Inclusion dans les Cités de l'Éducation

Défis, Cultures et Ressources

Inclusion in the Cities of Education

Challenges, Cultures and Resources

Jean Pierre Pourtois, Anna Pileri, Nicola Giacopini, Roberta Caldin, Clara Silva (Eds.)

CONNEXIONS DANS LES CONTEXTES D'APPRENDISSAGE

CONNECTIONS IN LEARNING CONTEXTS

FrancoAngeli

CONNEXIONS DANS LES CONTEXTES D'APPRENDISSAGE

Direction:
Roberto Dainese, Anna Pileri, Mark Alter,
Jean Claude Kalubi-Lukusa

La collection "Connexions dans les contextes d'apprentissage" se consacre à la recherche et à l'étude de l'apprentissage ainsi que les connexions nécessaires pour le soutenir sur base d'actions partagées et coordonnées. La référence à la perspective systémique-écologique, suivant le modèle bio-psycho-social de la CIF (OMS, 2001), est donc privilégiée.

Cette collection met l'accent sur le rôle essentiel que joue la création de liens lorsqu'il s'agit de répondre aux besoins des élèves avec handicap et de leurs familles. Ces liens dépendent d'enseignants compétents et passionnés. Ils sont essentiels pour favoriser l'apprentissage individualisé et personnalisé, de même que pour guider les trajectoires de vie. En effet, les enseignants vont se montrer capables d'accompagner tous les élèves, de favoriser la réussite sociale, de soutenir les familles et de créer un environnement dans lequel tous les élèves peuvent s'épanouir, quelles que soient leurs capacités.

La collection accueillera aussi des travaux de recherches – de niveaux national et international - axés sur l'expérience d'apprentissage dans des contextes allant de la crèche à l'école secondaire. Dans ces contextes, il s'agit de la mise en oeuvre d'actions de planification et d'enseignement destinées à tous les garçons et à toutes les filles, à tous les élèves, est devenue incontournable, de façon à prêter attention à la synergie entre la participation spécifique et leur réussite, dans l'apprentissage, dans la vie présente et future.

Les thèmes couverts sont inévitablement interreliés : de la formation, des perceptions et des compétences des opérateurs scolaires (directeurs, enseignants, éducateurs) avec la collégialité, en utilisant outils multiples et innovants, y compris des outils technologiques. Cette collection porte également attention à l'impulsion inévitable à donner à l'apprentissage pour tous, grâce aux outils multiples et innovants, y compris des outils technologiques. L'espace offert permettra d'entrer en résonance avec de multiples réflexions scientifiques, des recherches et des projets centrés sur la pertinence et l'engagement didactico-pédagogique.

Concernant tous les élèves et ceux en situation de handicap, différents types de connexions s'avèrent nécessaires, afin d'assurer la coordination des actions structurées dans le cadre des projets individualisés et personnalisés. La planification et l'accompagnement de projet de vie apparaissent indispensables. De plus, ces connexions influencent les actions de soins et de réadaptation, les services à la personne, les services à la personne, les initiatives de participation sociale, ainsi que le soutien en matière de collaboration écolesfamilles- communautés.

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En hommage à Huguette Desmet, son engagement pédagogique reste pour nous une source précieuse d'inspiration.

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1.2. Families with young people with PIMD[1] Disabilities and Quality of Life: pedagogical analysis for new prospects of intervention

Noemi Del Bianco[2], Ilaria D'Angelo[3], Catia Giaconi[4], Simone Aparecida Capellini[5]

1.2.1. Introduction

The Quality of Life (QoL) construct has been internationally recognized as a conceptual framework capable of guiding practices across different contexts (Boehm & Carter, 2019; Schalock & Verdugo Alonso, 2012; Prieto-Flores et al., 2012).

The ecological interpretation, articulated through the mutual relationships between individual and their contexts, is proposed allowing us to grasp the importance and meaning of QoL at three levels of the system (Macrosystem, Mesosystem, Microsystem) (Schalock & Verdugo Alonso, 2012).

In this direction, at the Macrosystemic level, the QoL construct represents the reference framework for the implementation of social policies (Ibid.). It provides a conceptual foundation for administrative decisions regarding the reorganization of personal services (Ibid.), orienting the creation of inclusive educating cities. The QoL perspective is therefore outlined as a tool for the protection and guarantee the rights of people with and without disabilities (United Nations, 2006).

At the Mesosystemic level, the QoL construct can be employed within personal services to develop and monitor procedures aimed at improving the environments, services planning and the quality support provided (Schalock & Verdugo Alonso, 2012).

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Finally, at the Microsystemic level, the construct allows increasing the opportunities for participation in the overall process of one's life (Del Bianco, 2019; Wehmeyer & Schalock, 2001). Therefore, it represents the necessary dimension to be placed n the dynamics between the new model of human functioning (WHO, 2001) and educational interventions, contributing to the realization of targeted life projects (Cottini, 2016; D'Angelo, 2020a; Giaconi, 2015).

For these reasons, the construct of the Quality of Life assumes the role of «criterion of legitimation and validation of the theoretical reflections carried out in the field of research and biomedical and rehabilitative interventions, on the one hand, but also of those more generically linked to social policy and health care, program validation and cost evaluation, on the other hand» (Schalock & Verdugo, 2002, p. 25).

In light of this ecological articulation, this contribution aims to deepen the socio-pedagogical issues related to the care of families with young people with Profound Intellectual Multiple Disabilities (PIMD), both in the life stages in which the parents are still present ("During Us") and when family members are no longer able to take care of their sons/daughters ("After Us") (Giaconi et al., 2020). Specifically, during the Covid-19 outbreak, the condition of these populations was particularly fragile. The restriction of family mobility changed the ways of living the times and spaces of everyday life, of doing school, of spending free time and, above all, has changed the ways of interacting with others and services. The high criticality of the health conditions of people with PIMD, the closure of services, and the aggravation of care tasks reserved exclusively for family caregivers have led to our interest in investigating the perceptions of family caregivers during this period of the health emergency.

Before presenting the survey in detail, we delve into the state of the art of research concerning family caregivers of people with PIMD.

1.2.2. The Quality of Life of caregivers of people with PIMD

Starting in the 2000s, researchers began to identify the crucial aspects that reflect the family's Quality of Life (Giaconi, 2015; Schalock & Verdugo Alonso, 2006), particularly when a child with a disability is present in the family (Turnbull et al., 2004).

Most research on the subject focuses on the impact of Quality of Life, concerning the burden of assistance and care required by the functioning profile of the person with disabilities. In this case, many studies relate the to family's Quality of Life to the presence or absence of adequate socio-health policies, resources and services aimed at providing forms of

support for the family (Caldin et al., 2017; Pavone, 2009; Visentin, 2010). As underlined by Schalock and Verdugo Alonso (2006) «there is a general agreement that a positive quality of life should be the result of the policies and services that are implemented in favor of people» and how «the improvement of the quality of life for families could be the "only acceptable outcome" of policies and services» (2006, p. 200).

The Quality of Life of family caregivers is interconnected with the Quality of Life of the person, especially if he/she has intellectual disabilities (Schalock & Verdugo Alonso, 2006). Specifically, the presence of a person with PIMD requires all family members to adopt a daily response to the extended and generalized needs of assistance, which often remain stable throughout the lifespan (Nakken & Vlaskamp, 2007), making parental and caregiving tasks particularly demanding (Luijkx et al., 2019).

As already highlighted in our other research (Giaconi et al., 2020; D'Angelo, 2020a; 2020b), the Quality of Life of family caregivers decreases concerning different circumstances: for example, the discrepancy between the profile of the person's functioning and the demands of the context (Negri et al., 2019; Grey et al., 2018), the number of difficult situations to deal with (Minnes et al., 2007; Walden et al., 2000), the epileptic condictions (Grey et al., 2018, Kerr et al., 2009) or feeding problems (Killian et al., 2016), affecting the domain of "Physical well-being".

Other research (Del Bianco, 2019; Sherpa et al., 2018; Du et al., 2017; Middleton et al., 2014) investigates the changes in the caregivers' Quality of Life levels in relation to the variation of self-determination and autonomy of their child with disabilities (Del Bianco, 2019), or concerning the reduction of his/her social roles, such as the deterioration of the network of interpersonal relationships (Negri et al., 2019), affecting the domain of the QoL related to the "Social Inclusion".

Alongside these dimensions, the literature examines the aspect related to the family economy (Chou et al., 2013; Grey et al., 2018), since the costs of healthcare and physical well-being of the person with a disability risk harming the general condition of the family unit. This is related to the domain of "Material well-being".

Also, several studies (Luijkx et al., 2016; Negri et al., 2019; Tadema & Vlaskamp, 2010; Visentin, 2010) highlight a risk condition for family caregivers in coping with the amount of time needed to care for people with PIMD, often affected by co-morbidities, such as forms of epilepsy or dysphagia. Because of fatigue, frustration, and guilt feelings, caregivers frequently experience depression or symptoms related to the so-called burnout syndrome (Fianco et al., 2015). Always within the studies on the psychological impact of the PIMD's family caregivers, strategies such as

coping, positive appraisals, psychological acceptance, and internal locus on control play an essential role (Chou et al., 2010; Fianco et al., 2015; Grey et al., 2018; Negri et al., 2019) in the promotion of both personal growth and the social inclusion of caregivers and, therefore, to increase their Quality of Life (Chou et al., 2013; 2010; Fianco et al., 2015).

Previous studies (McCann et al., 2012; Visentin, 2010) show that free time and friendly interactions are the dimensions of the Quality of Life (Giaconi, 2015; Schalock & Verdugo Alonso, 2006) more at risk in the life of the caregiver. Having to dedicate more time to care activities in the daily lives of parents of children with PIMD, there is a significant reduction of the time spent on both housework and leisure activities, in the latter case, with a substantial impact on "Personal well-being" (Luijkx et al., 2016).

Also, in studies on families with young people with PIMD, investigations are focused on the role of siblings as the primary caregivers when parents become elderly or die (Hall & Rossetti, 2018; Luijkx et al., 2016). Research conducted on the perception of Quality of Life levels of young and adult siblings of people with PIMD is still limited (Hall & Rossetti, 2018; Luijkx et al., 2016; Nijs et al., 2016), especially regarding the transition phases, which often correspond to crucial moments of modification of roles and family balance (Giaconi, 2015).

In light of these considerations, the research presented in the next section aims to investigate how families with young people with complex disabilities have faced the pandemic. The spread of the Covid-19 represents a further criticality in managing a challenging daily life, with repercussions on the levels of QoL of caregivers and people with PIMD.

1.2.3. Research with caregivers of young people with PIMD

The Italian government introduced various measures to control the spread of the Covid-19 virus[6] that significantly impacted the entire population and even more families of people with PIMD. The interest of our research is to investigate the perceptions of families with young people

6. Several experts have pointed out how these measures (e. g. Legislative Decree 9 March 2020: "Io resto a casa"; Legislative Decree 17 March 2020: "Cura Italia"; Legislative Decree 26 April 2020: "Rimaniamo a distanza-Fase 2") scarcely payed attention to the difficulties of people with disabilities and in particular with PIMD or with Autism Spectrum Disorder. As we will see in the research below also from the perceptions of the families the interventions (increase to 15 days, for the months of March and April 2020, of the Parental Leave of law 104; closure of day centers; possibility that center operators and pupil assistants are registered in the home; measures in the matter of extraordinary leave and permits for those who assist a person with a disability) were not enough.

with PIMD related to the condition they were living in as a consequence of those provisions.

The survey presented in this section is part of a large international research project between the University of Macerata and the University of Arizona. This article will show the qualitative results of an extensive research protocol aimed at exploring the perceptions of families with children with intellectual disabilities or with PIMD during the Coronavirus outbreak.

The research protocol has two parallel phases (Table 1):

- Collection of quantitative data, through the administration of a questionnaire on an international sample of families with young people with intellectual disabilities aged between 15 and 30 years[7];
- Collection of qualitative data through focus groups with a group of family caregivers of young people with PIMD aged between 30 and 50 years.

Table 1 - Phases of research: quantitative and qualitative data collected

Research tool/procedure	*Amount*	*Research and analysis actions*
QoL Questionnaires addressed to the caregivers of young people with intellectual disabilities	207 questionnaires in total: 107 questionnaires administered in Italy and 100 international	Tabulation of results and analysis in the international research team
First focus group with caregivers of young people with PIMD, structured on caregiver's Quality of Life Guidelines (Schalock, Verdugo Alonso, 2012)	10 caregivers of young people with PIMD: 8 mothers and 2 sisters	Focus Group Management Transcription of the texts; analysis of the texts' contents; cross-reading of the materials by the research team
Second focus group to return feedback to caregivers of young people with PIMD	10 caregivers of young people with PIMD: 8 mothers and 2 sisters	Returning and sharing the results of the focus group content analysis with the involved family caregivers

7. The questionnaire is aimed at investigating the knowledge and impact of decrees in families with young people with intellectual disabilities, specifically the changes in everyday life (also in terms of psychological impact) relationship with the school, with the extracurricular and with the territory (services, such as Daycare Service or Family Centred Care). The research team translated the questionnaire into Italian and English and used the Limesurvey platform for data collection. The data are being processed by the international research team.

Table 1 summarises the design, applied methods and achieved quantitative research results.

In this section, we focus on the results of the first focus group. Focus groups were conducted and registered through an online platform and were attended by 10 caregivers of young people with PIMD involved in the activities of a Daycare Service in the Marche Region.

The focus group discussion was transcribed, and the written text was analyzed by staff who activated self-reading and cross-reading of the materials, according to the qualitative methodology.

After the focus group discussion, the analysis involved the following steps (Glaser & Strauss, 1998; Strauss & Corbin, 1990; Giaconi, 2012, p. 55):

- listening to the recording;
- transcription of the focus group discussion into written text;
- identification and analysis of the parts of the text (sentences, period), identified as significant text units;
- transcription of captions referring to significant text units, paying attention to maintaining the speaker's language;
- attribution to each significant text unit, with a related caption of a conceptual label;
- horizontally (intervention of each caregiver for text units, captions, and labels) and vertically (analysis of the caregiver interventions based on text units, captions, and inverse conceptual labels) rereading of the material;
- collection of the various conceptual labels in broader categories which can identify a particular dimension of the phenomenon investigated;
- conversion of categories into macro-categories;
- creation of a summary document;
- identification of the central categories;
- creation of a map by the coding staff.

1.2.3.1. *Analysis of the focus group data*

Focus groups created with family caregivers indicate some relevant issues, especially regarding their perceptions during the period of isolation.

In continuity with what has been reported in the relevant literature (Chou et al., 2013; Grey et al., 2018; Luijkx et al., 2016; Negri et al., 2019), the analyses of the interviews conducted show a decrease in levels of perceived satisfaction for the domains of "Social inclusion", "Emotional well-being", "Material well-being", and "Physical well-being" (Bertuzzi et al., 2021).

Parents perceived little attention from the government measures during the emergency period and felt like "invisible families" again. Quarantine measures resulted in limited educational and healthcare services (Muhammad & Prince, 2020).

All families with children with PIMD declared that they feel isolated from the community to which they belong, especially concerning limited access to formal and informal services (Muhammad & Prince, 2020). Caregivers were required to step in to dill the care gaps, which had a negative impact on their emotional and physical well-being.

The data also revealed that caregivers were obliged to withdraw from socio-economic life to care for their children, which added economic strains to the family. In line with the findings of other studies (D'Angelo, 2020a; White et al., 2021), caregivers were faced with job loss or reduced hours at work and economic difficulties. The uncertainty linked to future financial and welfare scenarios, coupled with the social distancing experienced by the caregivers of people with PIMD, worsened an already challenging situation.

Free time and interaction with friends, which are already affected by the needs of care, were very limited during the lockdown, further lowering the level of satisfaction perceived in their life and increasing their psychological strain (Colizzi et al., 2020).

Three out of ten families interviewed declared that they had activated effective strategies for managing their child's daily life by hinging on the support of siblings or collaboration between partners. Despite the perception of isolation, these families seem to have faced the pandemic period with more significant serenity and have experienced less emotional and physical stress. The remaining seven families, on the other hand, showed high degrees of frustration with the closure of services and the loss of the friend' support network (Colizzi et al., 2020).

Among the emerging criticalities, caregivers stated that the number of hours of care they provided dramatically increased. The extra demands of time for families have been highlighted as challenging to manage within a fixed daily routine, which does not spare time for the necessary rest for the caregivers' health (Kent et al., 2020; Rodrigues et al., 2021). With the interruption or reduction of home-care visits and the closure of daily service centres, activities like tube feeding, injections, bedsores' and catheters' care, prevention or management of epileptic seizures are assigned to family caregivers, who may not feel adequately prepared to carry out such medical tasks. At the same time, the services' proposal to activate home visits at specific times to assist in daily personal care and/or carrying out educational activities was accepted by only one family out of ten interviewed.

Even if caregivers would have asked for help and direct support, the fear of transmission of the virus, which could significantly aggravate the already critical health picture of loved ones with PIMD, stopped them from advocating for this kind of service (Del Bianco, 2019; Hole, Stainton & Wilson, 2013).

1.2.4. Pedagogical reflections and open questions: policies implementation

In light of the results, several central pedagogical reflections guide social policies and educational interventions for families with young people with PIMD, even in emergencies like the one we have experienced.

In this direction, the epistemological structure of the Quality of Life (Schalock & Verdugo Alonso, 2002) can increasingly support social policies and services in the construction of spaces for sharing and listening that are capable of guiding the management and planning toward life trajectories that are both of quality and meaning.

Despite the limited number of cases considered, wich do not allow a significant generalization, this study enables us to first reflect on creating a more solid structuring of integrated information actions within the support paths of the entire family network. The partnership between services and caregivers might enhance both the reading of the needs and desires of the person with disabilities and the alignment of the expectations of all the people involved in taking charge (De Geeter et al., 2002). We are aware of the centrality of the connection between the different perspectives and perceptions of the subjects involved in the implementation of the Individual Project for adults with disabilities; we also acknowledge that this «could compromise the creation of an integrated and functional intervention system for the quality of life of the person himself, just as it could weaken the desirable dynamics of co-design» (Giaconi, 2015, p. 87).

Therefore, we should act toward an increased sharing of information and co-design of focused actions within the network of personal services to support critical phases of families, e.g., the transition phase (Gauthier-Boudreault et al., 2018). We should understand more deeply the challenges that these families face – including the duration of the role of caregiving, worsening of the health problems with the aging of the person with PIMD and his/her caregivers, and planning of life paths for the future well-being of the family, especially regarding the “After us” phase (Giaconi, 2015; Luijkx et al., 2019).

These proposals will only be able to function through a strengthened integration of the service network, whose institutional cornerstone is the sharing of project horizons and educational continuity. Only a truly integrated system will be able to adequately support the care of people with complex disabilities.

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