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PECULIARITIES OF INTERACTION TEACHER WITH PERSONS WITH THE ACQUIRED DISABILITY

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The aim of this essay is mainly focused on how the acquired disability can induce the affected people to reconstruct a new identity. To do so, self- emotional supports such as resilience are paramount for the acceptance of the new self that will eventually lead the way to independence. The body is considered zero point of every look, of every perception, which faces the world. It is a here that cannot become a there, in its characteristic as a cognitive geometrical around which the world and the intersubjective dimension unveil to consciousness. But, to the phenomenological reflection, we will add that it is not enough to affirm that man is an incarnate consciousness since he is at the same time a self-conscious body. It is a matter that, after acquiring life, has become aware of its existence. The body represents the manifestation of man in the world, as a 'limen' – a border, a passage between two worlds, the internal and external world. Thanks to his being a body in communication with the world, man acts and creates culture. Surprising that, due to the amputation of a limb, the 'patient' continued to perceive the missing limb as still present, as an integral part of his body, precisely the so-called phantom limb. The phantom limb syndrome plays an important role in understanding the reason for existing sensations after the amputation, making patients sense and believe that they can still walk or stand on the missing limb. This phenomenon "shows how the sense of possession of a limb depends on the cerebral representation of the same; how the awareness and experience of one's own body constitute the anchor on which the sense of self develops.

Keywords: *acquired disability, identity, change, resilience, independence, phantom limb syndrome.*

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ОСОБЛИВОСТІ ВЗАЄМОДІЇ ПЕДАГОГА З ОСОБАМИ З НАБУТОЮ ІНВАЛІДНОСТЮ

Д. Аргіропулос

Мета дослідження в основному зосереджена на тому, як набута інвалідність може спонукати постраждалих людей віднайти нову ідентичність. Для цього емоційна підтримка, така як стійкість, має першорядне значення для прийняття нового "я", що в кінцевому підсумку прокладе шлях до незалежності. Тіло вважається нульовою точкою відліку, будь-якого сприйняття, з яким стикається світ. Це – незамінний компонент, що у своїй характеристиці формує когнітивно-геометричний простір сприйняття, навколо якої світ та інтерсуб'єктивний вимір відкриваються свідомості. Але до феноменологічної рефлексії додамо, що недостатньо стверджувати, що людина є втіленою свідомістю, оскільки вона водночас є самосвідомим тілом. Йдеться про те, що, набувши життя, людина усвідомлює своє існування. Відповідно, тіло являє собою прояв людини у світі, як "limen" – кордон, прохід між двома світами, внутрішнім і зовнішнім. Завдяки тому, що свідомість втілена у тіло, що комунікує зі світом об'єктивної реальності, людина діє і творить культуру. Дивно, що через ампутацію кінцівки "пацієнт" продовжував сприймати відсутню кінцівку як все ще присутню, як невід'ємну частину свого тіла – так звану "фантомну кінцівку". Синдром фантомної кінцівки відіграє важливу роль у розумінні причини наявних відчуттів після ампутації, змушуючи пацієнтів відчувати і вірити, що вони все ще можуть ходити або стояти на відсутній кінцівці. Цей феномен показує, як відчуття володіння кінцівкою залежить від мозкового уявлення про неї; як усвідомлення та переживання власного тіла становлять якір, на якому розвивається відчуття себе.

Ключові слова: набута інвалідність, ідентичність, зміна, стійкість, незалежність, синдром фантомної кінцівки.

Introduction of the issue. The body represents the manifestation of man in the world, as a 'limen' – a border, a passage between two worlds, the internal and external world. Thanks to his being a body in communication with the world, man acts and creates culture. As Bertolini states in *L'esistere Pedagogico*, "the movements of the body, the gestures, do not just follow and accompany the word, but they are also an indispensable condition for the word to become an explicit word" [1]. According to common sense, the majority believe that the word, the verbal language, is the only way of communication and expression of a human being. They ignore an aspect of its construction that stems primarily from bodily movements, or gestures, which are respectively connected to sounds that are produced in the air by these movements. Therefore, it is important to underline that the bodily movements, which are led by the central nervous system, generate the words and

not the other way around. In other words, verbal language comes under the category of motor skills and, like every voluntary expression, is produced through the body. Other sectors such as education, neuroscience, humanistic and artistic fields, in addition to the philosophical and phenomenological studies, have produced more exhaustive and scientific comprehension of the representative forms of the human body. For instance, within neuroscientific studies on body awareness, it has emerged that the person has changed the awareness of his body due to some types of brain injuries.

The phantom limb syndrome plays an important role in understanding the reason for existing sensations after the amputation, making patients sense and believe that they can still walk or stand on the missing limb. This phenomenon "shows how the sense of possession of a limb depends on the cerebral representation of the same; [...] how the awareness and experience of one's own

body constitute the anchor on which the sense of self develops" [1].

The concept of self-awareness is closely linked to the body self's concept that one witness during their existence. In childhood and youth, the individual undergoes physical changes with which we interact with other fellow beings and environments. Through this mutual interaction of the internal and external world, the individual achieves harmony, beneficial to their body and mind, as it has scientifically proven. However, this harmony could be very challenging for those people who have suddenly become disabled in their youth or adulthood. Depression, anxiety, stress, and demotivation are just some of the most common mental disorders to adversity, which frequently refrain people from the acceptance of their new self. Similarly, people with congenital disabilities would show the same reactions. However, these mental illnesses are more recurrent in people with congenital issues due to their interaction with the external world. Relationships with peers, family members as well as cultural, social, and scholastic participation become relevant. Within this external context, disabled children and teenagers normally have fewer friends than their peers 'non-disabled' and are exposed to an increased risk of being bullied. The psychological side effects of this discriminatory socialising context can induce disinterest in interpersonal relationships, withdrawal from the surroundings and inability to manage the completion of an activity. Consequently, disabled children and teenagers can lose the perception of themselves and their bodies. Furthermore, the others' views influence the disabled children and adults' behaviours, which often turn into a series of stigmatizing attitudes and behaviours and determine the role that others expect the person to play within their own life and society. However, despite that, disabled people can liberate themselves from external expectations

and judgements when they acquire a positive idea of themselves and their existence. Everyday experience and social interactions can positively strengthen, or denigrate, the conception that the person with disabilities has of themselves. Others can either overcome their limits by enhancing their abilities and potential or focus only on the limits used as concepts to define the person. When physical disabilities intersect with intellectual ones, the situation is more complex, but this does not mean that the chances of developing a positive perception of oneself and one's bodily - self decrease or cancel each other. As reported by the UN convention, it is stated that the importance of the right to health and the right of every person to enjoy the best possible state of being in good health, without discrimination. This principle is based on the relevance of the social context in avoiding the transformation of a health problem into a disability.

Current state of the issue. Acquired disability refers to a condition that stems from a traumatic event or a diagnosis of degenerative diseases that occurs throughout a person's life. The person undergoes a modification of the health and physical limits that they did not previously have.

Degenerative diseases can harm different parts of human functioning: motor skills, behaviour and thinking. Some examples of the acquired disability are the following:

- Cranioencephalic Trauma
- Brain damage due to drug use
- Stroke
- Muscular dystrophy
- Duchenne muscular dystrophy
- Amyotrophic lateral sclerosis (ALS)
- Multiple sclerosis
- Parkinson's
- Spinal injuries
- Amputation
- One or more limbs of the body, total or partial loss of vision, partial loss and/or modification of one or more limbs.

From the 2017 Istat survey "Aspects of daily life carried out on a sample of people who reported to have limitations due to health problems, it emerged that "people with multi chronic conditions or those affected by serious chronic diseases in 69 % of cases have severe or non-serious limitations and this share exceeds 77 % among the elderly" [1].

Chronic morbidity can become the cause of limitations: in fact, severe chronic diseases often involve not only a reduction in autonomy but also other pathologies, such as arthrosis, depression, asthma, allergies, etc., that can be the cause of disabling degenerative processes and progressive functional limitations. On the other hand, severe chronic diseases can also originate from functional issues coming from other events [1].

Results and discussion. The person who becomes disabled faces new conditions that will radically change their existence. Firstly, the acquired disabled person will cope with themselves and adjust to having a new perception of their body. Secondly, they will mentally shift into the new life that the disability has brought them in to rebuild a new life. In this regard, the attitude toward the future determines the new path/project of life that the acquired disabled person will undertake. As we all know, changes lead to personal crises and uncertainties when old motor habits cannot any longer fit the new physical condition. Indeed, dramatic and shocking events usually induce the person to wake up and become more sensitive and aware of their own body's movements, which are normally taken for granted for most non-disabled people. Therefore, the new physical condition leads the acquired disabled person to examine and revise the conception of their own body which is crucial for rebuilding a new identity with their acquired disability. How can the acquired disabled person achieve that? They can do it with rehabilitation. Rehabilitation is a particular process of

interventions incorporated into a network of professionals dedicated to assistance and promotion of independence. This network of expertise could function if the cooperation of the disabled person and the support of family and friends is effective. The outcome of this extensive network is to support disabled people to gently accept their disability by reviewing the concept of it as a limit. As the latter is solidly rooted in the concept of disability, as an uncomfortable truth, it should not be seen as a limitation but as a line where to redraw new possibilities out of limits. In other words, the disability should not be perceived as a burden, an obstacle, as we normally do, but as a resource where the person with a disability can rebuild their self-identity within a process of new life.

As defined by the ICF document, disability is a health condition that can involve anyone at any time of life due to an unfriendly environment. However, the hostile environment cannot be seen as a condition that defines the person. To determine oneself, a disabled person should start a process of rehabilitation focused on themselves. Accepting the new mental or physical body is a very challenging process. It involves the elaboration and re-elaboration of changes and the redefinition of self-image.

To learn to know and re-know oneself in a new dimension, which is no longer the same as before, is crucial. The trauma creates in the disabled person, at first, a sense of impotence, fear, non-acceptance that compromise the ability to elaborate the event itself. Furthermore, the trauma may cause panic attacks and negative psychological situations that make the disabled person unable to produce rational reactions. He would feel the need to escape from that dramatic reality imagined as impossible and full of suffering. Thus, the disabled person becomes less self-confident, feeling pervaded by a sense of precariousness and injustice. The

challenge, which sometimes can be problematic, is to find the right ways to restore an internal balance because the whole identity of the person, also their professional and social ones, is bound to break into pieces. Normally, the first psychological reaction is of a total and firm rejection of the new condition, perceiving it as an injustice, and refusing to counsel and support that other tries to introduce through different treatments. When the person falls in despair, even if indirectly, they try to ask others to understand their new condition and suffering as a consequence of it. However, on the other hand, this indirect or direct understanding is accompanied by a strong non-acceptance of the change, in particular physical, that one undergoes.

The first emotional outbursts such as *despair and anger will be replaced by elaboration and acceptance*. When the acquired disabled person accepts themselves and their new condition, everything else will change. The perception of the other will change. Similarly, the feeling of ashamed, humiliated or considered with contempt will disappear. In other words, the disabled person will be able to understand what is no longer existing, but what is still there, and what can be created.

Working on existing skills, enhancing talents, and recreating a daily routine are fundamental actions. As we have said, the disabled person loses some skills but acquires others, which can only emerge thanks to the commitment of the person himself, family's support and professional competencies in a rehabilitation plan that will allow the construction of a life project for the future. To ensure that a life project can be realized, a project requires effort from everyone. A project implies taking care of the other person in their totality and their peculiarities. It is the implementation of a cooperative collaboration that looks at the need or needs of the person by studying,

planning, evaluating and searching the possibilities, and the instruments to find the solutions for the independence and well-being of the acquired disabled person. In this work, the educational figures, in collaboration with the other professionals, are responsible for creating, planning, individualising interventions and taking care of the person with respect and dignity and freedom to decision-making. Within this context, the role of the educator can make a difference by reversing the concept of limit, as stated above, into possibilities to support the acquired disabled person to reshape new skills: A new person that combines their previous experiences with new possibilities in life, with meaning and recreates their certainty, by applying self-efficacy and self-esteem. Sometimes old ambitions, passions and talents re-emerge during the rehabilitation; this facilitates the reconstruction of new possibilities of life by combing the perception of 'knowing how to do' with the importance of feeling "being".

There is a feeble distinction between an acquired disabled person with potentials and a disabled person, perceived as a sick person and thus in great need of care and support. In this type of perception, the supportive relationship, which is predictable and static, must focus on the present, separate from the contexts of normality. Furthermore, the supportive relationship has essential characteristics aimed at the wellbeing and autonomy of the person. When this type of support is applied to the acquired disabled person, we should bear in mind that we are dealing with a person who needs help without repressing their possibilities or abusing their intimacy, which is easy to do when they are unable or incapable of reacting due to their fragility. In addition, suspension of judgement and prejudices is another crucial element within the supportive relationship in which the educator must go beyond the deficit of the disability of the person and sees in

themselves the opportunity for growth and changing one's self-identity. The supportive relationship is made up of good practices and complementary dynamics to put into practice. There are no absolute values because each person reacts differently to their treatments, which depends totally on their eagerness to change and be able to let the past life behind for new chances. Sometimes elements of fragility prevail over strength and the positive aspects of our being. But they also predominate over the knowledge of our abilities, our skills, our self-esteem, and the ability to manage daily events, especially those that make us fragile, that make us suffer. As Boris Cyrulnik argues, experiencing a moment of crisis does not necessarily imply permanent suffering, self-pity and passive reactions. When a person becomes disabled, as we said before, he must come to terms with the drama of the event itself and the changes that affect every sphere of his being. However, all this can overturn when the acceptance of the new self and the new psycho-physical condition is manifesting within and through the drama. From an educational point of view, it is interesting to explore the work of two important figures: the professional educator and the peer supporter. According to Boris Cyrulnik, what determines resilience is the relational systems that the subject has created before and after the traumatic or critical event. It is the moment in which the social and relational context of the subject's life assumes a determining role since it is from here that resilience arises.

The social educator has a fundamental role in the support and integration of the person with disabilities. He is a figure who plays a role of care, understanding and support of the disabled person. He has also to apply systematic observation to acquire an analytical and profound knowledge of the respective disabled person. Only in this way, the educator will be able to gather information essential for the

identification of the areas of intervention that will allow the person with disabilities to have the opportunity to be fully integrated into the society. The educator, therefore, is a mediator between the person and the context, a figure who identifies the road to social inclusion and employment. Furthermore, the work of the educator is characterized by vital tools such as listening and encouraging acceptance of the way the current disabled person is. Unconditional and positive acceptance allows the establishment of a relationship of trust, in which the educator must be equipped with empathic understanding and sincerity. It is also important that the disabled person comes and feels valued, stimulated. All this will allow the establishment of a relationship of mutual trust, which is fundamental to allow the disabled person to become communicative and consequently undertake that change towards the progressive acceptance of the new self and the acquisition of greater security. From this educational relationship, two fundamental aspects emerge dialogue and mutual trust.

The dialogue can take different forms. Sometimes the person with a disability wants to talk about their trauma, but other times they only withdraw and decide to say nothing; sometimes, they ask for an opinion or being heard. These processes are designed and tailored for every individual. There is no universal practise; each one reacts according to their ways to the trauma. When the disabled person is in crisis, he is trying to understand what happened to him, he is worried and overwhelmed by a whirlwind of emotions that do not allow him to be completely rational. He needs to talk about what has happened, but does so gradually, as the emotional load makes way for acknowledgement of their condition. It could also happen, however, that his vision remains within a completely negative perspective because the person is experiencing a strong

frustration, a state of depression could also arise, he could feel misunderstood and could not see a future. So, not advising, in this case, is useful because any advice would not be received. The same thing is true for non-judgment: the disabled person is afraid of feeling judged and at the same time he feels angry because he thinks that nobody can understand his situation. The educator, like anyone else who has a relationship with the person who has become disabled, must maintain a position of listening and supporting, which will encourage the disabled person to open up at their own pace. The need to find a reason for radical changes or to re-elaborate the change through comparison and dialogue or to receive an opinion and exchange information, stories, experiences and feelings, is what can happen in a relationship between peers.

Peer supporters are people with disabilities who share their direct experiences. They make it available to others, establishing an educational and mutual aid relationship based on equality and parity. The peer supporter makes him/her own experience available, valuing it, sharing it with the other person. The peer supporter acts in a way of listening to that becomes reciprocal, as the other person, who is undertaking the rehabilitation process, begins to feel no longer alone. One begins to acquire the awareness that the problem cannot be eliminated but faced, thus reducing the sense of limitation and incapacity, reducing the negative feelings of anger, frustration, fear, shame, which begin to make room for more positive attitudes and feelings, both towards oneself and towards the surrounding world. It is thus possible for the person with a disability to start on the path towards empowerment, a process in which they are not alone but are supported by several figures, one, in particular, who understands them, who provides them with the right tools to acquire the information needed to

overcome the state of passivity and impotence in which they are imprisoned, as well as the strong frustration that is slowly wearing them down. The peer supporter represents, therefore, a mediating tool towards the acquisition of a state of positive awareness of the new identity, of oneself, of one's capacities and limits, coming out of that state of complete and absolute negativity, of a person with no future, arriving instead at a more realistic and positive vision of one's own life, in which the person is the protagonist and an active, planning part, which is self-determining.

The health and social spheres, although they may seem distinct and separate, two separate units, are two complementary parts of the same pathway: the rehabilitation of the person with disabilities. The rehabilitation should not be understood, in fact, in the strict sense of the medical-sanitary point of view. The rehabilitation process involves the person in care holistically by including their private and social spheres. Therefore, it is fundamental to find the right plan and an educator who helps the disabled person rebuild the lost identity with a new one and enhance possibilities of physical or mental limits. The educator is a crucial figure who will support the disabled person along the transitionary period from leaving the hospital to reintegration in everyday life, with a social and work inclusion. According to the 1998 Ministry of Italian Health guidelines for rehabilitation activities, "rehabilitation is a process of problem-solving and education where a person is brought to the best possible level of life on a physical, functional, social and emotional level, with less restriction of their operational choices. The rehabilitation process also involves the person's family and all those close to them. Consequently, the rehabilitation process involves not only strictly clinical aspects but also psychological and social aspects. Any rehabilitation project to achieve a good level of effectiveness must be aimed at multiple objectives and

planned in an orderly manner. In this way, the autonomy attained in the various areas can be translated into independence for the disabled person as a better quality of life. The rehabilitation process, in particular, in the case of an acute episode, starts from the moment of the therapeutic intervention in the acute phase. This must be immediately treated through a careful balance of the possible outcomes of the disease in progress, taking in the therapeutic process of the acute phase, the measures that can limit them and providing the conditions that can facilitate the subsequent and immediate transition to the more efficient rehabilitative phase. ... the rehabilitation's healthcare activities, except for those of simple instrumental physical therapy for minimal, segmental and/or transitory disabilities, necessarily require the global clinical care of the person through the preparation of an *individual rehabilitation project* and its implementation through one or more *rehabilitation programs*"[3].

However, the health services still tend to give priority to medical action and the re-education of the disability, neglecting the phase of social/work reintegration, maintaining a line of action which is purely welfare, far from the vision of the service as an active part in supporting the achievement of autonomy. In response to this limitation, an attempt has been made to employ the mediation service in the healthcare sector, which has been contemplated by the Minister of Italian Health and realised in North Italy. The innovative aspect of the project is that a health worker is assigned the function of the mediator. After a training course, the mediator will have the knowledge and skills necessary to create functional connections, "bridges", between the hospital where he works and the territory in which he operates, aiming at long-term objectives for the reintegration process. This project is a striking example of network work that should be done when we talk about the social reintegration of the person, not

only with disabilities. The figure that is put in the field acts as a mediator between the different systems, allowing the meeting between the demand and the offer of work.

Lately, there have been attempts to develop more and more innovative and different ways to support the disabled person during the process of changes and acceptance of the new self. One of the experimental fields that are having success is theatre animation. Among transversal activities, in supporting the mediation of work beyond trauma, the theatre has become a useful tool to achieve objectives beyond the aims of the performance itself. The theatre embraces interventions, strategies, projects of different fields: educational, rehabilitative, social, cultural. Recently, some associations have realised their social projects and events by using the theatre as an effective communication tool to activate reflections, paths of self-knowledge and knowledge of the other, of otherness. The shows are built in an atmosphere of mutual respect, a trust that is built over time, with the activation of listening and knowledge. Experiencing theatrical pathways with people with acquired disabilities has several advantages and opportunities that allow the person to approach with awareness the process of changing their identity more positively and profoundly. Being involved in theatre projects enables people to play roles different from those in which they are "stuck". Furthermore, within an environment of collaboration and mutual understanding, in which the creativity and expressiveness of participants are encouraged, the awareness of their limits enables gradual and spontaneous and less anxious participation. As mentioned above, the ultimate goal of theatrical workshops for people with acquired disabilities is not the show itself, the product, but the process. What counts is how the experience is lived; how you feel, who you are, what your fears and what your desires are externalised and

communicated to others. In other words, it is a process of knowing and being known. In this way, thanks to its absence of views, the theatre becomes part of a social network of direct and closer contact with minorities. Within this context, these minorities rediscover their voice, visibility, skills, expression and communication that in other areas of life, perhaps overprotective or reluctant to know the other, do not emerge.

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