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Research paper

Children at birth, children growing up. Integration between healthcare and family educational care



*Enfants à la naissance, enfants pendant la croissance.
Intégration entre soins sanitaires et projet éducatif
familial*

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ABSTRACT

This research is based on the assumption that in order to improve the quality of life of children with major health problems in the early stage of their life, especially in the case of disability, it is necessary to ensure the continuity and proper two-way integration of early childhood educational planning and health care, both provided by the adults involved, that is parents and professionals. Therefore, we tried to explore and piece together the complex set of family support experiences, both in the process of forming an attachment and affiliation to the newborn and in the construction of a common evolutionary history, aimed at the well-being of the entire family unit. We considered the context and actors of the first few days and months in the lives of children with a difficult life course, in a city of Northern Italy. By means of qualitative investigation, we carried out observations in the neonatal intensive care units of hospitals over a period of 10 months. Our observations continued in the local healthcare, social, and educational services, entrusted with providing care to children and support to parents after hospital discharge.

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¹ Both authors have collaborated in the writing of this paper; Marisa Pavone has drawn up paragraphs entitled "The family's educational planning for a child in difficulty", "Research hypothesis", "Conclusions"; while Alessia Farinella has drawn up paragraphs entitled "The local context of our research", "Observations in Neonatal Intensive Care Units (TINs)", "From hospital to home healthcare", "Educational services of the Municipality of Turin for children in difficulty".

We also carried out observations in nursery schools, in order to highlight early forms of individualised educational planning, drawn up by the educators together with the family.

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R É S U M É

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Cette recherche part de l'hypothèse que, pour améliorer la qualité de vie des enfants ayant de sérieux problèmes de santé à la naissance et/ou pendant les trois premières années de vie – en particulier des problèmes liés à un handicap –, il faut assurer de façon précoce et continue de bonnes pratiques d'intégration, entre les traitements sanitaires et le projet d'éducation, par les adultes concernés : parents et professionnels. On a donc essayé d'explorer et de restituer l'entrelacement complexe des expériences de soutien à la famille, à la fois pendant le processus d'attachement et d'affiliation envers le nouveau-né en difficulté, et durant la construction d'une histoire commune, orientée vers le bien-être de l'ensemble du réseau familial. Sur le plan pratique, on a pris en considération les scénarios et les acteurs des premiers jours et des premiers mois d'un parcours de vie assez difficile, dans une ville de l'Italie du Nord (Turin, chef-lieu du Piémont). Par une méthode de recherche qualitative longitudinale, on a effectué des observations et des études de cas auprès des unités de néonatalogie en soins intensifs dans les hôpitaux ; ensuite auprès des services sociaux et de santé présents localement, dont la tâche est de fournir des soins au petit enfant et de l'aide aux parents, après la sortie de l'hôpital. Des observations ont aussi été conduites dans des écoles maternelles, pour mettre en évidence les premières formes d'un projet éducatif individualisé, élaborées par les éducatrices en collaboration avec la famille.

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1. Framework

1.1. *The family's educational planning for a child in difficulty*

In the Italian context of studies, research, and empirical evidence over the last decade, a family's early educational planning for a child with serious difficulties at birth and in early childhood, as well as during the developmental age – in particular, planning linked to disability – is an object of growing interest. Investigations have focused on the impact that a minor's fragility has on the family, seen as a dynamic system, and on the maintenance of its generative ability – understood as the responsibility to *form an attachment to and take educational care of* the child. Moreover, the way and the extent to which the family is integrated into the extra-familial context to which it belongs have also been analysed. The latter aspect is indeed coherent with the cultural tradition of attention to the dimensions of social inclusion. It can be asserted that there is widespread interest in the planning abilities of families living the experience of having children with severe problems (Pavone, 2009; Franchini, 2007; Battaglia et al., 2004).

A family can be described as a complex and multifaceted set of interlinked life projects, which influence each other along a continuum rooted in the past – the initial project of the parenting couple – and stretching into the future, as the children progressively develop and consolidate their autonomous life projects (Contini, 2001). Within this context, dealing with the health problems of a minor requires endless resources and adaptive abilities, which often go beyond the actual capabilities of the family. This may trigger a mechanism of self-protection, expressed by an attitude of isolation, of being placed

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