



## Children and adolescents with a chronic condition in the public school space – in search of an effective model of psychopedagogical support

**ABSTRACT:** Hanna Krauze-Sikorska, *Children and adolescents with a chronic condition in the public school space – in search of an effective model of psy-chopedagogical support*. Interdisciplinary Contexts of Special Pedagogy, no. 26, Poznań 2019. Pp. 205-318. Adam Mickiewicz University Press. ISSN 2300-391X. e-ISSN 2658-283X. DOI: <https://doi.org/10.14746/ikps.2019.26.14>

Chronic condition may, in time, become a specific kind of „stigma” that determines the formation of a specific “conveyor belt” which determines the trajectories of the fate of children and adolescents. Analysing the functioning of children and adolescents with a chronic condition, for which the school should provide (as for other students) the conditions of learning, both in the cognitive and in the directional aspects, one may indicate not only the imperfections of educational activities, but also a myth of noble ideas inscribed in the function of school, as a place of universal development of every student. The article is a proposal of employing, within the process of educating children and adolescents with a chronic condition, an eclectic model of activities, based on their complexity and sequentiality. The model refers to models proposed by Frederick C. Thorne, or Richard James, used in situations of crisis intervention: the equilibrium model, the cognitive model, and the social change model.

**KEY WORDS:** chronic condition, psychosocial issues of students with a chronic condition, the model of supporting children and adolescents with a chronic condition in the educational and social space of the school

## Introduction

A chronic condition, is one of the most traumatic experiences, both for a child and an adolescent. It may become a sort of a “stigma” that determines the constitution of a specific “conveyor belt” (one issue makes way for other issues), which determines the trajectories of the fates of the children and the adolescents.

For many years, schools have struggled in search of effective educational solutions, however, the issues related to the necessity of an effective support for children and adolescents with a chronic condition, not always echo in these activities, that would enable these students to fulfil themselves as fully-fledged participants of the process of learning – teaching, as well as, would allow to gather experiences, that would allow for a feeling, that they are not simply members of peer groups, but also of the school community.

Empirical studies indicate, that for many students with a chronic condition, the problem is not related solely to receiving optimal support in a given phase of education, but it also includes receiving proper support while traversing from one educational phase to the other. The lack of efficient support is a barrier for a progressive, versatile development, as the chronic condition, by excluding the student from the school community, turns the return to school to a constant re-adaptation, that helps neither the realisation of the possessed cognitive potential, nor “being among others, with others, and for others”. Unfortunately, the transition often contributes to the generation of subsequent issues of essential significance regarding the psychophysical well-being of children and adolescents with a chronic condition.

Therefore, maybe the teachers and the experts, that support the student in school, should search for the answers to questions regarding issues such as, *“To what degree, in school, is the basic right of the student with a chronic condition respected, not only to learn, but primarily, to learn with others, according to the principles of respecting others, being responsible for performed tasks, and developing own self?”*, *“Can the student with a chronic condition, experience the systemic sup-*

port?", "To what degree can the student with a chronic condition, experience friendliness, efficiency, and the modern character of the forms of support?", and "Does he really have a feeling, that school is a place, where he takes an important place, is among others, however, with retaining his original self?". Unfortunately, these questions appear as if contrary to the theoretical premises of integration, inclusive education, and social inclusion<sup>1</sup>, as well as, to legal acts. However, the answer to these questions, creates an opportunity to build the grounds for such a model of school education, that would aid the learning and the self-accomplishment of students with a chronic condition, resulting in creating a school that is favourable to such students.

### **“Lebenswelt” and sub-universes – on the multi-dimensional nature of the “lifeworld” of children and adolescents with a chronic disease**

The term “Lebenswelt” was introduced by Edmund Husserl, who indicated, that each man has his “Lifeworld”, that he assumes as something obvious.<sup>2</sup> Expanding the semantic range of the term, Alfred Schütz indicates, that the basis of the interpretation of the world is the personal and social experiences, which serve as a scheme of reference. The knowledge of the world, respectively, to the development phase of the human, and the specifics of his psychophysical functioning, is, of course, diverse; limited, fragmentary,

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<sup>1</sup> The analysis of terms: “integration”, inclusion, or inclusive education, used not only in pedagogy, allows to notice their diverse definitions, and the abundance of often co-occurring instances (e.g. social inclusion, educational integration, social integration, partial integration), that fail to help using these terms in practice. M. Bowen and J. Thompson e.g. note, that the terms educational, or social integration in relations to the actions aimed at the integration of persons with disorders with able-bodied persons, should be used with great care, as it suggests, that the individuals, that it refers to, are different, worse, and already excluded from the general system of educational services (2000, s. 66).

<sup>2</sup> E. Husserl, *Kryzys nauk europejskich*, Wyd. S. Rolewski, Toruń 1999, p. 53.

scantly coherent, often characterised by the common sense attitude, or wishful thinking about the world that is in us, and the world that surrounds us.

However, despite these differences, the world, both the physical and the social, does not cease to be an inter-subjective world, and our knowledge about it was learned through the process of socialisation. According to Alfred Schütz, the common existence in the world allows us to perceive the Other, not as an organism, but as a "fellow-man", and his "(...) its overt behavior not as an occurrence in the space-time world, but as our fellow-man's action (...)"<sup>3</sup> Additionally, Schütz believes that "(...) we normally 'know' what the Other does, for what reason he does it, why he does it at this particular time and in these particular circumstances. That means that we experience our fellow-man's action in terms of his motives and goals"<sup>4</sup> Their understanding, such as the understanding of all types of actions, demands, that we look at them from the perspective of a particular individual's biography, and the subjective meanings, ascribed by the individual to choices, motives, and the goals of actions. Additionally, such approach, related to the understanding of the Other, demands an insight into areas of reality, different than the "Lebenswelt", with every area having its own specifics. *Sub-universes*<sup>5</sup> are spheres defined by way of perceiving objects, different for every individual. Each of the sub-universes; the world of health and diseases, the world of ideal relationships, the world of individual views and fantasies, however, also the world of science, religion, or myth, are sub-universes that should be coherent and compatible,

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<sup>3</sup> A. Schütz, *O wielości światów. Szkice z socjologii fenomenologicznej*, Wyd. NOMOS, Kraków, 2008, p. 9.

<sup>4</sup> Ibidem.

<sup>5</sup> A. Schütz uses the *sub-universes* term referring to W. James' conclusions, who indicated that, depending on the ways of experiencing the surroundings, a number of spheres of reality may constitute, characterised by a specific, different from the others, way of existing, determined by the different way of perceiving them by the individual, and the actions, that are initiated by the "actor" that functions in these sub-universes.

however, at times, they function in a separate way. They constitute both the stage, and the object of actions, and of the interactions of the individual – the actor. The actor may change the sub-universes/sub-universe, however, the sub-universe may also change him.

Here, one should highlight, that the way the children and the adolescents, for whom a condition **is not** an inherent element of their everyday lives, understand the concept of a condition, as well as, the state that they are currently in, depends on the level of their development, and on their experiences; along with age, their content range expands, the information is organised in a coherent structure, and their character, from being particular, turns increasingly abstract.<sup>6</sup> Between ages 2 and 7, a condition is usually perceived as a phenomenon that exists outside of the body, that can enter it, or as a result of contracting illnesses, that exist in close proximity to the body and may attack just before the condition appears. When speaking of a condition, little children refer to their previous experiences, and identify its cause in cold air, germs, simultaneously, rejecting bad behaviour as the cause of a condition<sup>7</sup>, which also results in the child's way of thinking about the treatment process. In this case, from the viewpoint of a child, during the period of early and moderate childhood, it is imperative to create certain rituals, related, e.g. with frequent washing, or ventilating rooms.

Between ages 7 and 11, the condition is increasingly defined as something, that may be contracted, however, also that something be treated; the condition "leaves", when the medicine is taken, or certain prescriptions are followed. Children at this age often perceive a condition as a reversible phenomenon. During the period between ages 10–11, children begin to differentiate the somatic and the psychological conditions clearly, indicating that people with somatic conditions should be treated medically, while people with psycho-

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<sup>6</sup> R.J. Thompson, K.E. Gustafson, *Adaptation to Chronic Childhood Illness*. American Psychological Association, Washington DC. 1999.

<sup>7</sup> Zob. np. M.C. Roberts, W.B. Beidleman, S.K. Wurtele, *Children's perceptions of medical and psychological disorders in their peers*, "Journal of clinical child psychology" June 1981, 10(2), pp. 76–78.

logical issues should receive different kind of help. However, a condition as an internal process of psychophysical nature, is not recognised until age 11.

The studies, dedicated to health and illness, conducted by M. John-Borys, on a group of 120 adolescents, between ages 12 and 14, indicate that the majority of youth in the period of early adolescence, not only is capable of explaining the concept of a condition, in accordance with its scientific meaning, but also can indicate its diverse symptoms, including: somatic and pain conditions, vital exhaustion, sadness, depression, the lack of interest in other people, changes in external features, as well as, anxiety and insecurity.<sup>8</sup>

Analysing the perception of health and illness by children and adolescents, one must always consider its complexity and multi-dimensional nature, as they are affected by both internal and external determinants.

To summarise this aspect of inquiries, it is advisable to studies indicating that:

- (1) younger children, consider themselves healthy or sick, when someone tells them about it, or, when they recognise symptoms, that occurred before; they also list symptoms related to the physical aspect of health, to a much higher degree, than older children; and the concepts of health and illness themselves, they define on the basis of own experience (they do it much more often, than older children and adults);
- (2) older children define the concept of health with more precision; they also consider its various aspects, which is related to their increased knowledge; however, their communicational competencies are of significance as well;
- (3) children more often understand health, not as a “lack of illness”, but as a “well-being”;

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<sup>8</sup> M. John-Borys, 2002, cyt. za: H. Krauze- Sikorska, *Dorośli w świecie dziecka chorego terminalnie*, [in:] *Świat małego dziecka. Przestrzeń instytucji, cyberprzestrzeń i inne przestrzenie dzieciństwa*, red. H. Krauze-Sikorska, M. Klichowski, Wyd. Naukowe UAM, Poznań, 2017, pp. 143-154.

- (4) while describing the concept of health, adolescents refer to well-being, the ability to perform various activities, but also to various emotional states. Creating subjective concepts of health and illness, they indicate physical and energetic (body, the organism, the dynamics of action), psychological (emotions, experiences, feelings), and social (interpersonal and task-oriented) components;
- (5) the older the child, the more the concept of health is identified with the concept of the mother's health.<sup>9</sup>

The studies regarding the concepts of health and illness, evolving with age, allow us – adults – to understand the essence of the perception and the definition of these phenomena, by children and adolescents. However, one should realise the fact, that we are entering an area that is enormously difficult to study, as, for people who did not have long-term health issues, these concepts are but a small piece of their knowledge about the Self and the world, while in terms of children with a chronic condition, these concepts become one of the most important life issues. The concept of illness is strictly related to how they perceive their own condition; a cognitive structure is created, which some authors refer to as, not only an image of own condition, but its theory.<sup>10</sup>

Richard Lau and Karen Hartmann indicate, that within the structure of representation of own condition, one may distinguish five elements: (1) the identification of a condition, i.e. a name (label) given to the condition and its symptoms by the person with the

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<sup>9</sup> R. Kalnis, *Love Children's concept of health and illness – and implications for health education*, "Health Education Quarterly" no 2-3, 1982, pp. 104-115; M. John-Borys, *Koncepcja zdrowia i choroby u dorastających*. Wydawnictwo Uniwersytetu Śląskiego, Katowice 2002; B. Wojnarowska, J. Mazur, A. Kowalewska, H. Kołoto, A. Małkowska, *Zachowania zdrowotne i postrzeganie szkoły przez młodzież w Polsce w 2002 r. Raport techniczny z badań*. Wydział Pedagogiczny Uniwersytetu Warszawskiego, Warszawa 2012.

<sup>10</sup> E.D. Hale, G.J. Treharne, G.D. Kitas, *The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs?* "Rheumatology", Volume 46, Issue 6, June 2007, ss. 904-906, <<https://doi.org/10.1093/rheumatology/kem060>> [access: 11.04.2019].

condition; (2) the beliefs regarding its causes (hereditary, internal, external); (3) the expectations regarding the duration and the course of the condition; (4) the expected results and the consequences of the condition; (5) the belief regarding the possibility of curing and /or controlling the condition.<sup>11</sup>

John Weinman, Keith Petrie, Rona Moss-Morris, and Rob Horne, while discussing the essential aspects of a condition, that determine the perception of it, list the severity of the condition, its dependency on the behaviour of the individual with the condition, the ability to affect its course, the estimated time of its duration, and thinking of the condition in a coherent and logical way.<sup>12</sup>

In the case of children and adolescents, many of the aforementioned aspects may be deformed by the cognitive, emotional, and behavioural components, affecting the behaviour initiated in situations of experiencing illness and discomfort.

In cases of many individuals with a chronic condition, their progression is multi-stage; the condition may be a result of disorders appearing during the prenatal, or perinatal phase; they may also occur in the postnatal phase, e.g. due to the organism's prior vulnerability to pathogenic factors. In the last case, a significant meaning may be ascribed to the law of "clearing pathway" ("torowanie drogi"), and the law of „background" ("tło")<sup>13</sup>, while in other cases,

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<sup>11</sup> R.R. Lau, K.A. Hartman, *Common sense representations of common illnesses*, "Health Psychology" 1983, 2(2), s. 167–185, <<http://dx.doi.org/10.1037/0278-6133.2.2.167.pdf>> [access: 5.03.2019].

<sup>12</sup> J. Weinman, K. Petrie, R. Moss-Morris, R. Horne, *The Illness Perception Questionnaire: A New Method For Assessing The Cognitive Representation Of Illness*, "Psychology and Health" 1996, 11(3): 431–445 <[https://www.researchgate.net/publication/251957846\\_The\\_Illness\\_Perception\\_Questionnaire\\_A\\_New\\_Method\\_For\\_Assessing\\_The\\_Cognitive\\_Representation\\_Of\\_Illness](https://www.researchgate.net/publication/251957846_The_Illness_Perception_Questionnaire_A_New_Method_For_Assessing_The_Cognitive_Representation_Of_Illness)> [access: 3.03.2019].

<sup>13</sup> The law of *clearing pathway*, is related to the decrease of the immunity of the nervous system under the influence of a prior "clearing" occurrence of unfavourable factors. E.g. respiratory disorders are much more dangerous to children from pregnancies with complications. It is, because the defensive and compensatory mechanisms, weakened by the factors that damage the CNS, break down under the pressure of subsequent pathogenic factors. The other regularity, referred to as the

it manifests “unexpectedly” in the later period of life, however, with its determining factors possibly appearing much earlier. In the second case, the signals coming from the body, are not perceived properly, neither by the young people, neither by the parents. Instead, wishful thinking appears, referring to various aspects, indicated by the example sayings of adults and adolescents: “I am just having a bad day”, “I have been doing great so far, it is just a temporary issue”, “It will go away”, “You have never had any health issues”, “I do not understand why you feel so bad today, everything was fine yesterday, so it is probably nothing big”.<sup>14</sup>

Additionally, the child’s feeling of being unwell is often referred to school issues that appear (in various aspects), and often, they are considered to be the primary factor of the child/student’s malaise (“are you simply not trying to get away from school, this condition of yours happens a bit too often”).

Even when the parents/guardians decide for a medical diagnosis, they do not always receive information that would allow them to direct further actions, and look for professional support from experts. A significant diagnostic difficulty, not only of medical nature, may be the phenomenon, occurring in numerous chronic conditions, known as “waxing-waning”<sup>15</sup>; the increase and decrease of symptoms. The symptoms of the condition, may gradually increase, some of them decline, or “withdraw”, being replaced by others. The phenomenon of the amplitude of the amount and the intensity of particular symptoms, prevents diagnosis, as well as, taking effective action.

However, always, health issues that gradually limit the physical activity, influence not only the cognitive, emotional, social, or motivational processes, but also the self-image.

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*law of background*, indicates the unfavourable influence of the pathogenic factors that occur simultaneously with the primary factor; they enhance its strength.

<sup>14</sup> All the mentioned statements come from the author’s own study.

<sup>15</sup> Zob. np. H.U. Wittchen, R. Lieb, H. Pfister, P. Schuster, *The waxing and waning of mental disorders: evaluating the stability of syndromes of mental disorders in the population*. “Comprehensive Psychiatry”, 2000 Mar-Apr; 41(2 Suppl 1), pp. 122-132.

## Student with a chronic condition in school – expectations and needs, and the possibilities of their realisation

Education, focusing the concepts of learning, education, and teaching, is a process, which Zbigniew Kwieciński defines as a general assortment of activities related to leading the other person, allowing him to develop, to make use of his potential, which helps shape his identity, and become a member of various communities, e.g. social, national, cultural. Analysing the functioning of children and adolescents with a chronic condition, for whom the school (as for other children) should provide the conditions for learning, both in the cognitive and the directional aspect, one may indicate not only the imperfections of educational activities, but also the myth of noble ideas inscribed in the function of school<sup>16</sup>, as a place of universal development of every student.

Polish school has a problem with the tolerance regarding all forms of diversity, and difference between pupils<sup>17</sup>, which translates significantly both to the didactic issues of children and adolescents with a chronic condition, who have difficulties not only in meeting expected standards, but also in experiencing the acceptance of their *alterity*, by their peers.

The negative effects of the experiences, and the accompanying feeling of failure, regardless of the discipline, to which they refer, significantly determine the functioning of these students, not only “here and now”, but also in the subsequent phases of life and education; they influence the entirety of their development and may, in time lead to developing the *adaptive decompensation syndrome*.<sup>18</sup>

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<sup>16</sup> Z. Kwieciński, *Socjopatologia edukacji*, Wyd. Trans Humana, Olecko 1995, p. 14.

<sup>17</sup> M. Dudzikowa, *Mit o szkole, jako miejscu wszechstronnego rozwoju ucznia. Eseje etnopedagogiczne*, Oficyna Wydawnicza „Impuls”, Kraków 2001.

<sup>18</sup> Zob. H. Krauze-Sikorska, *Wsparcie społeczne w sytuacji wystąpienia Syndromu Adaptacyjnej Dekompensacji u dzieci i młodzieży z niepowodzeniami szkolnymi*, [in:] M. Piorunek (ed.), *Pomoc – wsparcie społeczne – poradnictwo. Od teorii do praktyki*, wyd. Adam Marszałek, Toruń 2010, pp. 407–427.

Unfortunately, the studies yield no optimism. The overview of the school reality, after conducting a study within a group of 50 children of early school age, and 50 children of school age, with asthma and/or atopic dermatitis<sup>19</sup>, indicated numerous unfavourable areas of school functioning, that had essential impact on the choices of the aforementioned students regarding educational and social challenges.

In the studies<sup>20</sup>, which encompassed two phases, the quantitative-qualitative approach was applied. In phase one, due to the interviews with the teachers of the examined children, and the observations of their lessons, it was possible to gather information regarding the teachers' working strategy. In this phase, abundant material was provided by the observation of students with asthma and/or atopic dermatitis during their stay at school (in various educational and social situations). Phase two of the studies, allowed to evaluate the educational and social situations, from the perspective of a student with a chronic condition.

In the analysis presented below, I focus primarily on this element of the studies, which indicates the experiences of the students, and their viewpoint regarding school.

The below average school achievements are experienced by 25 children of early school age, 37 children speak of being significantly overburdened by studying; 35 students declare difficulties in studying, 25 declare a high level of fatigue from studying, the lack

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<sup>19</sup> According to WHO data, there are c. 300 million people with asthma, and the number is increasing, to reach 400 million by 2025. The condition affects people of all races, both sexes, and people of all age. In Poland, according to ECAP estimates, the condition affects 4 million people, being the most common chronic condition of children and people up to the age of 30. See. P. Dąbrowiecki, I. Kupryś-Lipińska. D. Łęcka, *Raport, Astma ciężka. Sytuacja pacjentów w Polsce POCHP*, Wyd. Novartis, 2015, <[https://www.astma-alergia-pochp.pl/download/Raport\\_Astma\\_Ciezka\\_maj%202015.pdf](https://www.astma-alergia-pochp.pl/download/Raport_Astma_Ciezka_maj%202015.pdf)> [access: 19.05.2019].

<sup>20</sup> The study was conducted in 2017–2018 in public elementary schools, in urban and country environments: both the selection of the groups of students, and the groups of teachers, was intentional – the teachers were working with persons affected by asthma and/or atopic dermatitis.

of acceptance from peers (isolation within the group) is indicated by the experiences of 18 persons, the cases of bullying was experienced by 10 children, while the lack of interest “with me as a Person”, on the teachers’ part, by 17 children.

The values increase respectively to the age of the students. The below average school achievements are a problem of 37 students between 12 and 15 years of age. 40 students declare being overburdened with work, 41 persons experience difficulties in studying, 40 students indicate fatigue from studying. Additionally, one may note an increase of indications related to the lack of acceptance from peers - 32 students, experiencing peer violence - 17, or the lack of interest in the student as a Person, on the teachers’ side, felt by the youth - 28.

These factors determine secondary issues. Difficulties appear, in the transition between educational phases (from the early school phase, to the school phase), in the adaptation to the new environment, and in perceiving the school space as a place that is friendly to students with a chronic condition. As stated by Kasia “(...) *I like to study, but I’m not sure if I like school (...) no, I have no friends, but I get sick a lot, that is probably it (...) the teacher is nice, but she is the only one saying ‘look, Kasia is back, we will all help her, so that she feels nice with us... I don’t want to be nice, because the kids will not understand anyway, and Zosia said, that I don’t bother them, but they still won’t play with me, and when we have a workout, or they dance, I stand in the corner (...) but, you know, I have asthma (...)*” [age 8]

The student’s satisfaction drawn from learning, is always related to the fact, that he is learning reflectively, that he is looking for a sense, and the understanding of the surrounding world, sharing his new knowledge with others, and using dispersed knowledge. In reality, it often turns out just as Jarek says “*Im sick often, and I have to learn by myself (...) sometimes my mum helps me, and sometimes my tutor (...) in general, I am not doing too bad...*

*My teacher says that I must involve myself in various activities in the classroom (...) wonder how? Even, if I am in a group, the guys say, that I am working too slow (...) once I made a poster (you know, it turned out*

nice, my mum helped me find a lot of materials), still no one could pick it up from me, and I was sick again. So tell me yourself 'what for'?!"

[Jarek, age 9, asthma, immunological issues, he is often excluded from school life]

Just by analysing the given examples of the children's statements, one may notice the overlapping, in the case of a condition, crisis situations resulting in the fact that: (1) school situations get out of control quicker; (2) new blockades in learning cause the appearance of masks, stiffness and superficial behaviour; (3) the student receives and sends many false messages; (4) he does not cope well with polarised emotions; (5) the complicated nature of his relations to the environment increase.

Here, Tomasz Szkudlarek<sup>21</sup> speaks of a peculiar "incompatibility of the student with the school", however, it seems that one must clearly highlight the specific biofeedback; the student has difficulties in finding himself in the school space, but the school does little in order to change the situation.

However, (1) ignoring the difference between students by being blind to them; (2) the lack of the individualisation of educational activities; (3) didactic work focused on those, who follow the curriculum at a normal pace; (4) the silent treatment - marginalising the increasing irregularities in the student - student, student - teacher relations, and expecting nothing but obedience in the classroom; (5) stigmatising and discrimination - labelling students and dooming them to fail; (6) *suggesting* children with a chronic condition, to take up individual education, quickly leads, within this group of students, to the feeling of learned helplessness.

To this last point, one may refer the official statement of the Ombudsman for Children (Rzecznik Praw Dziecka), who, in reference to the Convention on the Rights of the Child, ratified by Poland, notes, that ascribing a child's education to a particular place results in: (1) the violation of the right of the child to live in condi-

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<sup>21</sup> T. Szkudlarek, *Pedagogika krytyczna*, [in:] Z. Kwieciński, B. Śliwerski (eds.), *Pedagogika*, vol. 1. Wyd. Naukowe PWN, Warszawa 2003, s. 370-374.

tions that guarantee dignity, allow to achieve independence, and aid in the active participation in the life of the society; (2) the lack of help provided to the child; help exercised in a way leading to achieving the highest degree of integration with the society, as well as, ensuring the child's personal development.<sup>22</sup>

Within this background, the studies of Barbara Olszewska are situated<sup>23</sup>, who studied the opinions of teachers regarding the educational situation of children with asthma (the analysis addressed their knowledge regarding the health and social problems, related to this group of students). The study was conducted on a group of 150 teachers employed in elementary and middle schools in the Łódź Voivodeship. Based on the information from the respondents, one may notice, that the teachers did not participate in training, or courses, that would bring them closer to the issues that are occur most frequently in cases of children with chronic conditions, including asthma. In the group examined by Olszewska, 63% of respondents does not now, or "is not sure", whether there are students with asthma among their pupils. The majority of them could list the right, and most frequent symptoms of the condition, that occur in cases of children, however, they worried, that their "overheard"

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<sup>22</sup> According to a PKPD entry, there is a possibility of the participation of a child in the school environment, as paragraph 9 states, that the "Children and adolescents within the individual pre-school education, or individual teaching, whose state of health severely handicaps their presence in pre-school or school, for the purpose of their integration with the environment and providing them with comprehensive personal development, the principal, within his capabilities, considering the prescriptions included in the opinion, and the current health, organises various forms of participation in the life of pre-school and school, in particular, allows the participation in extracurricular activities, celebrations, and school events. Cf. The Statement of the National Association of Management Staff in Education on the organisation of the individual education of children and adolescents (Stanowisko Ogólnopolskiego Stowarzyszenia Kadry Kierowniczej Oświaty w sprawie organizacji nauczania indywidualnego dzieci i młodzieży); <[www.oskko.edu.pl](http://www.oskko.edu.pl)> [access: 01.02.2019].

<sup>23</sup> B. Olszewska, *Uczeń z chorobą przewlekłą – zakres świadomości i odpowiedzialności działań edukacyjnych*, „Kultura i Wychowanie” 2011, 1, pp. 234-244.

knowledge was not sufficient. In response to the question: "Why do they not display involvement in providing help to students with a chronic condition?", they indicated, i.a. that they fear the responsibility for the condition of the child, and the problem lies with the parents, that do not report any issues (therefore, they presume, that the child manages well); they also raised a point, that "the child's condition is an embarrassing subject", and so, if a parent doesn't report any problems, the teacher won't create one.

Therefore, considering the factors that determine the issues regarding the student-school environment mutual compatibility, it is advisable to seek for efficient solutions, however it will not be made possible without an agreement between the teachers, the parents of children with a chronic condition, and experts, an agreement based on competencies, mutual trust, and the open attitude towards activities, allowing to determine the scale of the health, and non-health issues of children and adolescents.

### **The (Un)Realness of the effective support for a student with a chronic condition, in a school reality**

According to, not only theoretical principles, or solutions prescribed in the Salamanca Statement<sup>24</sup>, but also to the records of the Polish educational acts, or the educational core curricula, school should create such conditions for each student, that will allow children and adolescents with various experiences and biographies, to achieve educational success. Among the many records regarding educational priorities, still remain the statements about the necessity of supporting development and learning, both in the instrumental and the directional spheres, of students with "different development", with "developmental difficulties", or with "special educational needs".

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<sup>24</sup> Deklaracja z Salamanki oraz wytyczne dla działań w zakresie specjalnych potrzeb edukacyjnych przyjęte przez Światową Konferencję Dotyczącą Specjalnych Potrzeb Edukacyjnych: *Dostęp i Jakość*, Salamanka, Hiszpania 7-10 czerwca 1994 r., UNESCO 1994.

The basic, primary aims include, such support of the development of these students, that will enable them to use their potential in a way that will allow them to satisfy their needs, develop their own talents, shape their cognitive, emotional, and social processes, as well as, build motivation to act in a way that will allow each of them to become an active member of the school as a learning organisation.<sup>25</sup>

However, within this context, it seems that the process of education of children and adolescents with a chronic condition, allowing to care for them<sup>26</sup>, and support their learning and socialisation, is not just a matter of complying with regulations<sup>27</sup>, but rather, a specific challenge for each teacher, pedagogue/school psychologist, and other experts working in school, related to building a strategy based on the understanding of the principles of individuation, and of the social participation in life.

When we speak of the process of supporting children and adolescents with a chronic condition, it is advisable to refer to the basic principles, that should be considered; (1) grasping the problems of children and adolescents in a holistic and multi-aspect way; (2) using the organism ability to compensate; (3) discovering and developing the potential, therefore, these individual capabilities, and „Archimedean” (strong) traits, that may serve as the basis for the optimisation of educational, preventive, and therapeutic activities;

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<sup>25</sup> H. Krauze-Sikorska, *Praca z dziećmi o specjalnych potrzebach edukacyjnych i jej implikacje dla ich rozwoju*, [in:] *Dziecko w szkolnej rzeczywistości. Założony a rzeczywisty obraz edukacji elementarnej*, (ed.) H. Sowińska, Wyd. Naukowe UAM, 2011, pp. 479-534.

<sup>26</sup> None of the acts defines the details of the guardianship function of the teacher. The term “guardianship” is primarily a legal term, and the teacher does not provide guardianship in a legal meaning of the Family and Guardianship Codex (Kodeks rodzinny i opiekuńczy), therefore the guardianship role in regard a child with a chronic condition, may be interpreted freely.

<sup>27</sup> The right is highlighted by the Karta Nauczyciela (Teacher’s Ledger), which obligates the teacher to the earnest execution of his tasks related to his position, and the primary functions of school: didactic, educational, and guardianship function, including the tasks regarding ensuring the safety of the students (art. 6 sec. 1), as well as, supporting each student in his development oraz (art. 6 sec. 2).

(4) creating conditions that aid the adaptation of children and adolescents to the situation determined by their health; (5) creating a space of their physical and social life (family, school, outside of school), with the consideration of their needs, the realistic nature of expectations, but also their own activity.

We may speak of the effectiveness of support perceived as such, only if:

- creating new habits of learning, will be at the basis of the new principles of the reconstruction related to the physical and motor aspect.
- in the process of psychological adaptation the child/adolescent will be supported in transitioning through subsequent phases of coping with the experience of “being a sick person” – the shock, the hope for recovery, resignation, and feeling sorry for self. The support is also related to situations. The support is also related to situations, in which non-adaptive defence mechanisms appear, that are of significance for the actual evaluation of own capabilities, the adaptation to the limitations enforced by the condition, and creating relations with others (and, when an opportunity arises, also for others),
- within the process of learning social roles, due to the possibility of an occurring and progressing social alienation related to, e.g. withdrawal from the previous role, identification with a new role, developing within the framework of a new role, and integration of this role with the entirety of the previous roles, it is essential to support both the parents and the peers, often serving as the basis for creating a “new” image of the Self, and the process of self-actualisation, which is an accidental result of the intentional nature of the life of each human. Its essence is reflected fully in Karl Jaspers’ words, “Was der Mensch ist, das ist er zur seinen mach” (“A man is, whom he had become by his own doing”).

In the case of children and adolescents with a chronic condition, one must also consider other factors that modify the image of the self: the duration of the condition, the type of the condition, the

severity, and the difficulties that the condition causes, the circumstances, in which the condition had appeared, the level of intellectual development, and of the own activity of children and adolescents.

In creating a support process, it is advisable to refer to the proposal of coping in the face of a chronic condition, by Rudolf Moos<sup>28</sup>, indicating, that in a situation of a chronic condition, if an individual manages well, he executes tasks related directly to the condition, as well as, the general tasks.

Within the context of psychopedagogical activities, undertaken in school, the first ones should be dedicated to: (1) supporting the child in coping with the consequences of the condition, particularly, with symptoms and the reappearing loss of psychophysical efficiency, (2) supporting the child in adaptation and re-adaptation, regarding the school environment; and (3) allowing the student with a chronic condition, to build and maintain positive interpersonal relations. The general tasks are related to: (1) maintaining emotional balance; (2) maintaining a coherent feeling of Self, particularly, within the area of competencies and the feeling of effectiveness; (3) maintaining good relations with family and peers in the classroom.

Successful coping in a school educational and social space seems real, if, in educational activities, we consider the complexity and the sequentiality of activities, taking into account, e.g. the eclectic approach model, proposed by Frederick C. Thorne<sup>29</sup>, or Richarda James<sup>30</sup>, being a hybrid based on the integration of the basic models used in the situations of a crisis intervention: the equilibrium model, the cognitive model, and the model of social change. Here, it is important to: (1) identify and verify the elements of each system, and to integrate them into an internally coherent whole matching the behavioural data, that is to be explained; (2) analyse everything that refers to the problem – the theories, methods, standards of evalua-

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<sup>28</sup> R.H. Moos, J.A. Schaefer, *The crisis of physical illness*, [in:] R. Moos (ed.), *Coping with physical illness* New York. Plenum Press, 1984, pp. 3–26.

<sup>29</sup> F.C. Thorne, *Principles of Personality Counseling – An Eclectic Viewpoint* by Publisher: Ind Press, 2011.

<sup>30</sup> R.K. James, *Crisis Intervention Strategies*, Cengage Learning, 2016.

tion and clinical data; according to the latest state of knowledge; (3) apply unbiased evaluation, without the “artificial” bending of the evaluation for the purpose of a particular theory, and remaining an open mind, that aids searching for such strategies and approaches, that yield the best results. An important aspect of the activities, is to remember about their multi-phase nature:

**Phase 1** is the definition and the understanding of the problem from the student’s viewpoint (with the basis being the systemic diagnosis).<sup>31</sup>

**Phase 2** is to minimise the physical and the psychological threats, i.e. providing the student with the feeling of safety.

**Phase 3** is the unconditional acceptance towards the student; ensuring him, that he is a person, about which we care, and that we see and appreciate his effort.

**Phase 4** is to recognise, together with the student, his capabilities, finding efficient solutions, and indicating that some choices may be better than others (choices must be appropriate and realistic). The activity is based on situational support; parents and peers may be the source of support. It is important to develop, with the student, the means to cope with difficulties (activities, behaviour, environmental assets), and the modification of looking at the issue; creating models of positive, constructive thinking.

**Phase 5** encompasses the planning of activities that aid the reinstating of emotional homeostasis. Here, the identification of the sources of emotional support is necessary (home, school), providing a means of coping with difficulties, motivating the student to take up certain activities that are possible, therefore, based on the available assets; the essence is to understand the sense of activities and accepting them; the student must have a feeling of independence, and remain in control over the activities.

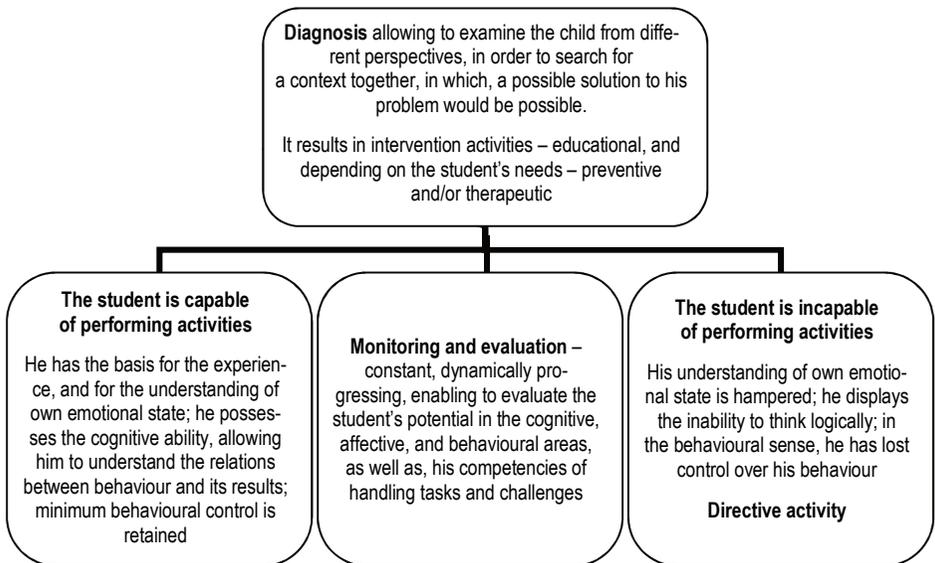
**Phase 6** is the result of the realisation of the premises from the previous phase, therefore, developing the student’s feeling of au-

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<sup>31</sup> H. Krauze-Sikorska, *Mikro- i makrokontekst w procesie systemowej diagnozy psychopedagogicznej dzieci i młodzieży z trudnościami w uczeniu się*, Studia Edukacyjne, 2014, np. 33, pp. 19-34.

tonomy, and control over the performed activities, remains the basis. This phase is not just the support of a student in his activities, ensuring his feeling of safety, but also cooperation, still allowing him to build his self-efficacy.

The analysis of the particular phases, allows to sketch out a model of an activity, that could efficiently support and aid students with a chronic condition, during the process of school education (fig. 1).



**Fig. 1.** The proposal of a model of supporting and aiding students with a chronic condition

Source: own research.

The application of the above proposal, would, in my opinion, be justified also in building optimising activities for the aid for children/students from different risk groups regarding educational and social setbacks, as the model includes the necessity of a holistic look at the student, along with his biography, and various experiences.

## Conclusion

The occurrence of difficulties and setbacks in learning, and in social relations, that, exceptionally often, seems to encompass children and adolescents with a chronic condition<sup>32</sup>, limits not only their choices in subsequent phases of schooling that determines their educational, and professional profile, but also, their opportunity to achieve a position within the social structure, the adult life.

One of the essential risk factors of setbacks, is probably the fact, that the school period, in which the need to become competent becomes essential, which is related to the psychosocial crisis; feeling of competence vs the feeling of inadequacy.<sup>33</sup> When the child begins the systematic acquisition of knowledge, and studying becomes an essential form of activity, a time comes, to realise developmental tasks, the aim of which is to meet the expectations of the school, and of the parents. Erik Erikson describes this period of life as the age of industry or inferiority. It is related to the shaping of the feeling of competence, and of efficiency, in activities, that are the result of the intentional activity of an individual, as well as, of intensive learning. All success leads to the development of the feeling of competence, and of the belief regarding own efficiency.<sup>34</sup>

Thereby, one of the aspects of activities taken up during the process of education, that links the processes of learning – education and teaching, should be assisting students in achieving self-actualisation, as the danger, existing in this phase of development, of the appearance of the feeling of inferiority, related to the lack of success in learning, in both the instrumental and the directional spheres, usually carries over constraints and irregularities in the development of the entire personality. Already, more than fifty years ago, Stefan Szuman noted, that "(...) Without developing own knowledge

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<sup>32</sup> J. Bąbka, *Nie integrować nadmiernie*, Edukacja i Dialog 2002, no 1, pp. 3–11; B. Jachimczak, *Dydaktyczne i pozadydaktyczne uwarunkowania efektów nauczania indywidualnego dzieci przewlekle chorych*, Oficyna Wydawnicza „Impuls”, Kraków 2011.

<sup>33</sup> E. Erikson, *Dzieciństwo i społeczeństwo*, Wyd. Rebis, Poznań 2000, pp. 269–272.

<sup>34</sup> *Ibidem*.

of the world properly, the child cannot acquire a broader and indispensable orientation in own environment; without acquiring this orientation, necessary at a given age, the child cannot act intentionally; if the child is not sufficiently active, he or she does not acquire experience necessary for developing own mind; if the child secludes self from people and other children, does not recognise them, and has no opportunity to test own strength and capabilities against them; if the child is emotionally unstable, he or she cannot achieve balance; if the child is explosive, he or she falls in conflict with the environment and becomes neurotic (...)"<sup>35</sup>

However, in the realisation of tasks, that may be defined as pro-developmental, children and adolescents with a chronic condition, need educational and life success, determined by the cooperation with others, a community of aims, based on the analogy of the systems of value of the students with a chronic condition, their parents, teachers, experts, as well as, peers, among whom they function. In the specific case of a condition, when it "excludes" from the school life for a period of time, maintaining contact with others becomes a problem. In such conditions, it is difficult, not only to develop cognitive, or emotional competencies, to learn how to be with, and for others, but also, to design own future. These challenges may create another area of difficulties, primarily related to the reevaluation of the attitude towards life, and accepting life as it is, in its a priori mutability.

However, the efficiency of, how children and adolescents with a chronic condition, will handle the challenges ahead of them, will depend not only on their personal assets, but also, activities within the school environment. This last element, is strictly tied to the creation of a model of such support – theory is its basis, however, its principles should result in pedagogical practice.

The model shows, that in school, due to the atmosphere that ensures the feeling of safety, the student can "leave" the role of a "sick child" and no longer be perceived through the prism of own condi-

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<sup>35</sup> S. Szuman, *O dojrzałości szkolnej dzieci siedmioletnich*, Nowa szkoła, 1962, no 6.

tion. It is important, to reinstate the child's value as a Person, possessing strong and weak points, own interests and dreams, that learns achieving success and coping with setbacks, that every person experiences.

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