

COVID-19 SEEN THROUGH THE EYES OF DISABLED FAMILIES. A NEW WAY OF LIVING THE FAMILY

IL COVID VISTO CON GLI OCCHI DELLE FAMIGLIE DEI DISABILI. UN NUOVO MODO DI VIVERE LA FAMIGLIA

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Abstract

The COVID-19 pandemic and the resulting social distancing has turned our habits and interpersonal relationship upside-down. Many families had to face a reality that was utterly different from their everyday life, in which working spaces and private ones blended, leading to put intrafamilial relationships through the wringer. For those families with disabled children, facing the problems accentuated by the pandemic has been even more difficult. The COVID-19 pandemic pointed out significant weaknesses in the educational systems, such as their incapability of ensuring a process of integration and inclusion for those fragile categories which needed further support. It made clear that society needs flexible and solid educational approaches in order to guarantee a high-quality school to everyone.

Starting from the scenery created by the pandemic earthquake, this essay aims to propose a reflection on the complex educational situation that came together with the lockdown and still exists nowadays, as well as on the negative impact on the development of inclusive processes and on the learning level of many students, especially the more vulnerable.

Abstract

La pandemia dovuta al Covid-19 e il conseguente distanziamento sociale hanno sconvolto le nostre consuetudini di vita e con esse la sfera delle relazioni interpersonali. Numerose famiglie si sono trovate ad affrontare una realtà lontana dalla loro quotidianità: dove gli spazi privati e lavorativi si sono fusi tra di loro, contribuendo a mettere a dura prova le relazioni intrafamiliari. Molto più complicato è stato affrontare le criticità accentuate dalla pandemia per le famiglie con bambini con disabilità. Il coronavirus, infatti, ha messo in evidenza importanti vulnerabilità nei sistemi educativi che non sono sempre riusciti a garantire quel processo di integrazione/inclusione per le categorie già fragili e bisognose di un supporto maggiore, rendendo chiaro come la società abbia bisogno di approcci di istruzione flessibili e resilienti al fine di garantire una scuola di qualità per tutti.

Partendo dallo scenario delineato dal terremoto pandemico, il contributo intende proporre una riflessione sulla complessa situazione educativa delineatasi subito dopo il periodo del lockdown e prorogatasi finora e il conseguente impatto negativo sullo sviluppo dei processi inclusivi nonché sul livello apprenditivo di numerosi alunni, soprattutto di quelli più vulnerabili.

Key words

education, family, disability.

educazione, famiglia, disabilità.

Introduction

The relationships between the members of the family have changed deeply, together with the communication codes between genders and generations and the relationship between the family and the surrounding environment. Up to now, several familial forms have taken shape beyond the marriage-based family, and the attention has been drawn to the different ways of living generated from the crisis of the institution of marriage. There are some demographic phenomena that furnish proof of these transformations inside the familial system: the decrease and lateness of marriages, the increase of births outside of marriage, cohabitations, separations and divorces (Corsi, 2021). Nowadays, we are used to terms like “de facto relationships” (based on a free union), “incomplete” or “single-parent” family, when composed of only one parent (widowed or divorced) and children living with “rebuilt” families, born because of the union of two divorced people: all these forms represent for many aspects, and together with the de facto relationships, the newest family forms par excellence (Pati, 2018).

Any of us can notice the transformations inside the family system. We focused on the family as an overall complex, observing that with the passing of time the individual family nuclei have evolved taking different shapes, which need to be analysed not in relation with the needs they are going to satisfy, but looking at the culture of the single society in all its minor details – and driving the attention also on what might seem unimportant at first sight.

The pandemic stroke us unexpectedly and we had to go through various limitations to fight the virus: this showed that the index of the individual health condition is always connected to the environment we live in; that period made us realise that functioning and feeling good do not depend strictly on us, but on many external variables which is not always possible to control.

The COVID-19 pandemic and the consequent social distancing abruptly interrupted our routine and the complex of interpersonal relationships, producing on one hand a surplus of closeness in the familial intimate relationships (Siva et Gigli, 2021) and, on the other hand, a drastic and never seen decrease of the daily relationships.

We could talk about a “suspended family”, in precarious balance between undeniable difficulties that almost overcame it and the capacity of activating within itself resources to turn those changes into an occasion to grow.

For the family system the suspension time has become a time for changes with a strong regenerative component.

The sanitary emergency led to serious consequences for disabled people, because unfortunately these consequences have fallen upon a part of the population which is already fragile and needs support, and

the restrictive measures have not kept in mind these peculiar needs since the very first moment. (Caldin, 2018).

The familial distress: a crisis blown up together with the pandemic?

Characterised by living a new and unexpected situation, potentially dangerous for one's own health and for that of the family members, the emergency following the COVID-19 pandemic has caused an unavoidable feeling of loss of control, activating potential reactions due to stress (Gigli, 2021). The family and relationship dynamics have been clearly influenced by this event (Rania et al., 2020), and some people managed to find a new balance while other entered a deep crisis; many couples forced to live constantly one next to the other have put to the test their structure, often with the result of "blowing up".

Parents had to reinvent their lives, dividing the familial context into two moments: the performative time, made of tasks to carry on (such as video lectures, smart working) and "other" time, in which the time for children has become a time with children. Habits and routines have been completely altered, and this meant a remarkable adaptation effort for all the family members.

The pandemic highlighted the importance of social relationships inside and outside the family. The virus forced us, for sanitary reason, to avoid connections but, how do you live without any connection? Relationships are a pivotal element and their pedagogical-educational specificity springs directly from them: they are of use for the growth and the well-being of every single person involved and of all the totality of society (Pati, 2018). The family has rediscovered itself as the most important element of a sound and prosperous society in a new light, as a relational family, in which the connections between men and women, as well as between generations, are established upon confidence, cooperation and reciprocity as a reflective project of life. In other words, a social structure based on caring relationships which contains within themselves, due to the generativity of the couple and the generational transmission, the capacity of realising a specific project for a common life.

When the pandemic irrupted, the time for living has been blocked and we had been forced to reflect deeply on many internal and external changes, such as the sudden impossibility of taking part to the social, scholastic, working and ludic life, – essential for the psychophysical well-being of every person – the feeling of loneliness and isolation, the uncertainty and the confusion, the forced proximities and the impossibility to spend time with the significant people, and what emerged was anxiety, fear, rage and sadness statuses, interchanged with confidence, joy and calm. With the passing of time fear it turned itself into a consciousness about the need of changing our lives, of "pausing" it while shaping once again our time, relationships and daily routines regarding work, education, private life and family. In this historical moment in everyone's life it is important that the families have tried to rebuild their habits, even if in completely different situations than before.

To face it all a great deal of support is necessary, as well as the presence of concrete resources and the capacity of resilience of the people involved (Corsi et Stramaglia, 2009).

Today more than ever, we need to rediscover the familial context as a place of responsible choice, capable of increasing its own potential through the net of connections and the responsible choice regarding the type of relationships, so that combining the relationship with the other it can turn itself into a determining educational exchange, fundamental for the inner growth of all those who open themselves to the comparison with someone else who is different.

The family represents the most qualified social actor, able to provide the growing subject with sense and dignity and therefore, in order for the family to best perform its protective and healing function as an irreplaceable part in education, healing and socialisation, it is essential that we support it in every moment of its life cycle and in every condition, both in fragility and distress and in a supposed

normality (Corsi et Stramaglia, 2009, p.93).

In particular, the family constitutes a pivotal educational and relational context indispensable for heritage transmission and identity constitution (Pati, 2019), intended as the possibility for the young ones to develop transverse capacities, also called “soft skills”, that are fundamental to the formation of personal identity and the establishment of confidence relationships.

In this mixed chaos made of a continuous expansion of frenetic rhythms which is the face of the society, the tool of the educational relationships becomes an essential prerogative in every educational context since the very beginning.

Normally inside the familial system we find a frame of mind of being together and for the other: it is the famous “couple sacrifice”, which is the basement of the unconditional compromise and an endless project that affect life in all its dimensions (Elia, 2016), being clear that entering the world of relationships supposes to go beyond the limits that nowadays society imposes to the parents’ choices, degrading their role and limiting their legitimate authority. The most evident aspect is the weakening of the familial nucleus and its educational authority, which threatens the complex of relationships because the family system is crushing itself more and more, and by doing this it loses the capacity of accomplishing its intrinsic responsibilities and overcoming its limits to allow the children to mature with the richness of relationships and definitely become “people”.

The family intended as an original nucleus in which every member manages to be what he wants to be, accepting the other and understanding that freedom is not breaking boundaries, is a place to live real relationships with genuine values. Thus, couple life is defined as the place for generativity par excellence, because generativity constitutes the original tension in every partner’s choice, and it reveals itself by taking care of others and with the worrying about leaving something behind us as a heritage, such as parenthood (Vinciguerra, 2015).

Even if we may look at the family as the base unit of society, we cannot ignore or underestimate all those problems, anxieties, crisis and efforts that, often in intense ways, concern the couple life, the intergenerational communications and the accomplishment of the educational task.

Many people are fighting to confer again to the educational and auto-educated family a central role; those people are convinced that, even with so many contradictions and affirmations, debasements and revaluations, the family is the strategic resource to achieve a total human growth. The idea is that (Cunti, 2019) the hypermodern family (Rossi, 2017) is endowed with unique and irreplaceable functions, even in the current conditions, and that it is a place for a human and spiritual growth of all its members, as well as for their support, defence and promotion – so that every member is always able to exercise his rights and perform his duties (most of all the educational ones), be conscious of his role into the society, of his dignity and potentialities, and so that these richness and resources are at disposal for the society, making everyone comprehend one’s own responsibilities, capacities and evolutionary responsibilities.

The educational relationship needs to start again the long journey through the interpersonal relationships (Bholinger et al. 2015) and it can’t disregard some pivotal concepts, such as the individual, the context and the community; because it is necessary to restore a meaning for an identity and individuality-based life project, in order to fulfil the empty space imposed by evolution and change. The real evolution cannot be based on loneliness or isolation, as instead these represent its limits. It is necessary to recover the idea of places in which it is possible to establish positive relationship with other people, both young and significant adult, to express ideas, vital energies, musical, artistic or cultural tastes, and the ways of perceiving and putting into practice the social compromise.

The most important aspect is the will to build an educational relationship, in the modalities and manners analysed up to now, that can be based on the principles of caring and helping.

In other words, we can certainly assume that educating means giving a part of oneself, not only materially but also, and above all, morally, in a dimension made of solidarity and acceptance of the

differences set as a principle for equality. This complex relationship creates a place, a context, useful to the development of the following and different relationships; that community, in substance, becomes the ideal place to have the individual grow and thrive facing the challenges that the contemporary world presents (Balzano, 2019).

The virus doesn't make any distinction between the families

The COVID-19 pandemic has deeply changed our life habits. At first the lockdown, followed by all the other phases, with the gradual recovery of the several relational and productive activities, marked our time in a significant way. The reaction to the virus has been influenced by many variables, such as the income, the social class and, finally, children and teenagers with special education needs.

The families with disabled children had to face the emergency with additional problematic situation to be managed, due to the difficulty of people with disability to understand properly what was happening. Indeed, the same facts we experienced have an amplified significance for the disabled people, and normally they require further support and concrete and fast applicable resources, conditions impossible to be guaranteed during an emergency.

One of the most considerable effects arisen in the families with a disabled member has been the loss of the significant other: teachers, classmates, educators, volunteers, who had a great significance for what concerns presence and support to the life project of their family member. People with disability conceive and build this project in collaboration with the family and the several social contexts, such as the scholastic and working one, but also that of the free time activities, expanding the horizon. Educators and professional workers become reference points to guarantee stability and continuity to life projects.

The pandemic and the consequent social isolation, which is a harmful experience for the psychophysical activity, must make us think about the necessity of supporting the families in their possibility to understand the distress of their disabled members, support their parental capacity to sustain their children, rediscover their capacity of doing things together, but also of being a presence capable of containing and managing the most severe behavioural reactions.

The new technologies help in part to overcome that distress, and they can temporarily compensate for the loss of the human relationship by providing an alternative concept of proximity.

During the pandemic the families had to create the conditions to guarantee the continuation of the personalised programs, modifying the modality of realization of the activity: before the lockdown most of the job was carried out in centres attended by the disabled child, but after, those important routines had to take place in the house; in some cases, the educational institutions made an effort to promote innovative solutions in order to guarantee the progress of classes and curricular activities, implementing and empowering the e-learning based systems (De Biase, 2015), by means of the massive supply of the distance learning. So, we first saw the school system facing with enthusiasm the challenge of the distance learning but, soon after, it was clear that the most fragile components were left behind, and this confirms the serious nature of the equality problems generated by the pandemic.

Nevertheless, people with disability found very difficult to access technology, digital didactic material, assistive technology, technical support provided by structures and the teachers' competences regarding disability and accessibility (Isidori et Ciraci, 2021). In fact, in such a crucial field like disability, the digital learning launches significant challenges. In particular, regarding the use of inclusive technologies, in our country support teachers still have a lack of formation about the usage of specific educational technologies for students with disability, both in physical and online learning (Bocci et al, 2021).

And if the digital came to our aid to join us in the distance (Pellai, 2020), the use of electronic devices didn't mean the same for everyone. We witnessed educational methods, more or less exclusive, that

pointed out in some cases the isolation of the students with disability: virtual classrooms (during the emergency phase) and physical classrooms attended only together with the support teacher.

During the experience of the pandemic, and always in relation to disability, while on one hand the collaboration between teachers and families and between the teachers between each other has turned out to be productive, on the other hand the level of participation of the classmates proved to be scarce, with a consequent isolation, also in the social field, of the disabled students (Ianes et Bellacicco, 2020). The forced and temporary stop to the scholar routine for the disabled students, together with the closing of all the extra-curricular activities, has naturally reduced the real inclusion (Canevaro, 2020), provoking a decrease both at relational and learning level, and generating frustration and uncertainty.

Nevertheless, we don't have to forget that learning is an interactive process: if it is not significant and people are not actively involved in the process, if it is not useful and related to the belonging context it can be lacking (Caldin, 2018).

Many parents of disabled children denounced the effects of this isolation inside the isolation. First, the undeniable inadequacy of the online didactical activities and the subsequent reduction of personalised educational paths produced a significant regression regarding the quality of the inclusive processes, and then it led to the interruption of necessary evolutionary paths, provoking a serious damage to the potentialities of development.

Without the school, little by little the students have lost many abilities, their autonomy and their self-esteem, which they had gained with a lot of effort thanks to the support programs conceived especially for them and, most important, they have lost their well-being (Bellacicco et al. 2022).

Conclusions

Together with the sanitary system, the educational field was one of the most relevant aspects that the society needed to face to react to the virus: the change we have been through during the last two years made visible all the weak points in our educational services, especially regarding the inclusive processes: the pandemic highlighted their weaknesses and criticality, and these were some of the aspects of school life more deeply involved in distance learning.

In front of such a situation, demanding responsibility from the institutions has become more necessary than ever in order to plan a "rebuilding" with the acknowledgement of these weak points that the families have been experiencing for a long time.

With students with complex disabilities, it was difficult to carry out an adequate distance learning system, to the point that during the second wave it was conceded to students with disability to attend the physical classes. This choice run the risk of generating new forms of exclusion and, at the same time, of disregarding the fact that learning and socialisation are two processes that always need to be linked together (Lucangeli, 2020). The relationship between these two educational factors is essential, generative and useful to react to critical situations, since it forms an educating community.

The "revelation" of the virus concerned the inadequacy and fragility of sanitary, scholar and educational systems: the latest disinvestment in these fields, the bad functioning and the lack of resources, apart of the fact that they were considered more like problems than talents, are nowadays very clear to everyone and show the importance of developing support and cultural reinforcement paths (Silva et Gigli, 2021).

Families and schools have developed over the past months resistance and resilience strategies to promote the well-being of children and teenagers, and to learn how to establish new and richer relationships born after a deeper acknowledgement.

It is necessary, thus, to put into practice interventions aimed at foreseeing the effects of certain actions on the equilibrium of familial relationships and the social consequences derived from those actions.

The wish is to create a net not too far from the historical memory of the family, intended as the pivotal nucleus in which one educates himself at the very beginning, and to restore those places in which the

comparison with the other is never sterile, as instead, it can follow the progress without creating unfillable empty spaces.

The COVID-19 pandemic showed the weak links of society and school, which need immediate interventions, care and attention. To really become inclusive, the school system must face all the new post-pandemic challenges, with a deep review of the learning environments and the interactional approach between the teacher and the student, not to mention the didactic planning.

It is undeniable that students with disability struggle to attend online lessons, but it is only thanks to the technological instruments that during an emergency it was possible to overcome distance.

All the educational needs of the teaching staff regarding digital competences such as the use of the tools and the ability of collaborating in teamwork emerged.

The new didactic manner, anyway, should be completed by the attention for diversity and equality, to create a school which is inclusive and respectful of everyone's needs.

Overall, focusing the work on education, research and educational planning, and considering all the innovations and criticalities in the auto determination and participation processes, represents the real inter-disciplinary challenge of great social impact for today's world.

Indeed, the school as the only non-sanitary service with a strong presence in the disabled and their families' lives. It is fundamental not only in relation to socialisation, but also because it provides the child with a possibility of inclusion in a wider context than that of the family; it also plays a role of social support for the families. Lastly, the pedagogic care for an individualised educational path above all, but not only, with disabled students.

Then, one has to ask himself "how" to take charge of the disabled children and their families, and how to involve them in a main role in the global personalised project, how to come with them without replacing or abandoning them, how to interact with them and to their tutor associations.

Disability teaches us to capitalize that marvellous treasure of the value of the whole community, the general well-being.

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