

AperTO - Archivio Istituzionale Open Access dell'Università di Torino

**Children at birth, children growing up. Integration between care and family educational care.
Enfants à la naissance, enfants pendant la croissance. Intégration entre soins sanitaires et projet
éducatif familial.**

This is a pre print version of the following article:

Original Citation:

Availability:

This version is available <http://hdl.handle.net/2318/152699> since 2016-01-19T08:59:56Z

Published version:

DOI:doi:10.1016/j.alter.2014.02.003

Terms of use:

Open Access

Anyone can freely access the full text of works made available as "Open Access". Works made available under a Creative Commons license can be used according to the terms and conditions of said license. Use of all other works requires consent of the right holder (author or publisher) if not exempted from copyright protection by the applicable law.

(Article begins on next page)



UNIVERSITÀ DEGLI STUDI DI TORINO

This is an author version of the contribution published on:

Questa è la versione dell'autore dell'opera:

ALTER, Children at birth, children growing up. Integration between healthcare and family educational care, 8/2014, 2014 pagg. 69-81

DOI 10.1016/j.alter.2014.02.003

The definitive version is available at:

La versione definitiva è disponibile alla URL:

<http://www.em-consulte.com/it/article/894846>

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. 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.

Keywords:

Difficult birth, Family project, Care

Résumé

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.

Mots clés :

Naissance difficile, Projet familial, Soins

Framework

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 in a borderline situation and finding it difficult to regain a condition of balance, well-being, and the ability to look to the future (Morvan, 2010; Walsh, 2008; CISF, 2007; Anaut, 2006).

Drawing on classical research based on therapeutic/clinical approaches (A. Freud, Bettelheim, Farber, Mannoni) and on the most recent international scientific publications (Scelles, 2010; Stiker, 2009; Ebersold, 2007; Gardou, 2006; Brazelton, Greenspan, 2001; Minuchin, 1996; Sausse, 1996), several Italian scholars have highlighted the negative consequences that the birth of a child with very serious health problems may have on the family, particularly on the mother figure. The ensuing condition of stress and difficulties in planning a future for the family unit deeply affects parents and siblings, as well as the minor in question (Sorrentino, 2006; Moretti, 2006; Di Nuovo, Buono, 2004).

In conjunction with the dissemination of reports on experiences in which minors with disabilities have been integrated into contexts of normality (enhancing educational, ethical, juridical, social, and cultural needs along with healthcare needs) and thanks to the emergence of theoretical and practical interpretation models (proposing a social approach along with or as an alternative to the clinical approach), there is increased awareness that, in many cases, the family not only survives the situation, albeit working at “reduced capacity”, but copes with it actively, developing positive values and vital resources and harnessing external help. It has been emphasised that the child’s psychophysical condition brings about the willingness and opportunity to build a new balance and new combinations of resources; it is an exercise in willpower and care, a project to be shared with others (Ianes, Cramerotti, 2009; Favorini, 2007; Lizzola, 2006; Zanobini, Manetti, Usai, 2002). Some have also considered the possibility of extending the concept of resilience to families having the experience of disabled children (Dondi, 2008; Malaguti, Cyrulnik, 2005).

Other studies aimed at describing how the family’s lifecycle develops (Milani, 2001; Scabini, Cigoli, 2000; McCubbin, 1988) confirm that early educational planning by the family system manifests itself discontinuously within the lifecycle of the minor, of individual family members, and of the family system as a whole. Almost non-existent when the infant is first diagnosed with a severe condition, and during his or her early years, it progressively takes shape as the child grows older, until it becomes more or less fully defined at the time of “*integrazione scolastica*”¹, mainstream formal education (Pavone, 2010; Caldin et al., 2009; Favorini, 2009; Canevaro, Eds., 2007).

As the period of schooling starts, the parents’ view of the future, together with those of teachers and healthcare specialists, becomes an indispensable variable for the co-building of an individualised educational plan for the minor. Thus, the parents’ generative potential, which was previously considered hardly worthy of attention, suddenly comes into the spotlight. This is triggered by the child’s entering the school system, where the educational perspective and learning objectives are prevalent. Several studies, both theoretical and practical in nature, emphasise the parents’ “naive knowledge”: family members should make their contribution to the objectives of the plan for the *integrazione scolastica*, since they are holders of “raw” knowledge drawn from their living with the child every day and they are

¹ The process of “*integrazione scolastica*” has characterised the Italian experience of co-education of students with disabilities in normal schools of all types and levels together with their peer group. For a comprehensive explanation of the concept, see Canevaro – de Anna (2010); in this article, the Italian expression is not translated.

responsible for the child's future (Nocera, 2009; Moletto, Zucchi, 2006; Dal Molin, Bettale, 2005; Hanau, Cerati, 2003).

Despite general agreement on the fact that the family is the primary network in which a disabled child finds the right motivations, stimuli, and preconditions to develop, there are still very few studies following a pedagogical approach, for example, focusing on how to develop the overall well-being of individual family members and on how to improve the quality of family life as a whole during the early phases of a frail infant's life. It is as if the generative spaces (original source Erikson, 1950; see also Catarsi, 2008; Scabini, Rossi, 2006; Pati, 2005; Iori, 2001) have difficulty being transformed into expectations, looks, gestures, and words at life's difficult start. The scientific literature has addressed this matter through various approaches – clinical, rehabilitative, psychological, and sociological – but not yet sufficiently from an educational point of view. The question is dealt with “one piece at a time”, concentrating only on the mother, or on the parenting couple, or on the siblings; on the impact of the different types of impairment; on children or on adolescents; nonetheless, the approach rarely includes the extended family (e.g. grandparents and relatives).

On the contrary, it is particularly important to focus on educational planning during early childhood, to free the minds of family members and professionals involved in the medical, rehabilitative, and enhancement therapies from thoughts devoid of hope, as well as to support the parenting unit in the process of forming an attachment and affiliation to the child and, as a consequence, in the construction of a common evolutionary history. The parents' generative ability vis-à-vis their child in difficulty and the endurance of their family project are strictly related. It is a holistic *care*² approach, in which babies are considered in their anthropological dimension and not in relation to individual disabilities, fostering an attachment between the parents and the newborn that is indispensable in order to nurture a family project (Belfiore, 2004). Indeed, re-asserting the worth of the family system, thus re-defining the meaning of parenthood, predisposes the parents to the acquisition of new skills for taking care of their child (Pavone, 2009).

Research hypothesis

The qualitative research described here, entitled *Children at birth, children growing up. Integration between healthcare and family educational care*, was supported by the Chair of

² The term care indicates the set of actions offered to newborn children to promote their well-being and to develop their physical and relational potential to the fullest.

Special Pedagogy of the Department of Education Sciences of the University of Turin³, and carried out in 2009-2010 in two medical centres and in some neighbourhoods of the same city, the regional capital of Piedmont.

A few months earlier, the results of a research project conducted in Milan (Lombardy) by the International Centre for Family Studies (CISF) had been presented. The main problematic issues highlighted by the stories of these “resilient and weary” families were: the perception of not being listened to and not feeling equal when communicating with the healthcare and social services operators; being kept in the dark about the special healthcare treatments administered to their children; long waiting times for access to care and being sent back and forth between services; lack of coordination among the various bodies. Their requests to the healthcare and social services included: being involved as partners in the choices made (sharing of the same language and the personalisation of interventions), and being supported and given suitable importance along the care path. Another need was that the services’ interventions should not be interrupted during the transition from hospital facilities to home care (CISF, 2007).

This survey supplied evidence that confirmed the assumption of our research, for example, the belief that rehabilitative-enhancement interventions at birth and during the child’s difficult early years face conflicting tendencies: having to preserve an unstable balance between the urgency, on the one hand, of intervening on the “aching body” and the concern – understood as investing time and psychosocial resources – for the child as a whole and for the child-parents system on the other. In Italy, there are still few facilities that have shifted from the old *task-oriented* approach, limited to the carrying out of technical duties, to the *relationship-oriented* care method, based on communicative relationships embracing educational features (Ferrari et al., 2006).

Fundamentally, the aim of this research is to determine whether at crucial points in time and space – in particular at birth, during hospitalisation in Neonatal Intensive Care Units (NICUs, the equivalent Italian expression is *Terapia Intensiva Neonatale*, hereinafter TIN), upon discharge from hospital, and in relation to everyday care at home – the professionals involved display not only an interest in the healthcare provided as expected, but also thoroughgoing concern for the quality of life of the child and family. Hence, the concept of state of health emerges as a complex construct, necessarily multidisciplinary in nature, deriving from the coordinated reflection and action of professionals belonging to different sectors. This concept

³ Full Professor Marisa Pavone is the holder of the chair and the scientific director of the research; Piera Bagnus and Alessia Farinella collaborated as researchers.

of state of health draws on an anthropological approach compatible with the biopsychosocial model of the *International Classification of Functioning, Disability and Health* – ICF (OMS, 2002, Italian trans. by Erickson), which is receiving ever greater attention from several institutional environments (i.e. healthcare, educational, and social) in Italy. This plural approach must be agreed upon above all with the family, not only because the family has the legal responsibility for the development plan concerning the minor, but also in order to prevent the child from receiving several uncoordinated and disoriented types of treatment. Hence, another key objective is to enhance the role of the family as an active interlocutor of the hospital and local services professionals.

An important aspect of our investigation was to verify the existence of continuity (from the hospital to local services) in project planning between the healthcare field and the educational context, and to understand whether a clearly identified reference person is present and/or whether the services are systematically coordinated. Perinatal and post-natal services must be well organised and protocols must be defined, so that such delicate care duties are not left to improvisation or to the good will of the staff. Therefore, we also analysed (albeit indirectly) the actions of the staff of the healthcare and socio-educational services, in order to raise their awareness of the fact that even a serious diagnosis should not prevent them from adopting an educational perspective, aimed at boosting the growth and development potential of the children and their families, so that their dignity and rights are respected (Nussbaum, 2007).

The local context of our research

Our investigation began with a comprehensive examination of the most recent Italian and foreign literature on the topic, followed by the identification of the areas of concern and phases of the project. The target areas included: hospital services, at birth and during hospitalisation (TINs and follow-up outpatient departments⁴; Bruscaignin et al., 2011; Colombo, Eds., 2011, Heimer, Staffen, 1998; Anspach, 1997); local healthcare services, when the child is discharged from hospital and goes home (duties include providing care to the infant and support to the parents; Prezza, Eds., 2006; Pergolesi, Eds., 2002); and socio-educational services, whose institutional responsibilities include drawing up, together with the family, early versions of an individualised educational plan (municipal nursery schools; Malaguti, 2011; Ricci, 2005). We then identified the geographical reference area for our

⁴ This term refers to the set of periodical check-ups performed after discharge from hospital and usually until two years of age. During this period, the development of the child is monitored, allowing for early detection of possible conditions and prompt intervention.

observations, in particular some healthcare and socio-educational service facilities and two large hospitals in the city of Turin.

The first portion of the study was conducted in 2009 in the neonatal intensive care units of the two hospitals referred to above by two researchers selected by the Department of Philosophy and Education Sciences of the University of Turin. It was aimed at shedding light on: the living conditions of hospitalised new-born children with major health concerns; the ways in which doctors and parents communicate; the available care in health facilities, at home, and concerning early education, as well as family support schemes; the procedures related to hospital discharge and referral to local services.

The chief facilities we focused on were the TINs of the Maria Vittoria Hospital and the Sant'Anna University Clinic. Both wards are third-level health facilities (as per Regional Law no. 61/1997), whose aim is to provide assistance in case of high-risk and pathological pregnancies and of children born before the gestational age of 32 weeks. However, they cater to different groups of users. Maria Vittoria is one of the five general hospitals serving the metropolitan area of Turin, whereas Sant'Anna is a so-called *Azienda Sanitaria Ospedaliera* (ASO)⁵, catering to all the citizens of the Region of Piedmont. The Sant'Anna ASO alone accounts for 24.1% of births in Piedmont. About 86.8% of women residing in the region who are diagnosed with a pathological pregnancy⁶ come to this facility to give birth. Sant'Anna's University TIN is also a major facility at national level, as shown by the number of hospitalisations per year, with a highly experienced team encompassing wide professional skills and offering extremely specialised and qualified assistance to newborns considered to be in a critical state, due to reduced weight and gestational age and/or affected by serious conditions⁷.

Our targeted observations and contacts with the staff and family members of the hospitalised infants provide a significant, although partial, picture of the overall situation, since these two facilities play a key role within the regional hospital system.

In the period between 2009 and 2010, the two researchers conducted a field survey in the follow-up outpatient departments of the two above-mentioned hospitals, with the purpose of

⁵ The term Azienda Sanitaria Ospedaliera refers to a hospital facility providing high-quality health services and operating within the Regional Healthcare System.

⁶ In the regional documents, pathological or non-physiological issues during pregnancy are: two or more hospitalisations during pregnancy; risk of premature delivery; use of assisted reproductive technology; problems in foetal development; toxoplasmosis during pregnancy; being HIV positive; being positive on a VDRL test.

⁷ The excellence of this ward is recognised by the Italian Neonatology Society (Società Italiana di Neonatologia - SIN).

identifying the various issues linked to hospital-home healthcare transition, as well as the ways in which the families manage this change.

The last portion of the research, completed by one of the two researchers in 2010, focused on detecting which local services can significantly help the families in their transition from hospitalisation to everyday life at home, so that the path of care can be continued and the early educational prospects of the child can be kept alive.

Rather than describe a number of cases, our purpose was to verify whether all the professionals involved in the crucial phases of a difficult birth displayed a certain degree of concern for the overall well-being of the children and their families.

The information was gathered not through questionnaires and interviews, which are ill-suited to the type of relationship created with the parents and the healthcare personnel – who are not inclined to put their experiences and thoughts down on paper – but through direct observations and conversations. These “narrative” tools proved to be the most appropriate for our interlocutors, due to the ‘presence’, ‘time’, and ‘listening’ attitude which they implied, and were effective in collecting information on the background and experiences of the people encountered. Within this context, any decisions concerning what to observe, when, and who should be interviewed, were based on the circumstances at that time and driven not by predefined scientific procedures but rather by ethical considerations, linked to common sense and the researchers’ background and attitude (Anspach, 1997). Another significant aspect was how to manage the “dilemma of discretion” (id., p. 193), since breaching the emotional sphere of the individuals encountered in the hospital wards might have compromised the validity of the data gathered.

Implementation

Observations in Neonatal Intensive Care Units (TINs)

During the observation phase – carried out for an entire day per week in each ward over a ten-month period – the two researchers came into contact with various members of the healthcare and social services staff, involved with different duties in the highly challenging provision of care. The meetings made it possible to get to know this very particular system “from within”, shedding light on its specific features in terms of: how reception is organised, how the newborn is taken care of and how the family is supported, how professional-parent communication is managed, and how the facilities are laid out and equipped. Early contacts with the environment of the TINs were particularly difficult for the researchers, as they lacked

medical training. At first, they were strangers within their research context, but then they gradually built a relationship with the medical staff and families of the TINs, until they were fully accepted as members of the ward teams (Heimer, Staffen, 1998; Anspach, 1997). This first-hand experience enabled the two researchers to detect major differences between the facilities analysed as concerns care practices, although the mission statements of the two hospitals are identical.

At the organisational level, the wards were characterised by different approaches as to how the families were received. These included from being allowed to stay just a few hours to being able to remain with one's child for the whole day; from prohibiting access to any relatives except the parents to welcoming grandparents and siblings; from a total lack of rooms dedicated to the families to the availability of reserved hospitality areas. These possibilities, influenced by structural and logistic features, certainly have a major impact on the quality of care, from "tolerating" the presence of the parents to actively involving them in taking care of the newborn.

The core of the investigation concerned how the children were tended to in order to protect their fragility. In Maria Vittoria, we detected a mainly healthcare-oriented approach and, in general, greater attention to the schedule and the needs of the ward rather than to the children. For instance, when the newborns were fed, put to sleep, changed, or washed, or they had to undergo invasive and stressful procedures such as being moved elsewhere, the attention paid to their individual needs depended on personnel availability rather than on the rules of the ward.

The doctors and nurses of Sant'Anna's TIN received a specific form of training – the so-called *NIDCAP Method*⁸ – in order to offer frail newborns the highest possible level of well-being, at the physical as well as the cognitive and relational level. This method was devised in the mid-1980s by Doctor Als and her team (1986), in order to make neonatal intensive care units more humane, by observing and interpreting behavioural clues from the infant while also supporting and strengthening his/her bond with the parents. Nowadays, NIDCAP is recognised worldwide as the most valid and widely used newborn care method. In Italy the TINs in which doctors have a NIDCAP certificate are still rather limited in number (hospitals of Modena, Genoa, Milan, Reggio Emilia, Florence, and Rimini; Mosca, 2009; Smith, Butler, Als, 2007). The use of this methodology follows the guidelines of the *Italian Neonatology*

⁸ Acronym of *Newborn Individualized Developmental Care and Assessment Program*.

Society, which in the last fifteen years has endorsed the adoption of *Individualised Family-Centred Developmental Care* methods.

Concerning direct initiatives taken by the ward personnel to support parents in handling their child, very different practices were noticed in the two TINs. The observations indicated that the staff of Maria Vittoria paid considerable attention to hygiene rules related to the parents' access to and stay in the ward, but the same did not happen with regard to regulating primary relationships. The researchers did not hear any mother ask a doctor how to breastfeed or hold her baby; indeed, the most common questions concerned news about the child's clinical situation and, above all, about the date of discharge. Indications on how to care for the infant were mostly provided by the nurses. Some mothers preferred relating to the physiotherapists who, unlike the doctors, focused much more on communication, including non-verbal communication, and suggested observing the children in order to learn their preferences, wishes, reactions, times, and movements.

In Sant'Anna's TIN, the protocol specifies that when parents come to the ward, they must be given a leaflet entitled "Open Ward. With us, at your child's side 24/7". Once they have become familiar with the ward, they receive a brochure with further information about newborns, equipment used and care practices, as well as testimonials and advice. The guidelines regarding the management of emotional dynamics (guilt, fear, stress) are very interesting. They underline the importance of communicating openly with one's extended family, friends, and the medical staff. In addition, they encourage keeping a diary on the progress of the baby, calling it by name, so that the parents will soon see their newborn as "their baby" and not "the nurses' or doctors' child".

Since 2003, the ward has also employed a counsellor to welcome and counsel parents at the time of hospitalisation and while their child remains in the ward. This specialised staff member deals with guiding mothers and fathers in their first contacts with their child, coaching and facilitating communication between parents and healthcare personnel – especially when bad news must be given, difficult decisions must be taken, or the situation is particularly delicate (problematic parents, complex issues, deteriorated relationships – and supporting parents during the pre-discharge phase. The researchers noticed that, coached by the counsellor, the parents were able to review information, ask relevant questions, and find out about any discrepancies between what they thought they had understood and what they had actually been told.

As for the organisation of the available space, soft colours were chosen for both wards, the rooms are air-conditioned and lighting can be adjusted in order to offer the mothers and their

infants a comfortable environment. Both TINs are equipped with new incubators, covered with coloured blankets to shelter the newborns from the light. Where possible, sound signals have been replaced with light signals, and the air-treatment system has been modified to ensure that the intensive and sub-intensive care units are at higher pressure than the surrounding areas, thus ensuring a sterile environment.

From hospital to home healthcare

In order to personalise care interventions, another major aspect regards accurate planning of hospital discharge followed by provision of support to the family unit as the home healthcare services take charge.

Our experience noted that the delicate hospital-home transition should take into account not only the infant's level of "stability" and self-regulating abilities, but also the quality of the parent-child relationship and whether the family perceived hospital discharge as a form of abandonment. We also noted that, as discharge approached, due to fear of change and limited trust in their own resources and abilities to deal with everyday life, some parenting couples asked, more or less explicitly, to extend the period of hospitalisation, often with no apparent reason. The healthcare staff also perceived that the parents found it difficult to leave the TIN. The procedures implemented by the doctors in Maria Vittoria's TIN strictly followed the regional guidelines (Piedmont's Regional Council Resolution no. 34/2008): handing over the newborn's Health Diary and information about enrolment with basic paediatric and healthcare services.

We wish to draw attention to some practices adopted at Sant'Anna's TIN, due to their outstanding quality within the national context, as acknowledged by the national assembly of the Italian Neonatology Associations during a conference in 2010. The approach adopted upon discharge is the same as that used in the ward, focusing on the specific features of this phase and paying great attention to the parents' experience. The doctors appear to be aware of the need to "wean" the parents, recognising the fact that a serene hospital-home transition also depends on the mother and father having already had the opportunity to experiment with their parenting skills in the TIN. Staff members make sure that the date of discharge is notified in good time, clearly explaining the reasons behind this choice – especially if the infant still requires medical care or any form of support for vital functions – and the necessary procedures for appropriate healthcare at home. Therefore, during the pre-discharge period the staff allow parents to take charge of all aspects concerning the babies' care, including their

healthcare, such as administering medications or using an oxygen mask. These procedures are aimed at acquiring “remote coached autonomy”. Once at home, the parents can phone the hospital any time they deem it necessary.

Upon discharge, the ward provides the families with a letter addressed to the paediatrician they have chosen, containing information on the child’s pre and post-delivery conditions. This is done in the belief that knowing about the most suitable therapeutic practices for the newborn can improve medical care quality, as well as lighten the burden of family responsibilities. The protocol concerning hospital-home transition also includes a plan for follow-up medical examinations.

The outpatient department of the neonatology ward at Sant’Anna routinely carries out a newborn, neuro-behavioural, and physiological follow-up plan, for the early detection of neuromotor disorders in infants up to two years of age. Regarding children weighing less than 1,500 grams at birth and all high-risk newborns, the monitoring plan is extended until school age. In the case of children diagnosed with a form of disability at birth, the ward follows them for about two months and then they are referred to their local healthcare services.

In order to find out more about the experiences and organisational needs of the parents once they go home with their child, we carried out observations for several months, during the follow-up meetings taking place at the outpatient departments of the neonatology wards. Overall, about thirty families from various areas of Piedmont were monitored, by being called in individually every two or three months. The meetings began with the parents talking about the child’s progress and difficulties, as well as their own emotions. A neonatologist, together with a physiotherapist, provided a general assessment of the child’s health and development and then gave the parents some guidelines on care and/or further diagnostic tests.

The accounts offered by the families confirmed that the key discriminating factor was the newborn’s health. If their child was discharged with a stable clinical profile, despite indications about certain precautions and measures to be taken, the families experienced both joy and exhaustion. This was due to the chance of finally being together in an intimate environment but at the same time, having to make room – both physically and mentally – for the newborn. In these cases, early contacts with the local healthcare services were linked to choosing a paediatrician, following the methods adopted in the majority of cases.

When, despite an overall stable clinical profile, it was necessary to use equipment to support the child’s vital functions – for instance, an oxygen mask – the hospital-home transition entailed the management of practical healthcare aspects which absorbed most of the family’s

energies. Thus, parents could rely on ward personnel or on follow-up meetings to find solutions to their problems through counselling and help, even long after their infant had been discharged.

As examples, we report the testimonials of two mothers. One of them, Sofia, said that, shortly before discharge, the Local Health Authority (*Azienda Sanitaria Locale* - ASL) gave her some life-saving equipment which was not suitable for her baby.

«It's not up to me to do their job. They are health personnel and should be able to meet our needs properly. I'm a mother, my job is to be a mother and not to worry about things that are not my responsibility». The impasse was overcome thanks to the collaboration of the doctors from the neonatology ward, who compensated for the inefficiency of the local health authority by supplying the family with the necessary equipment to treat the child at home after discharge.

In the second story, the problem concerned the local healthcare paediatric service, which responded in a standardized way to the very specific needs of the child and family. The mother, Giulia, explained that her daughter – who often suffered from bronchitis after being born preterm with a lung condition – was repeatedly administered an inadequate routine therapy by the paediatrician. She remarked: «The paediatricians from the local healthcare services are not ready for these children, who cannot be treated like all the others and need special consideration». It was only thanks to the hospital staff that the problem was finally solved.

As our fieldwork highlights, after coming into contact with the level of care available in the neonatology wards, it is paramount for families to find comparable quality in the local services. Indeed, care actions and parent support cannot stop once the children leave hospital; neither can they be limited to follow-up meetings at outpatient departments. As the family unit is engaged in looking for a new state of balance and harmony in the process of taking care of the newborn, it should be able to have access to a coordinated network of local support services which, taking its specific features into account, lets the parents focus their energies on developing their life project.

As for the network of local services, it must be noted that various facilities are connected to Piedmont's regional network of Maternity and Children Departments (DMI)⁹. They operate within each ASL (*Region of Piedmont – Social and Healthcare Services Plan 2007-2010*) and define the health, educational, and social actions related to pregnancy, birth, and the perinatal

⁹ The Maternity and Children Departments include all the local and hospital services of each ASL for mothers and minors.

period, making up the “Birth Path”. One of its purposes is to inform families about the network of interlinked local and hospital services (Piedmont’s Regional Council Resolution no. 34/2008). In the city of Turin a specific liaison figure has been created, that of the paediatric nurse. This is a healthcare professional who does not deal with educational issues but focuses on disease prevention and the promotion of health in cases of children with difficulties.

The general picture emerging from the accounts given by the families interviewed (around 30 families in total, two thirds of whom were met at Sant’Anna) is certainly far from our expectations. In most cases, the parents – especially those coming from small towns or rural areas – were not aware of the range of mother-and-child services available in their local area. Moreover, they stated that the practical help and affection they received from their extended family, in particular from grandparents, were fundamental in overcoming both discouragement and weariness.

Educational services of the Municipality of Turin for children in difficulty

The last part of our research focused on the actions implemented by the Municipality of Turin. There are a number of reasons for this. Firstly, Italian Municipalities have specific responsibilities and authority in the matter. Secondly, the city of Turin stands out on the national scene thanks to some farsighted choices made by its local administrators. Lastly, our decision was motivated by the fact that, starting from our investigation in the city hospitals, our research as a whole concentrated on the local context.

Our analysis led us to identify the Home Educational Counselling service (*Consulenza Educativa Domiciliare* – CED) as an extremely important resource in building a network of local educational care around the family unit. Established in 1984 by the Municipality Department for Education and managed by a team of five teachers, especially in its first twenty years of operation, the CED has offered precious home support to families with children aged 0-3 suffering from evident disabilities or in situations of distress.

This service displays some innovative aspects, such as the fact that the educational action is performed at the parents’ home by a specifically trained professional. Furthermore, its rules prescribe that the mother or the primary caregiver should be present during the activities involving the child, so that they are supported in taking on their primary role in the relationship.

Besides looking after the family unit as a whole, another specific and distinguishing element of the CED is the activation of a network of family support services. Each CED professional (a nursery school teacher with at least five years' experience in municipal schools and who has completed a specific two-year course at the Training Centre of the Department for Educational Services of the Municipality of Turin) is appointed as reference educator for one or more family units. The reference educator is the figure that "pulls the strings of the project", coordinates the various actions, and participates in meetings with the professionals involved: the paediatrician chosen by the family, rehabilitation experts, child neuropsychiatrist, nursery school educators, social workers and others.

One of the CED's main objectives is also to promote and support the parents' wish to integrate their child into an educational institution, whether a nursery school or a day nursery. Achieving this goal entails the implementation of actions that, despite being carried out in everyday life – looking for an educational institution, preparing the documentation, settling-in phase – contribute to developing projects for the future. One of the teachers, Ornella, explains: «E's family moved to Turin from another city. I supported the mother during the process required for her daughter to be awarded an invalidity pension and also to be enrolled at a nursery school. I took charge of the entire family. I suggested that the mother should attend a course of Italian for foreigners, so that she would gain greater autonomy. I followed the daughter throughout the settling-in phase at the nursery school and every month, together with her mother, I participate in meetings with the educators, the neuropsychiatrist, the music therapist, and the social worker. It is I who coordinate E and her family's educational project».

By tracing the evolution of the service, through the records examined and staff accounts, we found out that, starting from year 2000, the reference age range has been extended from 0-3 to 0-6 years of age and the reference population has also been increased to include children that are considered at educational risk. Furthermore, in 2005 the CED was included among the educational and welfare-oriented actions provided for in the Agreement between the Municipality of Turin and the ASL, so that the service is activated only after the child is accepted into the care of the local Child Neuropsychiatry Department.

The main consequences of the above emerge from the files of the cases followed by CED teachers from 1999 to 2010. There was a gradual increase in the average age of the children at the time they accessed the service: from 18-20 months in the period between 1999 and 2004 to 27-30 months in the period between 2005 and February 2010. In our view, this results in

the loss of precious months devoted to the process of parent-child bonding, which is so crucial for the construction of a context oriented towards developing projects.

Currently, the CED is undergoing a phase of stagnation. Budget limitations have deeply affected the local institutions in the last few years. The fact that retiring teachers are not replaced and there is a lack of investment in this service by the new administrators appears to be seriously threatening its chances of survival.

Another key service characterising the local educational context and aimed at early infancy is that of the nursery schools of the Municipality of Turin. Starting from the late 1970s, these schools began a scheme for the integration of children with disabilities and/or major health problems, almost twenty years before this became compulsory by law¹⁰. After the first pilot schemes, as early as 1981 the General Regulations granted priority of access to nursery school¹¹ to children in a situation of “mental or sensory handicap” or with “specific health, psychological, and social problems”. In addition, the schools in question would have to increase their staff with specifically trained individuals, have suitable premises and equipment, and be able to rely on an educator specialised in psychomotor skills.

Our investigation revealed that the board of educators developed an Individualised Educational Plan (*Progetto Educativo Individualizzato* – PEI)¹² for each child in difficulty, in every nursery school we visited. The PEI included personal autonomy objectives (body awareness, motor activity, relational skills, communication, languages, sense-perception, and neuropsychological aspects) and social autonomy objectives, in line with the educational planning of the class. We also saw that the municipality nursery schools we visited integrated the families’ experiences, thus implementing joint counselling and support actions, with the aim of ensuring the children’s care and promoting their growth and integration into their peer group. Moreover, there were active contacts between the school educators and professionals working in other local services involved in specific cases.

Conclusions

The aim of this research was to piece together the mosaic of early educational planning actions focusing on children and their families, by observing the circumstances and actors

¹⁰ Law no. 104 of Feb. 5th 1992, Framework Law for the assistance, social integration, and rights of the handicapped, article 12.

¹¹ Attending a nursery school is not compulsory in Italy. Since the availability of places in public nursery schools is more limited than the demand, each Municipality compiles an eligibility list which considers disability/frailty as one of the main priority criteria for acceptance.

¹² The Individualised Educational Plan is drawn up for each child with special educational needs by the teachers, in collaboration with the family and the reference personnel from the healthcare and social services; it is compulsory from nursery to secondary school (Law no. 104/92, article 12).

characterising the first few months of a rather difficult life path. Therefore, we did not focus on the size of the investigation sample. As our project developed, we were able to follow only a small number of cases in their transition from the TIN to the local services. Furthermore, our observations were limited to some specific steps, such as from hospital to follow-up and from CED to nursery school. Once children were discharged from hospital, monitoring the transition to local services proved particularly difficult for two main reasons. Firstly, there was a lack of motivation shown by the families in interacting with services other than those of a medical-rehabilitative nature. Secondly, services had organisational problems, such as considerable geographical fragmentation and difficulty in finding services available at a local level, together with discontinuity linked to staff turnover, and lack of coordination between the different services.

As far as the hospitals are concerned, in the largest and best equipped facility included in our investigation (i.e. Sant'Anna), we found an approach attentive to the global personal needs of both the newborn and the parents. This was implemented professionally with coherent organisational choices. The adoption of this intervention model stems from the health professionals' openness towards the latest scientific research in the field, which emphasises the importance of combining medical and pedagogical points of view.

Despite formally complying with care principles indicated by regional laws and by the internal code of procedure, at Maria Vittoria we detected the presence of habits and behaviour focusing mostly on healthcare practices. In this regard, the national statistics for this sector show that – due to cultural, structural, and organisational deficiencies in Italian hospitals – only 29% of mothers can freely access the TIN where their infant is hospitalised and are seen as active interlocutors (Marconi, 2006). Nonetheless, both in the TINs and in the outpatient departments for support at a distance after discharge, we observed constant changes for the better, implemented “step by step” in order to perfect one procedure at a time, as suggested by the Italian Neonatology Society (Colombo, Eds., 2011).

Yet an open question remains as to who supports the families during the delicate hospital-home transition phase, when they have to meet the child's care and health related demands by establishing contacts with the local reference services and, at the same time, see to the creation of a new equilibrium. Our direct experience shows that it is extremely difficult to find non-hospital services capable of interacting effectively with other local services and with the families.

An innovative approach seems to consist in the implementation of a counselling model, which entails multidisciplinary coordination among the professionals involved in various duties. The

Municipality of Turin has been at the forefront, for almost thirty years now, thanks to a specific professional figure with educational skills who has been available to support and counsel families. At national level, there has been a constant increase in the number of similar experiences and intervention projects, building up positive practices of collaboration between institutions and the volunteer work sector. However, new circumstances, such as budget limitations and inadequate political foresight, are likely to overshadow the existing good practices or hinder the implementation of new ones.

Training is clearly needed for projects and processes to promote satisfactory living conditions for children in difficulty and their families, built up progressively from coordinated inter-institutional and inter-professional reflection and action. Ongoing training of specialised staff is the only viable approach to guarantee innovation in professional practices and to ensure a wider understanding, rather than merely focusing on predetermined tasks. Moreover, parents must be informed and coached in their everyday routine, so that they can get to know and bond more closely with their child, enabling its fuller integration within their family circle.

References

- Als H., (1986), *A synactive model of neonatal behavioral organization*, in Sweeney J.K. (Eds), *The high risk neonate: development therapy perspectives*, Physical & Occupational Therapy in Pediatrics, vol. 6, nn. 3/4, pp. 3-55.
- Anaut M., (2006), *Résilience familiale ou familles résilientes?*, in *Reliance*, 19, pp.14-17.
- Anspach R., (1997), *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*, University of California Press.
- Battaglia A. et al. (2004), *Figli per sempre. La cura continua del disabile mentale*, Roma, Carocci Faber.
- Belfiore G. (2004), *L'uso dello "spazio relazionale" nella dinamica riabilitativa*, in Di Nuovo S., Buono S., *Famiglie con figli disabili*, Troina (En), Città Aperta Edizioni, pp. 258-264.
- Brazelton T.B., Greenspan S.I. (2001), *I bisogni irrinunciabili dei bambini*, Milano, Raffaello Cortina.
- Bruscanin et al., (2011), *Manifesto dei diritti del bambino nato prematuro*, Ed. Vivere onlus;
- Caldin R. et al. (2009), *Crescere insieme: i giovani con disabilità tra famiglia, scuola e servizi*, in Pavone M., (Eds) *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*, Trento, Erickson, pp. 251-276.
- Canevaro A. (Eds) (2007), *L'integrazione scolastica degli alunni con disabilità*, Trento, Erickson.
- Catarsi E., (2008), *Pedagogia della famiglia*, Roma, Carocci.
- Centro Internazionale Studi Famiglia (CISF) – Provincia di Milano (2007), *Famiglie resistenti e affaticate: i volti della cura familiare. I nodi della politica sociale quando si incontrano le famiglie e le scelte di metodo della ricerca*, Milano.
- Colombo G. (Eds, 2011), *Con ragione e sentimento. Le cure neonatali a sostegno dello sviluppo*, Usmate (Mi), Grafica Briantea.
- Contini M.G. (2001), *La famiglia, crocevia complesso di progettualità*, in Milani P. (Eds), *Manuale di educazione familiare*, Trento, Erickson.
- Dal Molin M.R., Bettale G. (Eds), (2005), *Pedagogia dei genitori e disabilità*, Pisa, Del Cerro.

- Di Nuovo S., Buono S. (2004), *Famiglie con figli disabili*, Troina (En), Città Aperta Edizioni.
- Dondi A. (2008), *Disabilità, trauma familiare e resilienza. Il peso della normalità per fratelli e sorelle delle persone disabili*, in Quaderni di psicologia, analisi transazionale e scienze umane, n. 49, pp. 117-142.
- Ebersold S. (2007), *Parents et professionnels face au dévoilement du handicap*, Ramonville, Éres.
- Erikson E., (1950), *Infanzia e società*, Roma, Armando Editore.
- Favorini A.M. (2009), *La coeducazione del disabile negli anni della scuola primaria*, in Pavone M.(Eds), *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*, Trento, Erickson, pp. 221-250.
- Favorini A.M. (2007), *Alleanze educative e alfabetizzazione affettiva con genitori e insegnanti. Verso il progetto di vita*, in Canevaro A. (Eds), *L'integrazione scolastica degli alunni con disabilità*, Trento, Erickson, pp. 449-465.
- Ferrari F. et al. (2006), *La care in terapia intensiva neonatale*, in La Sala (Eds), *La "normale" complessità del venire al mondo*, Milano, Guerini Studio, pp. 241-250.
- Franchini R. (2007), *Disabilità, cura educativa e progetto di vita*, Trento, Erickson.
- Gardou C. (2006), *Diversità, vulnerabilità, handicap*, Trento, Erickson.
- Hanau C., Cerati Mariani D. (2007), *Il nostro autismo quotidiano. Storie di genitori e figli*, Trento, Erickson.
- Heimer C., Staffen L. (1998), *For the Sake of the Children: The Social Organization of Responsibility in the Hospital and the Home*, University of Chicago Press.
- Ianes D., Cramerotti S. (2009), *Il piano educativo individualizzato. Progetto di vita*, vol. I, *La Metodologia e le strategie di lavoro*, Trento, Erickson.
- Iori V. (2001), *Fondamenti pedagogici e trasformazioni familiari*, Brescia, La Scuola.
- Lizzola I. (2006), *Persone e legami nella vulnerabilità*, Milano, Unicopli.
- Malaguti E. (Eds) (2011), *Servizi educativi per la prima infanzia: costruzione di processi inclusivi e promozione di interventi di qualità*, in *L'integrazione scolastica e sociale*, n. 10/2, april 2011, pp. 103-150.
- Malaguti E., Cyrulnik B. (2005), *Costruire la resilienza*, Trento, Erickson.
- Marconi M. (2006), *La prematurità come condizione di rischio*, in Prezza M., *Aiutare i neogenitori in difficoltà*, Milano, Franco Angeli.
- McCubbin H. (1988), *Family Types and Strengths: A life cycle and ecological perspective*, Edina, Mn, Burgess International.

- Milani P. (2001), *Manuale di educazione familiare. Ricerca, intervento, formazione*, Trento, Erickson.
- Minuchin S. (1996), *La guérison familiale, mémoires d'un thérapeute*, Paris, ESF.
- Moletto A. Zucchi R. (Eds) (settembre 2006), *Con i nostri occhi. Un itinerario di "Pedagogia dei Genitori"*, supplemento di *Handicap & Scuola*, Nichelino (To), tipografia Impronta.
- Moretti G. , in Cannao M., Moretti A. (Eds), 2006, *Riabilitazione e integrazione del disabile. Dai principi ai metodi*, Roma, Armando Editore.
- Morvan J. S., (2010), *L'énigme du handicap. Traces, trames, trajectories*, Toulouse, Edition Érès.
- Mosca M., (2009), *Vedere il mondo con gli occhi del neonato prematuro: l'umanizzazione dei reparti di terapia intensiva neonatale e la NIDCAP*, in Pavone M., (Eds), *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*, Trento, Erickson, pp. 215-219.
- Nocera S., (2009), *Servizi territoriali a sostegno dell'impegno familiare per l'integrazione scolastica e sociale delle persone con disabilità*, in Pavone M., (Eds), *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*, Trento, Erickson, pp. 293-312.
- Nussbaum M., (2007), *Le nuove frontiere della giustizia*, Bologna, Il Mulino.
- Organizzazione Mondiale della Sanità (2002), *ICF/International Classification of Functioning, Disability and Health*, Italian trans. *Classificazione Internazionale del Funzionamento, della Disabilità e della Salute*, Trento, Erickson.
- Pati L., (2005), *Diventare genitori. Padri e madri nella complessità delle relazioni familiari*, in Pati L., (Eds), *Educare alla genitorialità tra differenze di genere e di generazioni*, Brescia, La Scuola, pp. 139-168.
- Pavone M., (2010), *Dall'esclusione all'inclusione. Lo sguardo della Pedagogia Speciale*, Milano, Mondadori.
- Pavone M., (Eds), (2009), *Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta*, Trento, Erickson.
- Pergolesi S., Eds., (2002), *A casa con sostegno*, Milano, Franco Angeli;
- Prezza M., Eds., (2006), *Aiutare i neo-genitori in difficoltà. L'intervento di sostegno domiciliare*, Milano, Franco Angeli.
- Ricci C., (2005), *Valorizzare le differenze individuali nella prima infanzia*, Trento, Erickson.

- Sausse S., (1996), *Le miroir brisé. L'enfant handicapé, sa famille et le psychanalyste*, Paris, Calmann-Lévy.
- Scabini E., Cigoli V., (2000), *Il familiare. Legami, simboli, transizioni*, Milano, Raffaello Cortina.
- Scabini E., Rossi G., (a cura di), (2006), *Le parole della famiglia*, Milano, Vita e Pensiero.
- Scelles R., (2010), *Fratrie et handicap, l'influence du handicap d'une personne sur ses frères et soeurs*, Paris, L' Harmattan.
- Smith K.M., Butler S., Als H., (2007), *NIDCAP: changing the future for enfants and their families in intensive and special care nurseries*, Italian Journal of Pediatrics, vol. 33, pp. 79 -91.
- Sorrentino A.M., (2006), *Figli disabili. La famiglia di fronte all'handicap*, Milano, Raffaello Cortina.
- Stiker H.J., (2009), *Les métamorphoses du handicap de 1970 à nos jours*, Grenoble, PUG.
- Walsh F., (2008), *La resilienza familiare*, Milano, Raffaello Cortina Editore.
- Zanobini M., Usai M., Manetti M.C., (2002), *La famiglia di fronte alla disabilità. Stress, risorse e sostegni*, Trento, Erickson.