

INDIVIDUAL PROJECT, INDIVIDUALISED EDUCATION PLAN, LIFE PROJECT AND FAMILY: THINKING ABOUT THE FUTURE TOGETHER

PROGETTO INDIVIDUALE, PIANO EDUCATIVO INDIVIDUALIZZATO, PROGETTO DI VITA E FAMIGLIA: PENSARE INSIEME IL FUTURO

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Abstract

The centre of the sustainable inclusive project of/for each person is characterised by the importance of collaboration, of the educational co-responsibility pact between school, family and other subjects, public and private, operating in the territory as essential elements for the promotion and realisation of an effective and reciprocal interrelation between Individual Project, Individualised Educational Plan and Life Project. The points of reflection proposed in this contribution aim at considering the overcoming of the medicalisation of disability in favour of the co-construction of an PEI on the basis of the ICF bio-psycho-social model, as supported by recent regulations (D. Lgs. 66/2017 and 96/2019, L. 328/2000, D.I. 182/2020). This perspective, supported by the instances of universal inclusive design, stimulates the development, also in a future perspective, of the self-determination of the person with disabilities within the most facilitating micro and macro existential contexts (school, family, society), aimed at ensuring and increasing participation and raising the quality of life.

Il centro del progetto inclusivo sostenibile di/per ogni persona è caratterizzato dall'importanza della collaborazione, del patto di corresponsabilità educativa tra scuola, famiglia e altri soggetti, pubblici e privati, operanti sul territorio quali elementi imprescindibili per la promozione e per la realizzazione di un'efficace e reciproca interrelazione tra Progetto Individuale, Piano Educativo Individualizzato e Progetto di vita. Gli spunti di riflessione proposti nel presente contributo, mirano a considerare il superamento della medicalizzazione della disabilità a vantaggio della co-costruzione di un PEI sulla base del modello bio-psico- sociale ICF, come sostenuto dalle recenti normative (D. Lgs. 66/2017 e 96/2019, L. 328/2000,

D.I. 182/2020). Tale prospettiva, supportata dalle istanze della progettazione inclusiva universale, stimola lo sviluppo, anche in prospettiva futura, dell'autodeterminazione della persona con disabilità all'interno dei micro e macro contesti esistenziali (scuola, famiglia, società) maggiormente facilitanti, tesi ad assicurare e a incrementare la partecipazione e l'innalzamento della qualità di vita.

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Keywords

Inclusion, Individual Project, Individualised Education Plan, Life Project, family, empowerment

Inclusione, Progetto Individuale, Piano Educativo Individualizzato, Progetto di vita, famiglia, empowerment

1. Introduction

The personal project, a pivotal tool for the implementation of the right to independent living for each and every person and to safeguard social inclusion, is at the heart of the UN *Convention on the Rights of Persons with Disabilities* (2006, art. 19). For the realisation of this project, the Convention hinges on two fundamental principles: reasonable accommodation and universal design. While the former encompasses the modifications and adaptations necessary and appropriate to guarantee the fundamental rights of persons with disabilities, the latter is aimed at designing products, facilities and services accessible to all, without exclusions or specialised interventions. The most relevant legislative measures in Italy in recent decades refer to the above-mentioned International Convention, which has been the background to the start-up and implementation of interesting regional experimental projects throughout the country aimed at the concrete support of the Individual Project (hereafter indicated by the acronym PI), from a social emancipatory perspective (Arconzo et al., 2020; Ferraro, 2020). These initiatives are framed within a common cultural horizon, based on inclusive education for all (Pavone, 2014), which requires intentional and systematic planning, intervention and evaluation processes and paths, both in school and out-of-school contexts, with a view to achieving a more equitable and just society (Caldin, 2022). It is by now well established that in taking care of persons with disabilities, from the first years of life to adulthood, the contribution of integrated work and intervention approaches supported by the educational action of parents, teachers and those (educators, social and health workers, public and private agencies, companies, social and work cooperatives, etc.) who are involved in accompanying the growth of a child or an adult who lives in a vulnerable condition is fundamental (Zenobini et al., 2002). This contribution intends to offer some food for thought on the role of the family in the co-construction of the Life Project (hereafter indicated by the acronym PdV), to which it jointly contributes together with the social network and the social-health services of reference (Maggiolini, 2020). The promotion of educational, accompanying, support and sustaining processes for the person with disabilities finds in parental networks, often organised in associations, a relevant active role in inclusive cooperation (Zanfroni, 2021), despite the complexity of difficulties, problems and the reduced effectiveness of welfare policies addressed to families (Taddei, 2021). The challenge to welfare models on the part of the main educational institutions, can take the form of research and implementation of more inclusive social and work trajectories that turn the spotlight on the evolution of the process of adulthood of the person with disabilities, between empowerment and construction of the Self (Zappaterra, 2014; Brusciaglioni, 2016). The discovery of the value of oneself, the development of a sense of self-efficacy, autonomy and self-esteem represent the founding aspects on which each person, with and without disabilities, can build and re-construct his or her own existential project, as F. Basaglia (2005) firmly maintained.

«If to exist means to be in order to place oneself with others, every existent will implement the way of being, his “behaviour” through the overcoming of his own situation in the choice of his project, of his aim. The moment of choice, therefore, is the unique, decisive moment for man who wants to make his existence his own. When he becomes intentionally aware of his world, of the relationships that bind him to it, of the place he holds in it, of his past, he chooses himself

in his own situation and overcomes himself in his project by implementing his personal responsibility and freedom» (p. 8).

2. The relationship between the Individual Project and the Individualised Education Plan

In representing the tool that gives identity to the person with disabilities by guiding the construction of the PdV, the Individualised Educational Plan (hereafter indicated with the acronym PEI) (Amatori & Bocci, 2021) summarises the fundamental phases of the knowledge of the student and the relative support project intervention, aimed at building an inclusive didactics, creating bridges between the class and the educational needs of the students (Montanari, 2020). Therefore, it is fundamental to anchor with the class (Ianes et al., 2021) regarding the teaching proposals, in the search for authentic points of contact with the pupil with disabilities in order to elaborate an PEI-PdV in an inclusive direction, an effective expression of the bio-psycho-social approach to human functioning, as provided for by D.Lgs. 66/17, by D.I. 182/20 and by the Guidelines for the assignment of support. In this perspective, the PEI (regulated, for the first time, throughout the country) becomes an expression of the anthropological-systemic vision proper to the ICF-*International Classification of Functioning, Disability and Health* (WHO, 2002), which identifies the person's functioning as the result of the interactive interweaving of physical conditions, bodily structures and functions, personal activities and social participation, environmental and personal contextual factors. Disability, defined by the relationship between the individual and his or her environment, therefore refers to the reduction, removal of barriers and increase of facilitators, both in the person and in the contexts in the name of a dynamic and stimulating tension. This eco-systemic logic, spilling over into the educational-inclusive spheres, places the PEI inside and outside the school, supports it as a tool that activates an increasingly synergic and operable relationship between the PdV and the PI (Cottini et al., 2021), placing the person with disabilities not as a user of individual services but as a subject with his or her own needs, interests and resources to be strengthened and promoted. According to Laws 328/2000 and 112/2016 (*During and After Us*) (D'Amico, Arconzo, 2016), the PI provides for the full school, work, social and family inclusion of the person with disabilities, through the coordination of the various interventions (health, social welfare, educational, etc...), not only to avoid inappropriate overlaps, but to dynamically orient them towards a pertinent response to the special and individual needs of the beneficiary person (Mura & Zurru, 2013). The innovative approach to the PI of each person, assisted and co-designed in the definition of roles and responsibilities, represents an act of planning that goes beyond what can be achieved in the hic et nunc, articulating itself over time according to the actions and services implemented by the institutions, the person, the family and the territorial community. In this perspective, the processes of social inclusion and labour insertion (Calvin & Scollo, 2018), inspired by the institutional support of the PI-PEI, have the possibility of being realised by allowing the person with disabilities to choose contexts and activities in respect of the right of self-determination (even when subjectivity fails to fully manifest its decision-making capacity), in order to escape semi-residential and residential services, as the only alternative of life. In an attempt to avoid as far as possible resorting to compensatory forms of welfarist help, the creation and promotion of support networks is integrated with the values of the person's functions in the contexts of life, defining the objectives contained and made explicit in the PI and in the PEI-PdV (Canevaro, 2021). From a bio-psycho-social perspective, the multidimensional and multi-perspective intervention project, promoted by the virtuous interweaving of the PI and PEI-PdV, tends to enhance the self-determination of the person with disabilities and to improve the quality of life, leveraging

on the significant testimony of one's original and unrepeatable existential history (Giaconi, 2015).

3. Promoting the Life Project: the role of the person with disabilities and the family in building a fairer world

The PI pursuant to art. 14 of L. 328/2000 is an administrative act, the outcome of a procedure at the request of a party. This aspect is absolutely to be taken into account, especially when one considers that the "part" that must take action by submitting the application is the person with disabilities or alternatively - where appropriate and necessary due to the person's age or legal status - his/her family members or legal representatives. The new PEI emphasises the appropriateness of PI reasoning starting as early as school age. In this sense, the Operational Working Group (hereafter indicated with the acronym GLO) becomes a valuable and unmissable opportunity for the empowerment of persons with disabilities and their families, the only possible activators of the administrative process leading to the drafting of the PI. Emphasising the relevance of such an investiture forces us to take the risk of restating the obvious, in underlining how much the idea has changed that traced the person with disabilities and his or her family back to the exclusive and exclusionary sphere of suffering, disorientation and illness (Parsons, 1981). On the other hand, reading in the folds of the history of scholastic and social inclusion in our country, we cannot fail to recognise how both the individual existences and also the associations of persons with disabilities and their families have been its promoters, the voice, the instance gathered, nourished and made to grow by the encounter with the passion of greats of our time: F. Basaglia, A. Canevaro, to name but a few enlightened authors. The path of empowerment of persons with disabilities and their families was born before the Basaglia Law, before Law 517/77, before Law 68/99, before the UN Convention and of these measures it is both instituting and establishing. This orientation continues until today to flow into significant experiences carried out on different territories and carefully documented (Marchisio, Curto, 2017) becoming, with the motto "nothing about us without us" (used for the first time in 1984 in an international context by Ron Chandran-Dudley) the plot along which the right to exist, to participate - not only to live - of the person with disabilities unfolds. Thus, the medical model of disability, with its corollaries relating to the need for specialisation, specialised language (Foucault, 2020), the interpretation of the person as a sick body to be cared for, welfarism and victimhood, has sunk to the educational level because it is undermined at the base by narratives of further, possible and even current life paths. The disabled person and the his family (Sorrentino, 2006) are, therefore, no longer hostages to a technical vocabulary that is not always comprehensible, nor are they no longer the "object" of conversation between experts, but are subjects who take the floor and participate in changing the world with their own language rich in meaningful and significant knowledge (Freire, 2014). GLO, with its reference to PI and the investiture that the latter confers on persons with disabilities and their families, can be the place where the practice of recognising the other, of their need for meaning (Frankl, 2017) continues in order to facilitate, through such capacitating action, their liberation. Liberation also from a stereotype: the one linked to pain, fear, inadequacy, lack of awareness and the desire for extreme protection of the person with disabilities. Such a conception would result in the impossibility of a projectuality adherent to reality and oriented towards overcoming, in challenge, the same. In this sense, it seems significant to us to report the experience of the Italian Association of Fragile X Syndrome which, over the course of thirty years, has abandoned the welfarist and pietistic approach aimed mainly at the families of people who present this disability - which is the first cause of hereditary type intellectual disability and the first monogenic cause of autism spectrum disorders (ASD) - to become a promoter of projects to support the PdV of the person with

Fragile X Syndrome. It has done so through projects aimed, in the ICF perspective, at promoting facilitators and removing barriers to the realisation of each person's project, through training courses for teachers accredited by the MIUR, family empowerment paths (Brunetti, 2015; Ghedin et al., 2016; Maggiolini, 2018), projects for the construction of a curriculum of skills spendable in the world of work, as well as work experience abroad within the Erasmus project. The role of the families in the Association is less and less that of users in search of a "cure" - understood as a drug - and more and more that of actors aware of their own rights and those of their families, capable of re-appropriating a project dimension for their own existence and that of their loved one with X Fragile and of promoting its realisation at an institutional level. Of course it would be demagogic to affirm that all the families and all the persons with disabilities that we include in the reflection on the PEI and in the drafting of the PI possess, always and in every case, the conceptual and concrete tools that allow them to speak, to say the appropriate words and to act those words with profound justice. We must, however, admit how valid this is for each of the other GLO members as well. Tagore (1998) reminds us that "small truths have big words, which are clear, while big truths have big silence". That silence that acts as a synaptic space between two interlocutors who dialogue and who in this 'dia' - which in Greek has the sense of separation but also of the middle - find new ways of projecting. It is the contamination that digs karst rivers in which flow meanings, ideas, projects, needs that, once listened to and metabolised, become an impelling stimulus for the school and, through the connection with the PEI, for society as a whole. In this way, the PEI, and the PI of which it is a part, become not only the liberating satellite navigator of the person with disabilities, but also of society, in assessing the latter's ability to respond to the existential needs of the most fragile and vulnerable (Canevaro, 2015). Therefore, the educational function of the scholastic institution emerges in all its scope, which, we like to emphasise, also and precisely from the assumption of responsibility for the challenge of inclusion, has become much more than an institution for the transmission of knowledge - in which nowadays it would be easily replaced by a common PC attached to the network - to become an instrument for the construction of a new democratic society, where no life is tiny (Gardou, 2015). An educational function that, consistently with the bio-psycho-social approach, we know cannot be addressed to a subject regardless of the reference context: family, friendship network, extended social context in a co-evolutionary dynamic (Canevaro, 2008) in which we are all, together, educators and educandi. Synchronic and diachronic gaze, self-esteem and recognition of the other, gratitude and at the same time altruism, humility in recognising oneself as a companion and at the same time awareness of one's own role, ability to respond with a sense of responsibility and at the same time ability to listen. And in this complexity emerges what can be the outcome of the recognition and co-design dimensions indicated by the new PEI legislation and its connection with the PI: "an inclusive school for a fairer world" (Canevaro, 2013).

4. Conclusions

From the reflection conducted so far, a number of critical aspects emerge on which it is appropriate to draw concluding remarks, which are certainly not exhaustive but subject to further in-depth developments. First of all, it is necessary to emphasise the possible risks to be avoided with regard to the construction, connection, observation and design of the PI-PEI-PdV. From this point of view, the individual model of disability, proposed by the medical perspective, may contain within itself the danger of educational sanitisation, translating mainly into a hunt for symptoms (Goussot, 2015), with the related request for technical-specialist interventions aimed at the specific disability. The person who is different, not being reductively included in the irreversibility of the deficit (Gaspari, 2017), needs a pedagogical outlook that

does not prejudicially replace the medical one but that orients interventions to the implementation and dissemination of the inclusive culture of *Universal Design for Learning-UDL*, that is, of good practices, both school and extracurricular, without barriers (Montanari & Ruzzante, 2021). Universal design conceived for everyone and everyone, centred on the concept of the person in the different contexts of life in which he or she is inserted, represents the stimulus for an innovative and responsible dialogue with several voices between school, family, social, etc., within a necessarily broad and fertile complex ecosystemic design dimension. It goes without saying that any dogmatic and self-referential positions of the school institution must be absolutely avoided, as they are the bearers of a parcelled out and implosive planning vision. In this sense, it is opportune to focus attention on the concept of *Quality of Life* that makes it possible to abandon and go beyond practices inspired by welfarism and normalisation, with their negative drifts (Medeghini, 2015), in order to enhance and/or maintain adequate levels of self-determination so that the person with disabilities learns to do things for him/herself, regardless of his/her abilities and skills (Cottini, 2016). The ability to enact self-determined conduct also depends on the possibilities offered by the micro and macro contexts of life, which must, of course, be implemented. The agentivity of the person with disabilities (Lepri, 2017) is inevitably linked to the learning experiences implemented in the family, at school and in the social sphere in order to broaden and evolve the possibilities of choice and empowerment, escaping the caring focus on the present and daily needs. At such a juncture, it is educationally pregnant to guarantee one of the fundamental rights of each person, namely that of freely choosing one's own existence in accordance with the role of central agent of the decisions that affect them (Bandura, 2000). And it is in this direction that the school and the family are called upon synergically to contribute, to dialogue, to collaborate, to plan and to organise, in the name of the categorical imperative of intentional thinking about the future of the person with disabilities, according to the motto "Think of me as an adult" by M. Tortello (illustrious editor of the magazine *Handicap & Scuola*), overcoming the limited and limiting perspective based on deficit. The PI certainly contributes to defining the gradual construction of adulthood, the accompaniment and transition to adult life of the person with disabilities, by the family together with and responsibly to the network of relationships, parental and community, through the adoption of appropriately customised paths (Lascioli & Pasqualotto, 2021). All this in view of a transformative change, towards the dimension of active citizenship promoted by the inclusive and supportive community (de Anna, 2014). In this way, an openness to the complexity of human living and its multiple, functional and dynamic relationships with differences and diversities is manifested (Bocci, 2021), beyond the short-sighted logic of rejection that fails to grasp the whole of humanity in the fragments, nor the dignity, integrity and unique value of the person, despite the deficit (Larocca, 1999).

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