning activities proposed and also, in the case of a long-term stay, work together with the child's normal school on planning schemes of work. Above all, creative activities help overcome the sensation and the fear of being un-able, frail and alone, in the hands of others and subject to their will.

5. Conclusions

Sterling proposes four descriptors for sustainable education, considered "educational policy and practice which is sustaining, tenable, healthy and durable". It is sustaining in that "it helps sustain people, communities and ecosystems", tenable in that "it is ethically defensible, working with integrity, justice, respect and inclusiveness", healthy in that "it is itself a viable system, embodving and nurturing relationships and emergence at different system levels", durable in that "it works well enough in practice to be able to keep doing it" (2008, p.65).

Schooling in hospital can be seen as a highly specific, interesting and pertinent example of each of these descriptors in terms of the characteristics of sustainable learning

environments. Space, time, people and activities are all important and interdependent variables in creating an environment that is sustaining for all the people who interact in the hospital as a community and a socio-ecosystem, above all the children who are there because of illness. A child forced to leave familiar home surroundings and spend time in hospital needs to find within the new environment the presence of a daily routine, relationships and activities that provide fundamental affective, symbolic and concrete values. Although it takes place in unknown, anonymous and ascetic surroundings, schooling in hospital must aim to keep alive and active the child's sense of personal identity in that every new patient comes not just with an illness but also a particular way of being in the world, a part which is healthy and will create resilience and be determining in the process of getting well again.

Illness can have significant and debilitating consequences both in the short and long term. Making schooling in hospital tenable is of vital importance in terms both of ensuring that educational opportunities are not lost and of promoting wellbeing as an essential component of the process of healing. There is inevitably a high level of variability between levels of seriousness of illness and kinds of

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cure or even chances of recovery and lengths of time spent in hospital, yet provision for all is a clear example of an ethical imperative based on integrity, justice, respect and inclusiveness. Although involving children who are ill, schooling in hospital must also be healthy, inasmuch the environment is in itself a factor in healing and within this context the teacher has the vital role of providing the professional competences necessary both to sustain the children's sense of personal identity and counter the risk of regression in terms of their development and learning processes.

Providing personalized, enjoyable and motivating learning opportunities as an integral part of children and young people's stay in hospital promotes both solidarity and empowerment. It is particularly important to consider not just the part of the child that is ill but also that which is healthy and needs to be supported and nourished since it will vital for healing the ill part. Rendering it durable is a question of providing adequate in-service training for specialists who work there, maintaining an environment capable of facilitating their work as a team and fostering collective and individual resilience so as to keep up levels of engagement and effort and withstand shocks and stresses during transformative healing processes.

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