

SHORT REPORT

INFANT- AND FAMILY-CENTRED DEVELOPMENTAL CARE FOR PRETERM NEWBORNS IN NEONATAL CARE



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■ FOREWORD

What is more beautiful than the birth of a child? New life with a whole future ahead of it. New life that parents patiently look forward to for nine months in order to welcome it into their midst, into their family, into the world.

Unfortunately, pregnancy and birth do not always go as expected. Many babies have to be admitted to a neonatal ward, sometimes for a short time but often for weeks or even months. The spontaneous intimacy between parents and child, which is necessary for building a good bond and for the child's development, is therefore less obvious or sometimes even impossible. Since the 1950s, numerous scientific studies have demonstrated that a good bond between a child and its parents is necessary for the child to grow into a healthy, balanced adult. For this reason, new care models have gradually emerged on an international scale in neonatal wards, which are intended to promote child-parent bonding, and thus the child's early development.

It is therefore time to consider this issue in Belgium as well. KCE was asked to study how infant- and family-centred developmental care could be implemented in the neonatal wards. All the more so because, since 2015, there has been a tendency for mothers to stay in hospital for a shorter period of time after giving birth, which makes this issue even more acute.

What models of care have been described in the literature to effectively address this problem? What are best practices abroad to address the separation between child and parents in the neonatal ward? How are the Belgian departments organised? Does infant- and family-centred developmental care already exist in Belgian neonatal wards, and what are barriers and facilitators to its further development? What could be solutions to the identified problems? These are the questions this report seeks to answer. The primary focus was on infant- and family-centred developmental care for preterm babies, but of course these results are relevant to all babies admitted to a neonatal ward.

Investing in infant- and family-centred developmental care is an investment in the future of our children, and hence of our society. We hope that this report will help to convince that this is the right way forward and generate the necessary willpower to overcome the current practical barriers.

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■ SHORT REPORT

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
APIB	Assessment of the Preterm Infant Behaviour
ATVV	Audio, Tactile, Visual, Vestibular intervention
BFHI	Baby-Friendly Hospital Initiative
BTP	Baby Triple P
CEpiP	Centre d'Épidémiologie Périnatale
CHU	Centre Hospitalier Universitaire
CLE	Compréhension du langage de l'enfant
COPE	Creating Opportunities for Parent Empowerment program
COVID-19	Coronavirus Disease 2019
CRC	Convention on the Rights of the Child
EACH	European Association for Children in Hospital
EFCNI	European Foundation for the Care of Newborn Infants
FINE	Family and Infant Neurodevelopmental Education
GLANCE	Global Alliance for Newborn Care
H-HOPE	Hospital to Home: Optimising the Infant's Environment
IFCDC	Infant- and family-centred developmental care
LOS	Length-of-stay
NIDCAP	Newborn Individualised Developmental Care and Assessment Program
PAM	Pacifier-activated music player
PBIP	Parent Baby Interaction Programme
RCT	Randomised clinical trial
SPE	Studiecentrum voor Perinatale Epidemiologie
SSC	Skin-to-skin care



TRT	Triadic parent-infant Relationship Therapy
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
UZ	Universitair ziekenhuis
VIG	Video Interaction Guidance
WHO	World Health Organization



1. INTRODUCTION

In this short scientific report, we describe the main scope, research objectives, methods, results and conclusions of the KCE study on infant- and family-centred developmental care (IFCDC) for preterm newborns in neonatal care. For more details regarding methods and results, we refer the reader to the [scientific report](#). Next to this short scientific report, there is also a Dutch and French synthesis available.

1.1. Infant- and family-centred developmental care (IFCDC)

Importance of attachment and non-separation early in life

Separation early in life between newborns and parents can have a significant impact on the child's development later in life.¹⁻³ Babies are biologically programmed to look for the physical proximity of an adult that responds to their baby's need for protection. However, the quality of his/her attachment varies according to the responses of the environment. Therefore, it is imperative that these responses are adequate, leading to the ability of the baby to use attachment as a safe and secure base.^{4, 5} Furthermore, the concept of caregiving is a reciprocal motivational system between child and parents: parents give proximity and comfort in response to the attachment needs of the baby. This is supported by the concept of "attachment", which is defined as "a deep and enduring emotional link between two human beings, that makes us search and find a sense of comfort and security".² This bond is especially crucial in the first years of life. Difficulties in attachment building may lead to psychiatric illness and medical morbidity.^{6, 7} One of the best ways to support parenting and promote the baby's development is thus to minimise parent-newborn separation at birth and increase the quality of the parental responsiveness. Early separation is harmful to both newborn infants and their parents since it disrupts the biological and emotional bonding.^{8, 9} These act as a stressor with effects on the physical and mental health of both the newborn infant and family and may interfere with breastfeeding¹⁰ and alter the bonding and attachment process.¹¹

The issue of non-separation early in life is particularly important for preterm newborn infants. Mothers are usually discharged from the maternity ward before their newborn infant leaves the hospital (depending on the level of prematurity and/or comorbidities, neonatal hospitalisation can last up to several months), leading to a period where parents and their newborn infant are (in some way) physically and/or psychologically separated.

What do international charters and standards recommend about IFCDC?

Several international charters and standards contain the expectations that children and their parents can have towards IFCDC. For instance, the United Nations (UN) Convention on the Rights of the Child (CRC)¹² states that "*The child [...] shall have the right to [...] be cared for by his or her parents*" and "*States Parties shall ensure a child shall not be separated from his or parents against their will [...]*".

This is in line with the European Association for Children in Hospital (EACH) charter¹³, which stipulates that "*Children in hospital have the right to have their parents or parent substitute with them at all times*". Concerning parental support, EACH states that "*Accommodation should be offered to all parents and they should be helped and encouraged to stay*", "*Parents should not need to incur additional costs or suffer loss of income*" and "*In order to share in the care of their child, parents should be kept informed about ward routine and their active participation encouraged*".

Furthermore, the European Standards of Care for Newborn Health¹⁴ (initiated by European Foundation for the Care of Newborn Infants [EFCNI]) make numerous recommendations towards IFCDC care for newborns. The Global Alliance for Newborn Care (GLANCE), which is the global initiative of EFCNI, developed a long-term campaign: "Zero separation. Together for better care! Keep preterm and sick babies close to their parents".¹⁵ The campaign's goal is to raise awareness for the benefits of zero separation of preterm and sick babies and their parents in NICU in times of COVID-19-precautions.



Definition of IFCDC

EFCNI defines IFCDC as “a descriptive term that entails the framework of newborn care incorporating theories and concepts of parent-newborn interaction, parental involvement, neurodevelopmental and neurobehavioral care, breastfeeding promotion, environmental adaptation and change of hospital systems”.¹⁶

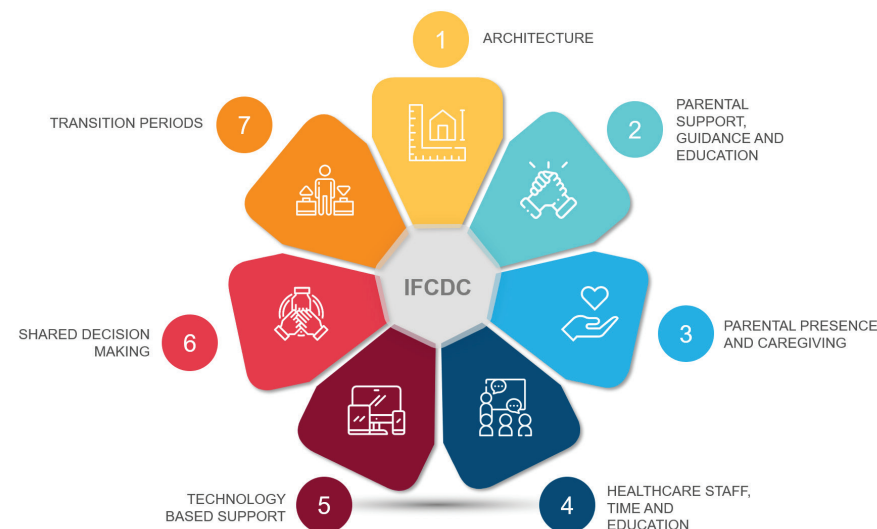
Therefore, according to EFCNI, IFCDC should:

- be based on sensitive care relying on infant behavioural communication and cues, giving the newborn a voice^{17, 18};
- be beneficial for brain growth¹⁹;
- support parental wellbeing and the infant’s development through parent engagement²⁰⁻²⁴;
- tailor the NICU environment and hospital system as a whole to the needs of the infant and family.²⁵

IFCDC delivery as a multifaceted concept: related concepts and models

The existing body of literature contains a wide variety of terms, methods or theories to deliver IFCDC. However, some of these terms or methods are used interchangeably and are probably in some conditions overlapping, demonstrating the complexity and versatility of IFCDC as a multifaceted concept. The distinction or overlap between these terms and methods is not always clearly stated in the literature. To clarify the main elements to deliver IFCDC, we performed a concept mapping to summarise the main operationalisation elements for IFCDC delivery (Figure 1).

Figure 1 – Flower diagram of the main elements of infant and family-centred developmental care



The concept mapping is visualised as a flower to highlight the importance that all concepts stem from a general centre: the preterm infant(s) and their family (i.e. parents, siblings or other family members and friends). Important to note is that there is not necessarily a hierarchical relationship between the different main elements (the petals), but that they are all interconnected, mutually reinforcing and blending into what is defined as a philosophical approach and set of principles to guide the delivery of neonatal healthcare (rather than a list of all possible interventions).²⁶

1. **Architecture:** refers to the physical environment in which the newborn infant, family and healthcare professionals are located. The design of neonatal wards should accommodate the central role that families take in the care and enable individualisation of the environment for each newborn.²⁷ Several standards recommend the availability of single-family and couplet care rooms, family support spaces (e.g. lounge area and family education areas) and transition rooms (i.e. intermediate space between highly medicalised NICU environment and discharge).



In addition, the infrastructure should also provide adequate stimuli in the sensory environment of newborn infants (e.g. adjustments of the care environment in terms of light and sound), families and staff and meet personal, professional and administrative needs of the staff by installing staff-support spaces.

2. **Parental support, guidance and education:** parents who have a newborn infant hospitalised in a neonatal ward need support to cope with the experience and to be emotionally, cognitively and physically able to parent their infant²⁶; therefore, psychosocial and psychoeducational support is considered to be an important part of neonatal care.^{28, 29} Psychosocial support includes the availability of neonatal care providers and mental healthcare professionals, but also peer-to-peer support provided by volunteer parents who have had the experience of a child in the neonatal ward.³⁰ Furthermore, parental guidance and education on how to read the infant's cues and respond appropriately is a fundamental part of developmental care. Educational interventions should be tailored and individualised to the parents' needs and preferences and could be reinforced by the presence of educational material (e.g. pamphlets or videos). Sibling support can be delivered by organising sibling support activities to promote sibling attachment and decrease sibling anxiety.³¹ Involvement of the close environment of the family (like friends or extended family) adds an important pillar of support. Last, it is also important to have a feedback loop in which parents are allowed to assess the support received and to improve future quality.²⁹
3. **Parental presence and caregiving:** important in the context of preterm newborns is the responsiveness of the care to the preterm infant's competencies.³² A preterm baby is adapted to live in the environment of the uterus, the brain is not yet mature and premature extra-uterine sensory experience may cause alteration in their development. Stimuli of parents cannot be replicated by others.³³ Parental presence is, therefore, essential for the development of a newborn infant and can be achieved by providing parents 24/7 accessibility and/or provide accommodation (in or adjacent to the neonatal ward) so that parents (or significant others) can stay with the baby without interruption.³⁴ In addition, parents can be encouraged to provide routine care for their newborns like diapering, bathing, clothing and feeding. Breastfeeding is

identified as the optimal method for infant feeding.^{27, 35} Breastfeeding promotion can be achieved via maternal support and the presence of lactation consultants.³⁶

Developmental care practices require minimising parent-infant separation, and include, but are not limited to skin-to-skin contact (SSC), support in positioning or holding, adjustments of the care environment and provision of other positive sensory stimuli like the parents' voice via reading or singing. Developmentally supportive methods are sometimes formalised into complex models of care. One of these models is kangaroo mother care (KMC), which refers to the positioning of the naked newborn chest-to-chest and skin-to-skin with one of the parents.³⁷

A common method to make stimuli-responsive to the infant's competencies is the Newborn Individualised Developmental Care and Assessment Program (NIDCAP).¹⁸ NIDCAP is a comprehensive care programme for the NICU, developed by Als et al.³⁸ The core of the programme is that care should be developmentally supportive and individualised to the newborn's goals and level of stability. Healthcare professionals educate parents and take care of the newborn in collaboration. This can be achieved by direct observation of the newborn within their environment in the intensive care setting. Using a detailed observational tool, often referred to as the NIDCAP observation, the newborn's behaviours can be interpreted as steady and relaxed or as representing stress or discomfort. By observing and interpreting behaviours of newborns within their environment and as reactions to care they receive, developmental care plans that best support the newborns' overall goals and efforts at self-regulation can be developed.

4. **Healthcare staff, time and education:** safe and effective caregiving is dependent on appropriate training of the healthcare professionals both from a clinical care point of view and from a developmental care point of view.³⁹ Learning from qualified experts on how to understand and respond to newborn infants is essential to put developmental care in practice.³⁵ Training in developmental care requires considerable investment from both the individual trainee and the institution. Training in positive communication is necessary to improve parents/staff



communication in the ward. Furthermore, IFCDC implementation implies a shift in the quantity and quality of time devoted by healthcare staff in supporting the newborn infant and family. This time should be acknowledged by the leadership with adequate time and supplies and supported by governmental decisions.⁴⁰

5. **Technology based support:** electronic technology can be used to contribute to the family-centredness of the neonatal ward.⁴¹ A variety of communication means (such as web cameras, videoconferencing or text messages) can be used to enhance communication or interaction between the neonatal healthcare professionals, parents, or infants, education of parents, or a combination of both.^{41, 42} Videoconferencing technology can be used for (i) viewing the infant by parents (or other significant family members such as grandparents or siblings) who cannot be physically present⁴³ or (ii) by healthcare professionals to monitor the infant once it has been discharged home.⁴⁴ Next to these communication possibilities, mobile applications and web platforms can also be used for educational purposes, permitting mobile access to pertinent information related to the infant's health.⁴¹
6. **Shared decision making:** creating the appropriate environment and opportunities for the family to communicate and collaborate with healthcare staff in the neonatal ward enables them to become part of the decision-making process, sharing all relevant information including prognosis and choice for care for the infant.^{27, 45} A possible strategy to include parents in clinical decision-making is permitting their participation in clinical rounds.⁴⁶ In cases of uncertainty in the preterm newborn's treatment (e.g. cases where benefits of keeping or withdrawing treatment are not clear-cut), shared decision making is the ethically preferred approach. In these cases, healthcare professionals should elicit the values and preferences of the parents and connect them to the possibilities at hand (instead of making decisions in a paternalistic way or giving the parents' full autonomy and freedom of choice).⁴⁷ Shared decision-making on a macro- and meso-level requires parents' representatives to be consulted as stakeholders by leadership and management when policy or institutional decisions are made regarding the organisation of neonatal care.
7. **Transition periods:** the moment when the newborn infant and their family make the transition from one care setting to another is a crucial one. During the antenatal period, it is important for women with a high-risk pregnancy to have access to counselling from a multidisciplinary staff (neonatal and obstetric teams), psychological support and the opportunity to visit the neonatal ward before the delivery.^{48, 49} The transfer of pregnant women or preterm infants between wards of specialist care needs to be done in a timely manner to avoid separation.⁴⁹ Therefore, the in-utero transfer is to be prioritised and zero separation should be the aim during intra- and inter-institution transfer. Transition to home for hospitalised preterm infants requires technical skills, factual knowledge, emotional solidity and confidence of parents.⁵⁰ Discharge preparation includes involving the parents in the process of discharge planning.⁵¹ Discharge classes and educational material are employed to facilitate this process⁵², so are the use of web-based or mobile apps.⁵³ Support and education should be accessible even after the infant's discharge. Support of both formal (professionals) and informal (peers, family and friends) support is important during this transition period.⁵⁴ Home care provided by staff affiliated with the neonatal ward may make discharge easier and smoother, ensuring continuity of care and making hospital stays shorter.⁵⁵ A structured follow-up programme is necessary to timely detect potential long term sequelae.⁵⁶



1.2. Some IFCDC initiatives in Belgium

1.2.1. *Baby-Friendly Hospital Initiative*

The Baby-Friendly Hospital Initiative (BFHI) is a global effort to implement practices that protect and promote breastfeeding. The initiative was launched by the World Health Organization (WHO) and the United Nations International Children's Emergency Fund (UNICEF) in 1991, following the Innocenti Declaration of 1990. The initiative is a global effort to implement practices that protect and promote breastfeeding.⁵⁷

Since the launch of the BFHI plan by the FOD – SPF Public Health in 2005, 30 Belgian hospitals have been awarded the "Baby-Friendly Hospital" certificate after an training contract of 4 years.⁵⁸

1.2.2. *NIDCAP, FINE and CLE*

NIDCAP is an internationally recognised comprehensive neonatal care program. Its aim is to tailor the overall care provided in neonatal intensive care units to the behaviour of the newborn in order to support development and promote attachment. The programme is currently coordinated by the NIDCAP Federation International. There are currently two recognised NIDCAP training centres in Belgium: Universitair Ziekenhuis (UZ) Leuven (UZ Leuven NIDCAP training centre) and Centre Hospitalier Universitaire (CHU) Saint-Pierre (Brussels NIDCAP training centre in St. Pierre). Currently, NIDCAP training is only offered to healthcare professionals working in a NICU. Most of the hospitals with a NICU have started NIDCAP training for (part of) their employees.

Healthcare professionals working at a neonatal ward can also follow a training in Family and Infant Neurodevelopmental Education (FINE). FINE is based on the framework of NIDCAP and provides a comprehensive overview of the theoretical, practical and scientific aspects of developmental care and provides insights to the healthcare professional to reflect on the own practices and how they impact the family and their child. The Brussels NIDCAP training Centre has also developed and intermediate developmental care training program: "Compréhension du langage de l'enfant (CLE)". CLE is also based on the NIDCAP framework and has been followed by healthcare professionals working in several neonatal wards.

In combination with the BFHI training contracts, FOD – SPF also offers a training contract to hospitals in the context of developmental care.

1.3. Scope and objective of the report

Research questions of the report

The results of this report should assist public authorities, the hospital sector and healthcare professionals in setting priorities and making strategic decisions regarding the implementation of IFCDC in Belgian neonatal care. The general aim covers the following research questions:

1. How is neonatal care for parents and newborns in NIC and N* wards currently organised in Belgium?
2. What is the profile of preterm newborns hospitalised in NIC and/or N* wards in Belgium?
3. What are interventions to promote IFCDC for hospitalised preterm newborns in high-income countries? What is the effect of these identified IFCDC interventions on several parental and newborn outcomes (including medical and other outcomes)?
4. What are the strengths (facilitators) and weaknesses (barriers) in the organisation and funding of neonatal care for preterm newborns (and their parents) in Belgium in the context of IFCDC?
5. What lessons can be learned from international good practices regarding IFCDC?

Scope of the report

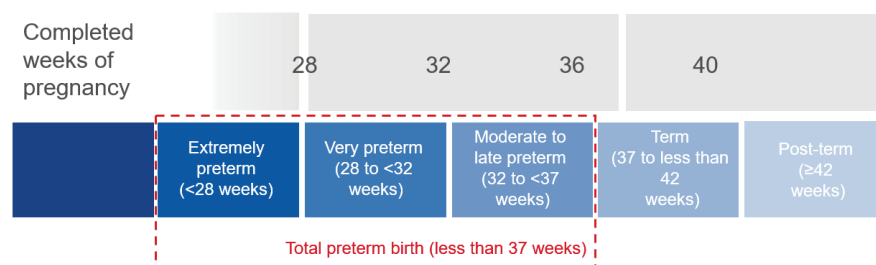
The target population, on which all these research objectives focus, will be preterm newborns. Preterm birth is defined as babies born alive before 37 weeks of pregnancy are completed.⁵⁹ There are sub-categories of preterm birth, based on gestational age:

- Extremely preterm: newborns born before 28 completed weeks of gestation;



- Very preterm: newborns born between 28 and before 32 completed weeks of gestation;
- Moderate to late preterm: newborns born between 32 and before 37 completed weeks of gestation.

Figure 2 – Categories of preterm birth



Source: authors' own reproduction based on World Health Organization (2018)⁵⁹

1.4. Methods

This section will present a brief overview of the main methods used. Details on these methods are outlined at the beginning of each chapter of the full [scientific report](#).

- **Organisation of Belgian neonatal care:** an analysis of legal documents was performed to map the current organisation of neonatal care services in Belgium. (See Chapter 2 of [scientific report](#))
- **Profile of hospitalised preterm newborns:** administrative databases with characteristics of preterm newborns and their birth have been analysed (2016-2018). A summary of the latest reports published by the Centre d'Épidémiologie Périnatale (CEpiP) and the Studiecentrum voor Perinatale Epidemiologie (SPE) has been added as complementary information. (See Chapter 3 of [scientific report](#))
- **Identification of IFCDC interventions:** a systematic review of the literature (focused on randomised controlled trials (RCTs) in high-

income countries) was conducted to identify IFCDC interventions and their effects on several parental and newborn outcomes. We identified 59 RCTs describing 24 IFCDC interventions. The search strategy was updated until the first week of July 2021. (See Chapter 4 of [scientific report](#))

- **Interviews with Belgian parents of preterm newborn infants:** the perceptions and experiences of parents of preterm newborn infants who were hospitalised at neonatal wards were collected through semi-structured online interviews. All together, we conducted 25 interviews (of which 25% were exclusively mothers and 75% were couples; 52% Dutch-speaking and 48% French-speaking). The quotes included in this short report have been translated to English (for the original quotes in Dutch or French, see Chapter 5 of [scientific report](#)).
- **Focus groups with healthcare professionals working in neonatal care services:** we conducted eight online focus groups with healthcare professionals working in neonatal wards to collect their perspectives on IFCDC. In total, 40 healthcare professionals participated in the focus groups (60% Dutch-speaking; 40% French-speaking). The quotes included in this short report have been translated to English (for the original quotes in Dutch or French, see Chapter 6 of [scientific report](#)).
- **International comparison of IFCDC best practices:** four foreign neonatal centres were selected as IFCDC best practices: (i) Karolinska University Hospital (Sweden), Sophia's Children Hospital (Netherlands), Centre Hospitalier de Valenciennes (France) and Hospital Universitario 12 de Octubre (Spain). Data and information on these international best practices were collected through semi-structured interviews with healthcare professionals working in the field. (See Chapter 7 of [scientific report](#))



2. CURRENT ORGANISATION OF NEONATAL CARE AND PROFILE OF PRETERM NEWBORNS IN BELGIUM

2.1. Perinatal organisation in Belgium

Perinatal care in Belgium consists of maternity services (M service), maternal intensive care department (MIC department), local neonatal care functions (N* function) and wards (N* wards), neonatal intensive care services (NIC service) and regional perinatal care function (P* function). The legal context of neonatal care in Belgium is mainly regulated in the Royal Decrees of 20 August 1996 and 21 March 1977.^{60, 61} Chapter 2 of the [scientific report](#) provides an overview of the legal context of these services, departments and functions. Because of the scope of this report, we only describe the organisation of the local neonatal care function, neonatal intensive care service and the regional perinatal care function in this short report.

Local neonatal care function (N* function) and N* ward

Every hospital with a maternity service is obliged to have an N* function. The minimum annual number of births in a maternity service should be at least 400 on average during three consecutive years.⁶² There are exceptions for this minimum number of deliveries in certain cases. Each N* function is responsible for providing regular neonatal care in the room of the mother including phototherapy if the neonate's condition allows or requires it. In addition, every N* function must have an N* ward, which is exclusively meant for the supervision, treatment and care of newborns with specific adjustment problems that require specialised, non-intensive neonatal care.

There are no programming standards or minimum number of beds for the N* function and -ward. However, as each hospital with a maternity service is obliged to have an N* function, programming standards for the maternity service are worthwhile mentioning. The national programming standards for the maternity service are 32 M beds per 1 000 births.

Currently, 102 N* functions are available in Belgium (April 2021) from which 58 are located in Flanders, 33 in Wallonia and 11 in Brussels.^a

Neonatal intensive care service (NIC service)

Every hospital with a maternity service with a licensed department for high-risk pregnancies (MIC department) is obliged to also have NIC beds. There is no legal requirement for a hospital with NIC beds to also have MIC beds. A NIC service is exclusively intended for newborns who are in a life-threatening or special condition. Newborns may stay at a NIC service until they have sufficiently recovered to be able to be transferred back to the referring hospital or service without any risks. If the function of local neonatal care (N* function) is integrated into the NIC service, both must be clearly distinguishable from each other and intensive care must be reserved for the licensed NIC beds.

National programming standards for NIC services are 6 NIC beds per 1 000 births. A NIC service has to fulfil at least three of the following activity standards: each year at least 50 newborns with a birthweight of less than 1 500 grams are admitted annually, (ii) at least 20% of the admissions per year relate to intra- or extra-uterine transfers, (iii) each year newborns in need of intensive care from at least 5 000 deliveries are treated through collaboration agreements with M services and N* functions, (iv) each year at least 50% of transferred NIC patients are returned back to the referring institution.⁶³ In addition, each NIC service should at least have 15 beds.

In April 2021, there were 19 NIC services in Belgium (7 in Flanders, 6 in Brussels and 6 in Wallonia) including a total of 380 beds (148 in Flanders, 123 in Wallonia and 109 in Brussels).

^a Centre Hospitalier Reine Astrid (Malmedy) has an N* function through association with CHR de la Citadelle (Liège).



Regional perinatal care function (P* function)

The regional perinatal care function (P* function) consists of a licensed department for high-risk pregnancies (MIC department) and a licensed service of neonatal intensive care (NIC service), on the same hospital site. Hospitals with a P* function act as a reference centre that must make collaboration agreements with hospitals with an M/N* function. Together, these hospitals must have at least 5 000 deliveries per year.⁶⁴ A hospital with a MIC department is obliged to have a P* function. In addition, a P* function can only be awarded if the hospital meets certain conditions (e.g. a genetic consult, a radiology service, 24/7 laboratory, emergency department, intensive care ward).

In August 2021, there were 19 hospitals with a P* function in Belgium (7 in Flanders, 6 in Brussels and 6 in Wallonia), as well as 2 hospitals with associated P* function (1 in Flanders and 1 in Brussels).^b

2.2. Profile of preterm newborns in Belgium

We described the profile of preterm newborns in Belgium by analysing national administrative databases. For more details regarding the databases, analyses and results, we refer the reader to Chapter 4 of the [scientific report](#).

Every year, an estimated 15 million newborns worldwide are born too early, equalling 1 in 10 babies.⁵⁹ In Belgium, approximately 8% of the births are preterm (< 37 weeks of gestational age)^c. Furthermore, 11.8% of the newborns in Belgium are hospitalised in neonatal intensive care wards (NIC) or local neonatal wards (N*)^{d, 65-67}

Mortality among preterm newborns

Among hospital stays for premature delivery between 2016 and 2018 (n=31 820), 6.95% of the babies died. Among those, 72.92% were stillborn, while the others died after admission (27.08%). More than half of stillbirths (53.01%) occurred before reaching the gestational age of 28 weeks.

Preterm newborns hospitalised in a neonatal ward: characteristics of the delivery and hospitalisation

Among the live preterm newborns (n=30 207), 26.09 % were not admitted to a neonatal ward. Because of the scope of the report, we only describe the characteristics of the preterm newborns that were hospitalised in a neonatal ward.

In the group of preterm newborns hospitalised in a neonatal ward, 83.59% were moderate to late preterm, 10.91% were very preterm and 5.06% were extremely preterm. The vast majority of the preterm newborns that are only hospitalised in a N* ward is moderate to late preterm (98.1%), 1.01% is very preterm and 0.53% is extremely preterm. Concerning newborns who are only hospitalised in a NIC ward is 60.57% moderate to late preterm, 23.64% very preterm and 15.16% extremely preterm. 70.86% of the newborns that are hospitalised in NIC and N* wards is moderate to late preterm, 22.73% very preterm and 6.21% extremely preterm.

32.43% of the hospitalised preterm newborns had a normal birth weight ($\geq 2\,500$ g), while 67.57% of the newborns weighted less than 2 500 g, divided into: 52.96% of low birth weight (1 500 g – 2 499 g), 9.24% of very low birth weight (1 000 g – 1 499 g) and 5.36% of extremely low birth weight (< 1 000 g).

^b In Flanders, this is AZ Sint-Lucas (Brugge) which is associated with AZ Sint-Jan (Brugge). AZ Sint-Lucas has M beds, but no NIC beds. In Brussels, this is Hôpital Universitaire Des Enfants Reine Fabiola – Universitair Kinderziekenhuis Koningin Fabiola (HUDERF – UKZKF) which is associated with Centre Hospitalier Universitaire (CHU) Brugmann. HUDERF has NIC beds but not M beds.

^c In 2020, 8.6% of the births in Wallonia were preterm (i.e. < 37 weeks of pregnancy), 8.0% in Brussels and 8.1% in Flanders.

^d In 2020, 9.6% of the births in Wallonia were hospitalised in a NICU or N* unit (3.7% and 5.9% respectively), 9.9% in Brussels (5.2% and 4.7% respectively) and 14.2% in Flanders (4.3% and 10.0% respectively).



We observed a lower induction rate (15.08%) compared to preterm newborns without a neonatal hospitalisation (i.e. 18.31%). However, the caesarean section rate was observed to be much higher (48.13%; compared to 28%). Approximately 4 out of 10 (40.38%) preterm deliveries with induced labour needed intensive neonatal care: 21.00% in a non-intensive neonatal ward and 19.39% in a NICU.

The median LOS for preterm newborns who were only hospitalised on NIC wards was 24 days, 10 days for hospitalisations on the N* ward and 28 days for preterm newborns who were hospitalised in both wards.

Nine out of 10 preterm newborns (89.28%) were discharged at home after a stay in a neonatal care ward. However, this proportion is lower when the stays included only NIC ward (75.86%) in comparison with those in N* wards (93.76% and 91.59%, respectively for N* bed only and NIC and N* beds). 7.22% of the preterm newborns were transferred to another hospital and 0.08% to another ward in the same hospital. The transfer rate is approximately three times higher when the stay occurred only in the NIC ward in comparison with stays occurring exclusively or partially in N* wards (16.05%, 5.59% and 4.50%, respectively in NICU, in both NICU and N* ward and in N* ward only).

Impact of the COVID-19 pandemic on preterm births

For this section, we use the results presented in the 2020 perinatal health reports of the regional perinatal study centres (CEpiP and SPE).⁶⁵⁻⁶⁷

The number of births decreased in all regions in 2020 compared to previous years. This decrease was more pronounced in Wallonia-Brussels, in which the number of births decreased by 3.72% in 2020 compared to 2019. This is almost 4 times the annual decrease observed during the period 2015 - 2019 (0.97%). Furthermore, during the first year of the COVID-19 pandemic (from 16 March to 27 December 2020), the proportion of singleton preterm newborns has decreased by 8.9% compared to 2019 in Brussels-Wallonia and by 6.0% in Flanders. The decrease was more pronounced at the end of the year 2020: -18.2% in Wallonia-Brussels and -9.1% in Flanders (compared to the same period in 2019). The proportion of newborns with low birth weight (1 500 g to 2 499 g) has decreased for the COVID-19 period in 2020 compared to 2019: -8.5% in Wallonia-Brussels and -11.6% in Flanders. The number of admissions in the N* ward and NICU has also decreased in 2020 compared to 2019: there has been 7.9% less admissions for the COVID period in 2020 (weeks 12 to 52, singletons alive) and 4.5% less in Flanders. The decrease is more important in the lockdown period: -15.7% in Wallonia-Brussels and -9.7% in Flanders.



3. MAPPING OF IFCDC INTERVENTIONS

Heterogeneity in definitions, interventions and data collection methods limits generalisation

In this chapter, we will describe interventions to provide IFCDC identified by a systematic literature review in high-income countries. The review identified 59 randomised controlled trials (RCTs) describing 24 IFCDC interventions in 15 high-income countries. Most of the RCTs were conducted in the USA (n=24), others were conducted in Sweden (n=4), Israel (n=4), Norway (n=2), Australia (n=3), the Netherlands (n=2), Canada (n=4), Germany (n=4), the United Kingdom (n=2), Italy (n=1), France (n=1), South Korea (n=1), Turkey (n=1) and Ireland (n=1). One RCT was conducted in multiple countries (i.e. Australia, Canada and New Zealand). Most of the interventions were studied in the NICU and there was a huge variation in prematurity definition in terms of gestational weeks or based on weights. Moreover, the (operationalisation of the) interventions were very different from one another and instruments/tools to measure impact on outcomes (i.e. parent-newborn attachment and interaction, length-of-stay [LOS] of the newborn, parental mental wellbeing and satisfaction, breastfeeding, neurodevelopmental impairment and costs of care) varied across studies. This heterogeneity makes it challenging to synthesise information.

3.1. Identified IFCDC interventions

Wide variety in interventions demonstrates the complexity of the multifaceted concept of IFCDC

The IFCDC interventions that we identified range from interventions focusing on skin-to-skin care (SSC) (including different operationalisations of SSC and kangaroo care), massage and the Audio, Tactile, Visual, Vestibular (ATVV) intervention, Newborn Individualized Developmental Care and Assessment Program (NIDCAP), mother-infant transaction program, family nurture intervention, CUES program, Hospital to Home: Optimising the Infant's Environment (H-HOPE) program, Creating Opportunities for Parent Empowerment (COPE) program, psychological interventions (such as early preventive attachment-oriented psychotherapy and Triadic parent-infant Relationship Therapy [TRT]), family integrated care, music therapy, Video

Interaction Guidance (VIG) and a wide range of individual interventions (among which a telemedicine programme, co-bedding of multiple-gestation newborns, Assessment of the Preterm Infant Behaviour [APIB], Parent Baby Interaction Programme [PBIP], free parking for parents of hospitalised newborns, Baby Triple P [BTP], parent participation improvement programme, financial support for parents and virtual family-centred rounds). This wide variety in interventions demonstrates the complexity of the multifaceted concept of IFCDC. Each identified intervention incorporates one or more of the dimensions described in the concept mapping (see section 1.1).

3.2. Effect on outcomes

Most RCTs found heterogenous results on the studied outcomes, however no major significant negative effects

- *Skin-to-skin care (SSC)*: six of the included publications studied the effect of skin-to-skin care on several outcomes.⁶⁸⁻⁷³ These publications were characterised by a wide variety in operationalisations of SSC (ranging from continuous or intermittent skin-to-skin care throughout the hospitalisation to SSC limited to the delivery room). Most of the effects on the studied outcomes vary or demonstrate mixed results. The lack of strong evidence is rather due to the wide variation in data collection methods and operationalisations of SSC. For instance, Mehler et al.⁶⁹ found a significant positive effect on mother-infant interaction following sixty minutes of delivery room SSC, while Sahlen Hemler et al.⁷² found no significant effect on the interaction between continuous and intermittent SSC.
- *Kangaroo care*: is a variant of SSC and refers to the positioning of the naked newborn chest-to-chest and skin-to-skin with one of the parents. SSC is offered as far as the parent-newborn dyad can tolerate it. The results of two publications suggested a positive influence on parent-infant interaction later in life.^{74, 75} Effects on mental wellbeing outcomes and newborn LOS showed mixed results (combination of positive effects and absence of significance).



- *Massage and Audio, Tactile, Visual, Vestibular (ATVV) intervention*: the two publications focusing on massage only studied the effect on parental mental wellbeing outcomes and showed either mixed results (on parental stress levels) or a negative effect (on parental anxiety or depression).^{76, 77} In addition, the ATVV intervention is a massage variant involving moderate stroking (tactile), eye contact (visual), talking to (auditory) and rocking (vestibular) of the newborn infant. ATVV was found to have a positive effect on newborn LOS and breastfeeding progression⁷⁸ and mixed-effects (combination of positive effects and absence of significance) on parental satisfaction⁷⁹, parent-newborn interaction and parental mental wellbeing.⁸⁰
- *Newborn Individualized Developmental Care and Assessment Program (NIDCAP)*: is a comprehensive NICU-based care programme (see detailed description in “Parental presence and caregiving” in concept mapping). Five publications in this systematic review studied the effect of NIDCAP on a variety of outcomes.^{20, 81-84} The results of these RCTs show that NIDCAP increases parent-newborn interaction, increases parental anxiety and has significantly lower total hospital charges.^{20, 81} The effect on LOS of the newborn, parental stress and neurodevelopmental impairment was unchanged or showed positive results.
- *Mother-infant transaction program*: is an early intervention programme that has been designed to improve developmental and mental outcomes of preterm newborns and their parents by enhancing the quality of interaction between mother and newborn. The initial programme consists of 11 sessions, carried out by trained NICU nurses. The aim of the programme is to help parents appreciate their infant’s unique characteristics, temperament and developmental potential, acquaint the parents with the newborn’s functioning and guide them in being more sensitive and responsive to their psychological and social cues, especially those signalling stimulus overload.⁸⁵ The mother-infant transaction programme showed to have a positive influence on parent-newborn attachment and interaction and breastfeeding rates.⁸⁵⁻⁸⁸ The effect on parental mental wellbeing was less straightforward (positive effect or unchanged).
- *Family nurture intervention*: is a dyadic intervention comprising repeated calming activities during a newborn’s NICU hospitalisation. Calming procedures included scent cloth exchange, calming touches and holding. Beebe et al.⁸⁹ found a significant positive effect of the intervention on mother-newborn interaction. The results of Welch et al.⁹⁰ revealed less maternal depressive and anxiety symptoms. The effects on the LOS of the newborn and breastfeeding were not significant or remained unchanged.
- *CUES program*: is a six-session programme for mothers of a preterm newborn hospitalised in the NICU and is designed to teach mothers to recognise signs of their anxiety or distress, apply various strategies to alleviate this distress, read newborn’s communication cues and respond sensitively to these cues and distress. The results of the two identified RCTs revealed a positive effect of the programme on parental satisfaction⁹¹ but a non-significant or unchanged effect on parent-newborn interaction, LOS of the newborn infant and parental mental wellbeing.^{91, 92}
- *Hospital to Home: Optimising the Infant’s Environment (H-HOPE) program*: is an integrated intervention consisting of twice-daily infant stimulation with ten minutes of ATVV stimuli and maternal education and social support through individualised participatory guidance. White-Traut et al. found marginally higher mother-infant interaction scores during feeding.⁹³ However, the LOS of the newborn did not differ between intervention and control groups.⁹⁴
- *Creating Opportunities for Parent Empowerment (COPE) program*: is a four-phase NICU-based educational behavioural intervention programme.⁹⁵ Each phase provides parents with information on newborn infant behaviour information, parent-role information and activities that assist parents in implementing the experimental information. Melnyk et al.^{95, 96} found a significant reduction in stress levels among mothers (but not fathers) following the programme. All other studied outcomes showed no significant or unchanged effects.



- *Psychological interventions*: two publications were identified in which two individual psychological interventions were studied: (i) early preventive attachment-oriented psychotherapeutic programme and (ii) the Triadic parent-infant Relationship Therapy (TRT).^{97, 98} Only TRT showed to have a significant lowering effect on parental stress and depression levels.⁹⁸
- *Family integrated care*: the implementation of family integrated care is focused on four pillars: (i) a parental educational programme, bedside parental coaching, parental involvement in medical rounds, training of staff about the importance of family involvement and tools to coach and support parents and psychosocial support for parents including peer-to-peer and professional support.¹⁰ According to the results of Church et al.⁹⁹, family integrated care increases parent-newborn interaction. The effect on LOS of the newborn, parental mental wellbeing and breastfeeding are either unchanged or not significant.
- *Music therapy*: was the intervention of study in six of the RCTs identified in the systematic literature review.¹⁰⁰⁻¹⁰⁴ The music therapy in these interventions ranged from live harp music (combined or not with kangaroo care), maternal singing, interactive live music and pacifier-activated music player (PAM). Live harp music seemed to significantly increase parental anxiety.¹⁰⁰⁻¹⁰² Effect of other interventions on parent-newborn interaction, newborn LOS and depression showed mixed results (unchanged or not significant).
- *Video interaction guidance (VIG)*: is a short-term, behaviourally focused video-feedback intervention that guides parents to reflect on their interactions with their newborn and is performed by certified professionals who work by a standardised protocol. The video recordings (of approximately fifteen minutes duration) are made during daily moments of caregiving (e.g. bathing, changing diapers, or feeding). Parents review these video recordings and discuss them with the VIG professional. VIG consisted of three review sessions during the first week of birth. Hoffenkamp et al.¹⁰⁵ found a significant positive effect on father-newborn bonding and interaction. These significant effects were not found for mothers. This is in line with the results of the more recent RCT of Twohig et al.¹⁰⁶ in which VIG did not have a significant effect on parental mental wellbeing.¹⁰⁵
- *Other interventions*: last, we identified ten IFCDC interventions that were only studied in one publication and were therefore put together in this category. These interventions comprised a telecommunication programme, co-bedding of multiple-gestation newborns, guided interaction and education through APiB, PBiP and BTP, family-centred NICU ward, free parking for parents, parent participant improvement programme, financial support for mothers of hospitalised newborns and virtual family-centred rounds. Results for these interventions on the studied outcomes were heterogeneous.

Heterogenous results can mainly be explained by the low methodological quality of RCTs

The majority of the RCTs that we have selected in this systematic literature review were found to be of low methodological quality. The limited level of evidence of IFCDC can mainly be explained by this weak methodological quality. This is in line with the results of several recent Cochrane Library reviews¹⁰⁷⁻¹¹⁰ in which the lack of high-quality quantitative research about the effects of IFCDC was highlighted. Most of the included RCTs recruited small samples (only 23 trials randomised more than 100 dyads). For instance, trials in which a significant effect on one of the outcomes was found, had usually recruited a small sample of participants or in other cases the clinical relevance of the effect was questionable. Therefore, further rigorous research is indicated to study the short- and long-term effectiveness of IFCDC as a model of care delivery.



Evidence does not have the power to point out one comprehensive IFCDC model that should be implemented

We identified nine high-quality randomised controlled trials (RCTs) of different interventions. Of these, four had significant positive outcomes on attachment or parent-newborn interaction. Nevertheless, most included RCTs found mixed effects on the studied outcomes. Important to note is that no major significant negative effects were found. This review suggests some benefits to support IFCDC for preterm newborns in neonatal wards; however, it has not the power to point out one comprehensive IFCDC model. This is in line with a recent literature review that studied family engagement interventions in both adult, neonatal and paediatric ICUs.¹¹¹

A detailed overview of the results per outcome for each intervention can be consulted in Chapter 4 of the [scientific report](#).

4. STRENGTHS AND WEAKNESSES IN IFCDC IMPLEMENTATION IN BELGIUM

To identify the strengths and weaknesses in current IFCDC implementation in Belgium, we conducted 25 semi-structured online interviews with parents of preterm newborns who were hospitalised at neonatal wards. In addition, we organised eight online focus groups in which 40 neonatal care providers were interviewed. It is important to emphasise that qualitative research aims to describe and understand the object of inquiry (i.e. here: the needs, wishes, concerns and experiences of parents and care providers in neonatal care) but does not explicitly aim at generalisation. Qualitative research is not about numbers, but about “how, where, when, who and why”. Although inevitably subjective, it is the perspective of the participants that is considered essential. By selecting a focused and balanced sample of participants, we obtain an accumulation of views that allows us to construct a rich and meaningful whole that transcends the subjectivity of any one individual. The findings coming out of the interviews with parents and focus groups with neonatal care providers are structured according to the main elements of IFCDC (Figure 1). We refer the reader to Chapters 5 and 6 in the [scientific report](#) for more details.

4.1. Architecture

4.1.1. Current infrastructure is often inadequate for IFCDC implementation

Lack of space and comfort

The neonatal care providers who participated in the focus groups mention that current hospital infrastructure is often inadequate to provide IFCDC, due to lack of space. Especially **rooming-in of parents is highly limited** by the often outdated inadequate infrastructure: lack of space in general and lack of available individual rooms. In the worst case, parents do not have the option to stay with their child overnight. In the best case, rooming-in is possible but only for a very limited number of children and/or for a limited number of nights.



The scarcity of individual rooms leads to the fact that staff has to decide which families benefit most from an individual room. Individual rooms are more likely to be proposed to the parents of infants who do not or no longer need intensive care, infants who only need a short stay or are approaching discharge. The mother should also be in a sufficiently good state of health, and she must be discharged from maternity. Mothers who are breastfeeding or have psychosocial problems are often prioritised to stay in individual rooms. Finally, preparing parents for discharge is an often-cited reason to offer an individual room, mostly one or two nights before discharge to give parents the possibility to familiarise with their child and learn to take care of the child 24/7.

“And rooming-in as we would often like to have it, is very limited in what you can offer, how you should organise it, how you should finance it. I call that a bit amateurish. It is there, but it cannot be developed properly because the infrastructure is simply not there.”
(Physician, N*, original quote in Dutch)

Notwithstanding the advantages of individual rooms, these are also more challenging for the staff, especially in terms of surveillance. The neonatal caregiver can only be in one room at a time and cannot keep an eye on the infants in other rooms simultaneously. According to the participants of the focus groups, central monitoring does not solve this issue completely, rather more available staff is needed. In addition, infants cannot be left alone in an individual room when parents are absent. Individual rooms with glass or adjacent to the nursing post are therefore preferred by the interviewed neonatal care providers. Finally, neonatal care providers mention that individual rooms can be lonelier for parents, as contact with peer-parents is less frequent.

“But on the other hand, when they are busy with these mothers, they cannot keep an eye at all the other babies, who are in the common room and who are less well. And that is sometimes quite complicated. And it probably requires extra staff to have individual rooms for all babies.” (Physician, N*, original quote in French)

The lack of individual rooms is also mentioned by interviewed parents of preterm newborns. Mothers feel that in an individual room they were able to be a full mother for her child. Parents also point to a **lack of comfort** in neonatal facilities, such as a lack of privacy, a place to put personal belongings, a family room to have a meal, a bed to sleep near the newborn, toilet facilities, a shower and accommodation for siblings. These can be elements that hinder parental presence in the neonatal ward (see 4.3).

Lack of space does not only translate in a lack of individual rooms, but neonatal care providers also highlight the lack of space in terms of a recovery room in the neonatal ward, room for siblings, parental lounge and stocking material.

Infrastructure cannot follow evolutions in neonatal care

Neonatal infrastructure always lacks behind evolutions in neonatal care. Changing infrastructure takes time, while new evolutions in neonatal care follow each other in rapid succession. Infrastructure cannot keep up the pace. Moreover, currently, there are no architectural norms or guidelines on how a neonatal ward should look like to adequately implement IFCDC.

4.2. Parental support, guidance and education

4.2.1. Need for more parental support

Need for emotional and/or psychological support

Having a baby hospitalised and the distress this separation brings about, causes parents of preterm newborns to report a need for emotional and/or psychological support. This need for support manifests itself throughout the entire hospitalisation of the preterm infant (e.g. during admission, breastfeeding, bad-news conversations or discharge) and can be provided by a wide range of actors (such as neonatal care providers, family and friends, peer-parents or psychologists). **Communication is reported to be clear, transparent, friendly, progressive, supportive and tailored to the parents' needs.** The communication between the neonatal staff and parents continues during the night and even after the newborn's discharge.



Neonatal staff also plays an important role in the translation of the information in lay language.

“I had the impression that everything was progressively explained to us, and it already removed a lot of fears. There was still stress, anxiety, etc. We had a lot of empathy at that level, from the whole department. People were asking how things were going and so on. And we had the impression that with each small step forward, the whole neonatology department was rejoicing. That gave the feeling to not be alone, of feeling to be supported. And we had a lot of explanations from the nurse and the doctors.” (Father, GA 32 to 37 weeks original quote in French)

However, interviewed parents report that **psychologists are less available** than other neonatal care providers because they are often not formally part of the neonatal ward. In addition, psychologists usually only work during office hours, which means they are not always available when needed. This lack is also highlighted during the focus groups with neonatal care providers.

“And especially on the psychological level [...]: the importance of having a psychologist to focus on the family, even when there are no problems in the family, the fact that the child is ill and therefore hospitalised, whereas it should be a happy event and there are complications, so I don't think that there is much funding for psychologists in this respect either. And they are - and even less - child psychiatrists, and so it's really important that they can be present.” (Physician, N, original quote in French)*

As mentioned above, family and friends are important providers of emotional and practical support (e.g. preparation of meals, picking siblings from school). Peer-parents of preterm infants are also mentioned as an important source of social support and understanding as they went or are going through the same experience. Parents exchange information and encourage each other during hospitalisation. Some parents develop close friendships and stay in contact, even after hospitalisation.

“We also met another twin there with whom we are still in contact. Eh, so it's nice because you can share it. You can't share the experience of neonatology with your family if they don't go through it. The sadness or the pleasure, the joy that you experience in neonatology, you can only share this with the people who also experience it. Because only they understand. Eh, you can't explain that I can't explain that to someone, to have to leave your child there again. But I can explain it to the people who are also going through it.” (Mother of twins, GA 32 to 37 weeks, original quote in Dutch)

Need for instrumental support

Instrumental support consists of administrative, financial assistance and childcare. Interviewed parents report that a neonatal stay brings along an **administrative burden** (e.g. application for paternity leave, advancement of medical expenses). Going through several administrative procedures is necessary to get allowances. However, parents are not always able to take these necessary steps because of the emotional distress associated with neonatal hospitalisation. At the time when parents are busy with these administrative tasks, they often cannot be with their preterm infant either, which makes them feel torn. Parents of preterm newborns would be more comfortable when they had more time to settle down the administration.

Interviewed parents also highlight the **financial burden** associated with preterm birth. Additional costs are e.g. medical costs, costs of an ambulance, travel costs, reduced income due to fewer working hours, parking costs, etc.



4.2.2. Parental guidance and education

Parents feel reassured by the supporting attitude and availability of neonatal staff, but some feel uncomfortable

During the hospitalisation of the preterm infant, neonatal care providers guide and learn parents to observe their preterm infant and read the cues so that subsequent actions can be adjusted if necessary. Interviewed parents feel reassured by the **presence, supervision, feedback and supportive attitude** of the neonatal staff. However, there can be a **downside** too. Some parents do not feel comfortable being watched all the time. For some being supervised is not reassuring, but instead, withholding them from carrying out care tasks. For others having the neonatal staff around all the time is frustrating, especially near the moment of discharge, when they feel sufficiently self-assured or skilled in managing care autonomously.

“It was the dad who was very insecure in his actions and having a nurse watching, supervising, it was just, it intimidated him enormously and so he preferred not to do anything. He hardly ever changed the boy during the three weeks. But he said to me, it's because I'm being watched...” (Mother, GA 32 to 37 weeks, original quote in French)

4.3. Parental presence and caregiving

4.3.1. Separation and accessibility

The separation of a newborn from his or her parents is perceived as extremely difficult and heart-breaking

Non-separation of parents and their (hospitalised) infants is one of the key principles of IFCDC. Although parents and infant(s) are kept together as much as possible, still every separation is one too much. Interviewed parents experience the **separation from their infant(s) as extremely difficult and heart-breaking**. This is especially the case when the mother is discharged from the maternity ward and has to leave her newborn infant behind. Being in the same hospital with the preterm newborn (and not necessarily on the same ward) is experienced as more comfortable and

reassuring compared to being at home (especially if the home is distant from the hospital). The fact of being in the same building reduces mothers' distress considerably. In addition, mothers appreciate **the intermediary role of fathers** when they themselves are unavailable (e.g. when they are in recovery after caesarean section). The father functions as “a bridge” between mother and child, passing through information.

“When I was told, “you're going back home today”, I really fell apart that day, it was very, very hard. Especially because I had been told that I would be discharged on Monday and then the nurse arrived on Sunday morning with her big smile, I don't blame her, she arrived and said: “well you must be happy, you can go home today”. And then I fell apart.” (Mother, GA 32 to 37 weeks, original quote in French)

This separation is even more pronounced when there are **siblings at home**. Interviewed parents experience it as very difficult to explain and feel torn between the siblings at home and the newborn at the neonatal ward. Siblings are a point of discussion and negotiation between parents and staff, as parents really want to unite their family around the newborn and introduce the newborn to its siblings. Furthermore, siblings withheld some parents from making use of an individual room and staying with their newborn in the hospital.

“Mother: Wow, that was really hard to leave him like that. And all alone. But on the other hand, we also had our daughter, whom I haven't been able to see for a long time, so I missed her too. Then you actually have to choose between your two children. That is difficult. But we knew that he was in good hands there, so that made it a bit more bearable. [laughs]

Father: [laughs] Yes, it's very strange ... He made it and, and you're finally a complete family but then you have to leave him there so far from home and that hurts, yes. [...] It's like my wife says. You have to choose between the two. You also have a daughter at home and you, you have him in the hospital. So it is a very nice experience to see him and to see him grow. And on the other hand, you have your other child at home. So that is difficult.” (Parents, GA less than 28 weeks, original quote in Dutch)



Unlimited access is not as unlimited as it seems

Interviewed parents of preterm newborns express a very strong desire to be with their infant. IFCDC recognises this important need and wants to facilitate parents in being with their newborn and avoid separation. However, a lot of **organisational and practical obstacles** influence this. In general, parents have unlimited access to neonatal wards to be with their infant. Neonatal care providers consider parents as partners in care delivery and not visitors. However, from the interviews with parents, we learn that although access can theoretically be free and unlimited, in practice parents experience barriers.

Physical infrastructure (e.g. doors, corridors or elevators) can act as a barrier to unlimited access. **Being dependent on others** to gain access or demand access to the neonatal ward is perceived as a strong limitation of access to the infant. The fewer the physical barriers, the more parents feel facilitated.

“Those first days I had to be brought. Then I had to wait for I don't know how long until they asked a nurse to bring me. Then I almost had to beg, “yes, please, someone, someone ten,” because it wasn't even ten minutes, because when they took the lift, they didn't even have to put me in the room because at the door a nurse from the neonatology took over. So it was just me rolling out of the door, from the maternity ward, into the lift and rolling out of the lift. That was it. And then you had to call a couple of times and ask: “Yes, please, when will someone have time?”” (Mother, GA less than 28 weeks, original quote in Dutch)

Interviewees confirm that it helps when their room was nearby the neonatal service. The staff knows each other, communication is facilitated and care seems to be more fluent. The absence of physical barriers or distance seems to soften the fact of not being with the child. Being in another building or on another floor is an additional stressor for mothers.

“I think [H1] did it well with the fact that the maternity ward and the neonatal ward were on the same floor, separated by a door. We had this impression of access, not like at [H2], where I had the impression that I had to go and ask for access to see my child. The fact that it wasn't on the same floor [...] made me feel like I had a

baby who stood out and, a baby apart from me.” (Mother, GA 32 to 37 weeks, original quote in French)

Neonatal staff and hospitals try to offer a wide range of creative solutions to overcome barriers

Some hospitals have a **hotel function** for parents to let them stay overnight. This might be in the ward, in the hospital but external to the ward or even outside (but close to) the hospital. Other hospitals invest in **rooming-in possibilities**, i.e. a room for parents and newborn. Also, here several modalities are possible in terms of duration, location, depending on the medical condition or gestational age of the newborn. Rooming-in at Belgian neonatal wards is usually implemented to prepare discharge, to start breastfeeding, to let parents familiarise themselves with their child and to grow self-confidence.

As nor the hotel function, nor the rooming-in is covered by the hospital payment system, the neonatal staff is obliged to find creative solutions (both practically and financially) to offer them. In some hospitals, the hospital management agrees to offer rooming-in at a very low price or even for free. Others discharge mothers of preterm newborns from the maternity ward to readmit them elsewhere. For newborns who only need a short stay at the neonatal ward, mothers are sometimes kept a few days longer at the maternity ward. However, this last creative solution has to be with the agreement of gynaecologists, because a maternity stay that exceeds 72h, is financially disadvantageous for the hospital.

Some hospitals also try to meet the financial burden that is associated with preterm birth by reducing the costs of rooming-in or parking discounts. Interviewed parents appreciate these concessions a lot.



“Now it's true that we're forward-thinking people too. So we also have hospital insurance that covers everything. And it's true that when we received the bill and we look at the full amount, we said to ourselves 'Fortunately, we have one' [laughs]. But yes, it's true that in terms of fuel and so on, it was perhaps a slightly heavier burden at that time. But next to that, there were perhaps other things that we weren't doing, so there you go, one in the other, it balanced out. As far as the hospital car park was concerned, we were entitled to a special pass which gave us unlimited access to the car park for €3 per day. So it was a big gain. The hospital also sets up things to help parents.” (Mother, GA 32 to 37 weeks, original quote in French)

COVID-19 restrictions had a major influence on accessibility and parental presence

The Coronavirus Disease 2019 (COVID-19) pandemic imposed in some waves severe restrictions which had a **big influence on the accessibility and availability of parents** at the neonatal ward.

For instance, some hospitals did not allow both parents to be present at the same time. This was experienced as very difficult for the parents and felt inhuman. Being alone made it more difficult to cope with the situation and with bad news. Parents who had to alternate said they only became a family when the baby came home. However, this was usually not a common practice but hospital- or wave-dependent.

“And then, gosh I think a week after that or so it was suddenly one hour a day. The day my husband came, I was sitting here at home banging my head against the wall. Your head goes crazy. You want only one thing, and that is to be with your child, but you are not allowed. [...] We really tried to fight it, but it was also a completely unknown situation for the neonatologists at that time, so they panicked a bit. In other NICUs, they were a bit more humane, but in [hospital] it was very extreme. I still blame them for that. But yes, somewhere you know, they didn't know what to do either, but that's something that I also passed on during the evaluation that it wasn't really humane.” (Mother, GA less than 28 weeks, original quote in Dutch)

Although the neonatal staff emphasised unlimited access to the ward, this was not how parents experienced it. There was restricted access at the entrance of the hospital during several waves of the pandemic. Also having to enter the hospital through the emergency department during night hours was also experienced as a barrier, as well as the staff's preference for long visits instead of several short visits. National restrictions such as the evening curfew were also very restrictive as parents could not travel between the hospital and their home during those hours.

4.3.2. Combination of hospital visits and daily life

Combining being at the hospital and daily life is a struggle for parents of preterm infants

Parents of preterm infants find it difficult to keep a balance between life at the hospital and daily life. This struggle is **especially telling among interviewed fathers**. Birth- or paternity leave is much shorter than maternity leave and fathers/co-parents are also not entitled to an extension of the birth leave in case of hospitalisation of a newborn infant. Most of the fathers that we interviewed returned back to work before the preterm infant was discharged from the hospital. This imposes a high degree of work-family imbalance and leads to a juggle of managing the household, caring for siblings and commuting between home and the hospital. It leads to physical and mental exhaustion and prevents them from being involved in daily care for their preterm newborn. At the same time, mothers felt alone in taking care of the newborn. Some interviewed fathers reported several long-term (mental) health consequences after an intensive period of trying to balance work and family life during the hospitalisation of their preterm infant.

“What affected him the most was the fact that he had just his 10 days of paternity leave and then that was that. A huge exhaustion, both mental and physical. Because having to manage to go to work, coming to the neonatal ward, sometimes you realise: 'Unfortunately, I'm so tired today, I can't go and see my daughter.'” (Mother of twins, GA 32 to 37 weeks, original quote in French)



Box 1 – Extension of parental leave in case of hospitalisation of the newborn

Article 39 of the Belgian Labour Act of 16 March 1971 provides an extension of the postnatal leave of the mother if the newborn(s) is (are) hospitalised during more than 7 days after the delivery. The postnatal leave equals the days during which the newborn is hospitalised after those first seven days and it is capped at a maximum of 24 weeks (including extensions). There is no extension for paternity/birth leave in case of hospitalisation.

For more information on parental leaves, see section 2.6 of the [scientific report](#).

Siblings make this struggle even more difficult

Interviewed parents highlight that siblings complicate and decrease the ability of parents to be with their preterm newborn, especially in combination with siblings being denied access to the neonatal ward as an infection control measure during the COVID-19 pandemic. Therefore, they suggest offering childcare solutions for siblings. These solutions can take several forms: e.g. childcare at home, childcare centres or at the hospital. Flemish parents also mention that the **maternity assistance service** (i.e. kraamhulp) **can be useful to support families**, even if the baby is still in the hospital.

Distance between home and hospital

As mentioned earlier, interviewed parents find it difficult to cope with having to leave their infant behind in the hospital (see 4.3.1). The greater the distance between the hospital and home (the greater the travel time), the more difficult it becomes. This distance also has an effect when mothers are discharged (and fathers are not available e.g. due to work), in that case, they have to rely on their network to bring them to the hospital. Sometimes, interviewed mothers who had a caesarean section have the feeling that they had not yet recovered from the delivery and were **discharged too early** from the maternity ward.

4.3.3. Breastfeeding

Feeding decisions and trust in the neonatal staff to respect parents' decision

The motivation to breastfeed is very high among mothers of preterm babies. Their motivation stems from their desire to give their baby the best feeding option, but also from feeling guilty about delivering prematurely.

Being able to trust the neonatal staff is an important element for parents as they are not continuously with their baby. Trust is especially threatened when parents feel that the neonatal staff disagrees with their decisions. Parents lose their trust if the neonatal staff does not respect their choice or makes decisions in their place. Some interviewees feel not at all supported in their decision to breastfeed and said they have to fight to make breastfeeding work. According to the interviewed parents, it is appreciated if neonatal care providers avoid giving pressure to breastfeed and respect the mothers' decision not to breastfeed or stop breastfeeding. Also, the way to administer milk (e.g. bottle, probe) is subject of discussions between parents and staff about what to prioritise, the rhythm of the baby or teaching the baby to drink.

Neonatal wards facilitate breastfeeding as much as possible

Neonatal wards try to facilitate breastfeeding as much as possible by providing privacy (e.g. availability of breastfeeding rooms, screens), the necessary equipment for milk expression and neonatal staff and/or lactation consultants for support. This support takes different forms such as counselling, ways to use the breast milk when the baby cannot yet suckle (e.g. use of breast milk for baby care or use of devices to learn suckling), or the support of speech therapists.

Stopping breastfeeding is a difficult decision

The transition from breastfeeding to formula is mainly motivated by the physical and/or emotional exhaustion of the mothers. The support of a lactation consultant helps mothers to make this transition. Some mothers report that they were unable to decide to stop breastfeeding. They needed



the approval of their partner or care providers to allow themselves to stop breastfeeding.

Factors impairing breastfeeding

Several factors were identified that impair breastfeeding of a preterm baby.

First, mothers experience the breastfeeding of their preterm infant as **not natural because of the mechanical milk extraction** with a pump. Mothers feel that they miss the beautiful aspects of breastfeeding such as the contact with the baby, watching the baby drink or bonding with the baby. Besides the mechanical dimension, the lack of solicitation of the baby to be breastfed induces an artificial rhythm. Second, **lack of privacy** also influences the success of breastfeeding. Especially open bay wards or shared rooms created a strong sense of discomfort and lack of privacy during breastfeeding or milk expression (e.g. due to the presence of other babies' fathers or other family members).

In addition, **care in the maternity ward is not always adapted to the needs of mothers with a preterm baby**. For example, if lactation counselling is offered in the maternity ward while the mother rather wanted to be in the neonatal ward with her infant. If the maternity ward and neonatal service are at a distance from each other, it becomes even more difficult to walk back and forth between the two, especially when just given birth. Once the mother is discharged from the hospital, they have to manage the milk expression, milk storage and milk transportation from home to the hospital, which brings a lot of logistical problems.

Last, during breastfeeding education and counselling neonatal care providers **create great expectations for the mother regarding breastfeeding**. The dominant narrative emphasises that breastfeeding is the best feeding option, especially for preterm babies as it increases their chances of survival. This seems to put a lot of pressure on mothers' shoulders. When breastfeeding does not work out well, mothers experienced a sense of failure, guilt and frustration. In addition, contradictory information of different professionals is very confusing for mothers who are already anxious and distressed about the prematurity of their baby.

4.4. Healthcare staff, time and education

4.4.1. Neonatal staff tries as much as possible to implement IFCDC principles, with the resources available

Interviewed parents perceive the **availability and support of the neonatal staff as impressive**. Neonatal staff is available to answer questions day and night, even after discharge. According to parents, this major availability allows the building of relationships on trust, which is self-reinforcing as it facilitates parents to ask questions without fear of being judged. Neonatal staff and parents become partners in care and gradually parents' autonomy grows. Parents differentiate between neonatal care providers based on familiarity. Not with all members of the staff, an equally strong relationship can be built.

Parents appreciate small gestures and flexibility of staff very much

During their stay at the maternity ward, mothers strongly **appreciate the flexibility of the maternity staff**. Mothers mention that maternity staff came over to the neonatal service to care for the mother (e.g. administer medication). If this flexibility is lacking, mothers feel pressured to be in their room at the maternity ward when staff passes by. This also accounts for other services such as physiotherapy and visits of ONE – Opgroeien. If the mothers are not there, they miss out the service, treatment or dose and/or in extremis are reproached for not being in their room.

"We actually made our own schedule during those six days. That was our schedule and the nurses who came to take my blood pressure even went from the maternity ward to neonatology to take my blood pressure there. So it was actually very flexible." (Mother, GA 28 to 31 weeks, original quote in Dutch)



4.4.2. *Sufficient number of staff is a conditio sine qua non for IFCDC implementation*

Current insufficient staffing leads to a schizophrenic situation

The interviewed neonatal care providers highlight that providing **IFCDC takes additional time**. Neonatal care providers evaluate the current situation as “schizophrenic”. On the one hand the importance of IFCDC is recognised, trainings are followed, awareness is created, but on the other hand **staffing levels remain insufficient**. Staff may be educated to provide IFCDC, adequate infrastructure can be foreseen, but if staffing levels are insufficient, it is all in vain.

Although most neonatal care providers seem to be convinced about the benefits of IFCDC and are willing to invest time and energy in adhering to its principles, the **actual implementation depends on the workload**. If the workload is too high in relation to the available staff, IFCDC moves to the background. Neonatal care providers try to maximise IFCDC with available means. A lot of flexibility, creativity and a high level of bricolage is reported by the neonatal care providers who participated in our focus groups. With bricolage, IFCDC is brought in accordance with the available means, such as staffing and infrastructure.

“We didn't talk about it, but I am not expert about it, but the whole “supporting” side of by the management and, above all, by the Ministry of Health. Because all of this need better funding in terms of staff, to have multidisciplinary teams that are really focused on developmental care, that requires a lot of money. It would help. And so each of us tries to do the best we can with what we have. We are all tinkering with our teams to try to optimise everything, but it's clear that the funding is really not there.” (Physician, N, original quote in French)*

This creates **frustration** among neonatal care providers. They feel like they cannot do their job properly and that quality of care is compromised. Also, sometimes support groups or workshops for parents and siblings cannot be organised, mothers and infants are separated after birth and trainings cannot be followed or must be postponed.

Reasons for understaffing

Interviewed neonatal care providers gave multiple reasons for the current understaffing. First, there seems to be a systemic lack of staff because of **outdated staffing norms**. These staffing norms were established at a time when there was not any IFCDC provision, making them no longer adequate. Neonatal care providers stress the urgent need for a new staffing norm taking into account quality of care standards, including IFCDC.

“The standard was issued in 1996. The Royal Decree of 1996 describes neonatal care. At the time there was no four-handed care, to apply family-centred care, among other things, to involve parents as much as possible. It is not because parents are primary care providers that you can lower your staffing standards. On the contrary. So I think that there is still, that it is quicker to wash the child yourself than to give guidance to the parents to care for them. And I think the new care insights around NIDCAP and so on actually require a different standard.” (Nurse/midwife, NICU, original quote in Dutch)

Furthermore, the shortage of staff is exacerbated by **lengthy absences** (e.g. sickness leave, maternity leave) not being replaced. Hence neonatal wards have to remain operational with fewer staff.

In addition to understaffing, neonatal wards are also very much subjected to **fluctuating workload**. Some services have no babies at all while at other times there are more than ten hospitalised. This seems to be especially problematic for (small) N* services. During our focus groups, neonatal care providers mentioned several ways to cope with the fluctuating number of admitted newborns and care intensity. At quiet moments some hospitals ask staff to go home and return if the workload increases. They have to absorb overtime or take up leave. In other hospitals, the staff is transferred to other services. This demands a lot of flexibility from the neonatal staff.



“It really varies, usually around six to eight premature babies, there are a few outliers of more than ten, but there are also days when there are only three babies. [...] But there is also an expectation that my colleagues should be extremely flexible, so if there are only three babies, for example, they have to go home. If there are suddenly admissions, they have to return. I find it difficult to expect so much flexibility from my colleagues.” (Nurse/midwife, N, original quote in Dutch)*

At peak times, additional staff on standby can be called upon or staff from less busy services are requested to help out. To enable the switching of staff between services, hospital-wide monitoring systems are put in place. If assistance is needed for several days, hospitals dispose of a mobile team that can be asked to join the neonatal staff until the workload decreases. The mobile team however does not necessarily have the same skills and routines, which may limit their contribution. A final option is to call on volunteers, mostly consisting of retired staff.

Workload measurement

To objectify insufficient staffing levels, services can perform **workload measurements**. This is usually not done systematically, but randomly during a limited time period. Some neonatal care providers use workload measurement to convince hospital management that more staff is needed and demonstrate that the number of admitted babies is not an accurate proxy for the workload. The workload is mostly determined by the intensity of care the newborns need.

“[...] they are looking with a magnifying glass. What are they doing there? And it's not the number of children they have to count. [...] They have to look at the care load. We can have more work with six children than with ten children who are stable and doing well.” (Nurse/midwife, N, original quote in Dutch)*

Leadership engagement

In addition to staffing standards and related funding, the hospital management has some manoeuvring space to allocate support to neonatal wards. The degree of leadership engagement, or the alignment and spirit of partnership between clinical professionals and administrators within a hospital, differs between hospitals. Some interviewed neonatal care providers could convince the management of their hospital of the importance of having sufficient neonatal staff, others report a daily battle with hospital management about staffing levels.

“We also have some nurses who are NIDCAP certified, but again, as we are understaffed in terms of nursing, it's sometimes complicated to be able to detach these nurses from the care, to have really daily NIDCAP assessments. So they can do it from time to time, but unfortunately not regularly enough in our opinion, but it's really a question of nursing staff. And it's a permanent battle with the management.” (Physician, NICU, original quote in French)

The support of hospital management is especially relevant in function of investment in staffing and infrastructure. Interviewed neonatal care providers mention that low care neonatal wards (such as N* wards) are not profitable for a hospital but are rather loss-making. In this respect, hospital financing has an unintended consequence for neonatal wards (see 4.4.3). Hospitals have to invest their own means to implement IFCDC, without being compensated for that via the hospital payment system



4.4.3. Impact of financing on IFCDC implementation

Unintended consequences of neonatal wards financing hampers IFCDC implementation

The neonatal care providers we interviewed mention several unintended negative consequences of the current financing of neonatal wards on IFCDC implementation: e.g. financing of N* based on the number of deliveries in the maternity ward, intrauterine referrals (although good practice) are disadvantageous for N* financing, fewer technical acts on N* wards, fewer back referrals to N* when NIC occupancy is low, etc. These unintended consequences are mainly pronounced in the context of insufficient financing of the N* wards.

“They expect family-oriented support and NIDCAP in N wards, that they go along with that story, but they don't get the resources like a NIC ward gets, that's double standards of course.”*
(Nurse/midwife, N*, original quote in Dutch)

This lack of financing resources has multiple consequences. For instance, **insufficient financial means hamper IFCDC trainings for N* staff members**. In addition, interviewed neonatal care providers highlight **insufficient staffing levels to carry out IFCDC**, as this is more time-consuming than standard care. This situation leads to frustration because of staff shortage, they cannot permanently offer care according to the IFCDC principles they were taught and which are expected by (back-)referring neonatal wards.

A profound redesign of the neonatal landscape is needed to further develop IFCDC

Interviewed neonatal care providers highlight the **need for a profound redesign of the neonatal landscape** to enable all neonatal wards to implement and develop IFCDC. To this end, a reform of the hospital financing for N* services needs revision, the admission criteria of every neonatal service should be explicit, transparent and subscribe in a national reprogramming of neonatal care services. In addition, referrals and back referrals should not impact hospital financing, nor physicians' remuneration, to get a correct attribution of infants to the most adequate level of care.

“But that requires a complete redesign of the perinatal landscape, which also requires a rethinking of the financing of medicine or perinatal medicine, so that referral patterns do not impact doctors' incomes or hospitals' incomes, but that, on the contrary, they are rewarded when they correctly refer patients to the services where they are needed. So I think it comes down to a redistribution of financial and human resources rather than an expansion of financial and human resources.” (Physician, NICU, original quote in Dutch)

4.4.4. Impact of the COVID-19 pandemic

The **COVID-19 pandemic has put IFCDC under pressure**. Principles such as non-separation, involvement of the whole family, including siblings, are difficult to reconcile with all precaution measures. Nevertheless, neonatal care providers observed also some positive consequences of the COVID-19 restrictions: parents are more focussed on the baby, have more time to spend with the baby, breastfeeding goes more smoothly, and parents, babies and staff are more relax. These unanticipated positive consequences incite a rethinking of the wards policy towards visitors.

Despite a decreased number of admissions during COVID-19 waves, neonatal care providers report a higher workload. Wards have to function with fewer staff because part of the staff was claimed to work at COVID-19 wards. In addition, staff has to be exempted from the care of infected infants. Precautions such as protective clothing and adapted workflows also increase the workload.

Other reported difficulties caused by the COVID-19 pandemic are staff feeling unsafe because of too many parents in one room, lack of interpreters hampering communication with foreign parents, the cancellations of efforts to involve siblings and trainings and the impact of face masks and other protective clothing on infants.



4.4.5. Education of staff

One of the other consequences of staff shortages is the **difficulty to free staff for trainings**. Interviewed neonatal care providers report cancelled trainings because of high workload. Nonetheless, trainings are said to be crucial as the stock of knowledge relative to neonatal care is evolving rapidly. Furthermore, **trainings in IFCDC (e.g. FINE, NIDCAP) are expensive and time-consuming** and demand a big investment of hospitals and staff. Finally, **only training one staff member is not sufficient**, because putting IFCDC in practice demands a drastic change in work attitude and processes. One trained professional has not the power to evoke this change.

The importance of IFCDC education cannot be underestimated. Several neonatal care providers witnessed that **IFCDC education has the potential to induce a service-wide change in approach**: a change in staffs' attitude towards IFCDC, a change in workflow and a revision of work processes.

"I think it's a mentality change that is happening within the team itself. I think that a couple of years ago, we as a team were perhaps very reluctant to engage in developmental care, [...] it's going to cause us more work and I don't know what else. But of course, with the FINE, where there are actually several reference nurses and they pull the team more, we see a nice evolution in that, so yes, persistence in the team grows, that takes time and that is very positive, the way it has now evolved actually. That's good to see because we have really grown as a team." (Nurse/midwife, N, original quote in Dutch)*

Some services take the initiative to share their knowledge and skills regarding IFCDC by organising the trainings for their own staff or from neighbouring hospitals. This kind of initiatives aims, for example, at streamlining the way of working across neonatal wards. In the case of referrals and back-referrals between services, it is beneficial for parents and newborns if services share the same work processes.

4.5. Technology based support

Multimedia tools (e.g. webcams or applications) are sometimes used in neonatal wards to ease the pain caused by the separation of the preterm newborn infant from his/her family. Parents are **positive** towards these tools; however, they are **not the ideal substitute** for being physically present with their infant. These tools can mainly provide relief in certain specific circumstances (e.g. during COVID-19 restrictions, unavailability to care for siblings or due to work, remote breastmilk pumping). Remote contact can also be useful for siblings or other family members to be able to see the newborn.

According to the neonatal care providers, online applications should remain an **additional facility**, not a replacement of physical presence. Although neonatal care providers report positive experiences multimedia tools, most of them were discontinued after a while, because of financial reasons.

"We don't have cameras because of the same obstacles. Mainly financial. [...] But we did participate in a project [...] about the NeoParent App that allows parents to communicate with the nurses, to upload photos that they can look at home when they can't be with their baby, can share with whomever they want, has a diary, contains a lot of information. [...] It is not the same as having a camera on-site, but that's part of the solution to keep in contact with the family when the parents cannot physically be at the ward. And we've actually had pretty good experiences with that." (Physician, NICU, original quote in Dutch)



4.6. Shared decision making

Parental involvement in care and decision-making is important for both parents and neonatal staff

According to the IFCDC principles, the whole family should be involved in taking care of the newborn. There is a broad willingness to broaden this involvement to the extended family among the neonatal care providers we interviewed (e.g. involving grandparents). However, this is currently mostly limited to intentions for the future as it is **not yet universally implemented** to the same extent.

The continuous invitation for parental involvement, makes parents feel useful and facilitates the development of their parenting role. Parents, especially at the start, may feel uncomfortable, redundant, or not in place.

Additionally, neonatal wards are also trying **to include parental perspective in the care policy of the ward**. This is done by involving parents and questioning their experiences via for instance surveys, focus groups, parental advisory boards or feedback during follow-up consultations).

“We have set up a parent advisory board for this purpose. These are parents of former preterm babies who are discharged from neonatology and provide us with their experiences to change or improve the way parents can be supported. We do get a fair amount of feedback from them. How it could be more pleasant for parents to stay in our ward.” (Physician, NICU)

Complete transparency of information towards parents

Communication and transparency of information facilitate IFCDC, in a sense that they are preconditions for parental involvement. Information transfer is organised in different ways and at different levels, depending on the way a neonatal service is organised and on the parents' wishes. For instance, parents report being invited by the neonatologist to attend medical staff meetings to be informed and to ask questions. Calling parents not by their name but rather 'mother/father of baby X' is a remarkable example of how parents experienced the staff's discourse as very stimulating. However, parental participation in medical meetings is not yet the case everywhere.

4.7. Transition periods

IFCDC requires special attention during transitions between wards, hospitals and discharge home to avoid undermining IFCDC implementation.

Contradicting information or attitudes of care providers do not always support IFCDC principles

The parents that we interviewed report **variability in the supportive and encouraging attitude of the neonatal staff**. In other words, not all neonatal staff is supportive to the same degree. Some parents sometimes get the feeling that some neonatal staff members preferred doing care tasks themselves due to time constraints.

In addition, interviewed parents also notice variation in the way neonatal care providers execute care tasks, which increases doubts and uncertainty. Also, variation in attentiveness between neonatal staff is mentioned (e.g. the intensity of observations).

“What was sometimes not so obvious was that there were many, many different people walking around there who also have different ways of doing things. So then, person A explains something to you, and then person B does it differently. And I found that quite difficult, I wanted to do it all very well. And then suddenly it's, yes but, wait. One person did it like that, and another like that and then I didn't know anymore. And that caused some awkward moments. But if you look at it from a distance, you think: okay, well, the big picture is the same, and there are just some differences in emphasis. But at the time, I couldn't see that clearly, and so it sometimes led to some uncertainty.” (Mother of twins, GA 28 to 31 weeks, original quote in Dutch)

Some mothers of preterm infants who were hospitalised at the maternity ward observed a different attitude or expectations of maternity staff in comparison to neonatal staff. This manifested itself in less attention, long waiting times, fewer questions about the newborn infants' condition, pressure to be in the maternity room instead of the neonatal ward, etc. They have the feeling that their identity as a mother was not always acknowledged as if the absence of a baby in the room made their transition to motherhood incomplete. The interviewed mothers, therefore, mentioned that an



individual room or couplet care room (both mother and preterm infant are hospitalised in the same room) could meet his different attitude or expectations.

Last, **hospital routines** or the way care was organised has potentially a discouraging impact on parents (e.g. when imaging occurred before the appointed time in absence of the parents). In addition, IFCDC is not developed to the same extent in every hospital. In case of a transfer, parents have to get used to a different approach towards parental involvement.

“So, then, we already gave a bath once in [hospital], of course. But then we had to do it again in [hospital], but it's all different and so on. So you actually did it yourself, when you were there, they took everything out of your hands.” (Mother, GA 32 to 37 weeks, original quote in Dutch)

*“**Mother:** Then [first name] also had to have an ultrasound taken from his head. They said that tomorrow we would have to take an ultrasound of his head. And I asked, can I be there? Yes yes yes, of course. It will be around two o'clock. I was there at two o'clock, I saw [first name] and I already saw that he had this gel on his head, so I asked, what is this gel? Ah yes, the ultrasound has already been done. Then I thought: ok, yes, good. That's not it, that was it. Why?*

*“**Father:** That was just not nice because you made an agreement with someone the day before.*

*“**Mother:** Yes. That, I thought that was agreed, but it wasn't.” (Parents, GA 32 to 37 weeks, original quote in Dutch)*

Preparation of the baby's discharge increases parents' autonomy

Some hospitals offer also **rooming-in possibilities** for parents of preterm newborns, mainly to prepare discharge. Preparation of the newborn infant's discharge by rooming-in for one or a couple of nights enables parents to care for their infant autonomously. However, as mentioned earlier, these rooming-in possibilities are not universally applied as they are subject to several limitations (e.g. lack of space and financing).

“And what does the hospital do, what do they offer? That is a rooming-in and that is actually the day before you can go home, you are welcome from four o'clock in the afternoon. And then you stay in the room with your baby for the first time. So then you get a room. They leave you alone, so they don't actually come to help. But they are there if anything should happen. And that is, actually getting to know them that first night before you go home. And that gives you a sense of security. I think that we would have been much more insecure if we hadn't had that.” (Mother of twins, GA 32 to 37 weeks, original quote in Dutch)

Interviewed parents also mention follow-up at home, help to organise follow-up at home, courses in resuscitation or the use of equipment needed to monitor the baby at home. Parents state that these efforts make a big difference. They feel more at ease to go home and care themselves for their child. Also, neonatal staff emphasises being reachable by phone at any time, even after discharge. A lot of parents make use of this kind of “hotline”.



5. INTERNATIONAL IFCDC BEST PRACTICES

Four international best practices in IFCDC were described based on information gathered through semi-structured interviews with key informants. These European best practices were: (i) Karolinska University Hospital (Stockholm, Sweden), (ii) Sophia's Children Hospital (Rotterdam, Netherlands), (iii) Centre Hospitalier de Valenciennes (Valenciennes, France) and (iv) Hospital Universitario 12 de Octubre (Madrid, Spain).

5.1. Facilitators to provide IFCDC in international best practices

Different levels of neonatal care

Neonatal care in the countries that we included in the mapping of the international best practices is organised into different levels of care. These different levels of care can be summarised as follows: basic care (level I), specialty care (level II) and subspecialty intensive care (level III and/or IV).

IFCDC is generally supported by both staff and management

Although IFCDC is not formally regulated by national or regional legal documents in the four studied countries, all four best practices are characterised by the fact that IFCDC philosophy of care is generally shared and supported by most staff and management members. The best practices usually have a written hospital-wide mission statement laying down the principles of care for hospitalised children and their families, such as the "Philosophie des soins – Charte du service sur le soutien apporté aux familles" of the Centre Hospitalier de Valenciennes.

24/7 accessibility

A common point in all four best practices is the 24/7 accessibility to the ward to parents. There are no restrictions to visiting hours or the number of visits. Access codes or badges are provided to parents to be able to access their newborn infant autonomously. In all described best practices, unrestricted access is also extended to siblings. Some best practices also promote accessibility by offering free parking tickets or discounts to parents with hospitalised children (Centre Hospitalier de Valenciennes offers free parking, while Hospital 12 de Octubre offers a 20-30% discount).

Architecture

Sufficient space is an important facilitator to provide IFCDC. All studied neonatal best practices have undergone recent renovations to diminish barriers to parental presence. For example, it is important to have at least enough room to have at least a comfortable armchair where parents can provide kangaroo care and, if needed, spend the night. All centres have spaces that allow parents' accommodation within the ward or in its vicinities and make their stay more comfortable (for instance, shared family rooms, Ronald McDonald houses^e or parental lounge rooms).

Support for both parents and siblings

Special attention is given to the well-being of the siblings in all the best practices that we studied. The interventions targeted to siblings' wellbeing include the availability of psychological support, adapted involvement during their visits and parent-oriented interventions to support the care for other children. Examples of this support are the babysitting service provided by the local authorities in Valenciennes and the volunteer's work in the Sophia's Children Hospital and the Centre Hospitalier de Valenciennes in which activities for siblings of hospitalised children is organised.

^e The foundation is part of the international organisation Ronald McDonald House Charities. In many Ronald McDonald houses additional resources are also available: such as accredited education programs, recreational activities,

non-clinical support services such as children's art therapy and music programs or sibling support services. There is also a Ronald McDonald house in Belgium: <https://www.kinderfonds.be/nl>.



In addition, parents are guided through the stay of their hospitalised preterm newborn by appointed developmental care referents. In all best practices parents are encouraged to participate in care, to be present during procedures and to participate in clinical rounds. Furthermore, various strategies of parental support are implemented: such as support of social work, psychologists and peer-to-peer support. For instance, in all best practices, social workers and psychologists are attached to the ward to support parents (sometimes shared with the paediatric ward). In Sophia's Children Hospital, these psychologists even provide support to medical and nursing staff by for example organising debriefing sessions.

Information provision and transition to home support

All centres offer pregnant women with a high-risk pregnancy a meeting with the neonatal team and, if possible, a visit to the neonatal ward before the delivery. Information about the transition to home is incorporated in routine care in all centres, sometimes pre-discharge rooms are available to pilot the families' autonomy before discharge. In the Karolinska University Hospital, part of the neonatal beds is home care beds, in which newborn infants are cared for in their home environment. Although there are no formal fixed eligibility criteria, these newborn infants should be stable in terms of cardio-respiratory and thermal parameters and do not need 24/7 observation. Home care is provided by experienced neonatal nurses, who perform 2-3 times home visits per week. Babies needing a higher level of care (e.g. still needing oxygen) may be cared for in advanced home care, with check-ups scheduled more often and nurses and medical staff that are available 24/7. In Sophia's Children Hospital (and in general in the Netherlands) there is a developmental care programme for very preterm babies: "Transmural developmental support for very preterm infants and their parents" and is known as the TOP programme (informally called "NIDCAP at home"). In this programme, paediatric physiotherapists support and coach parents in their interaction with children up to one year of age.

Sufficient parental leave

Parental leave is an important facilitator for parental presence during the newborn infant's hospitalisation, according to the key informants of the studied best practices. There is a wide variance in maternity leave across the countries that we studied (ranging from 16 weeks in France and Spain until approximately 69 weeks in Sweden). However, maternity leave is in almost all studied countries significantly higher than the co-parents' leave (ranging from 5 days in the Netherlands to 5 weeks in Spain). The only exception is Sweden, in which parental leave (i.e. leave for both mother and co-parent) is quite high and consists of 480 days. Parental leave in Sweden can be taken by either one of the parents, but 90 days are reserved for each parent. The extent of this parental leave for both parents in Sweden makes it particularly easy for parents to be with their hospitalised newborn infant.

In most studied countries, there is the possibility to take unpaid parental leave for several years (a maximum is usually set). France, Spain and the Netherlands are in the process of extending paternity or co-parent leave or have recently extended it. For instance, bills are going to be reinforced in 2022 to extend maternity and paternity leave to 9 weeks of paid leave in the Netherlands and paternity leave to 16 weeks in Spain.

5.2. Barriers to provide IFCDC in international best practices

The main barrier for the implementation of couplet care are architectural constraints

Couplet care is difficult to implement as it requires close collaboration between the neonatal and the maternity ward. For this reason, not all best practices offer it. The main reason for this limitation is usually architectural barriers: such as lack of space, unavailability of shared couplet rooms or the neonatal and maternity ward are not physically adjacent. However, the centres try to meet this limitation as much as possible, sometimes in a creative way. For instance, the neonatal ward in Centre Hospitalier de Valenciennes has no shared parent-infant rooms. One of the strategies for enabling the parents' presence is to extend the mother's hospitalisation as long as possible. The maximum allowed length of postpartum hospitalisation is in France 21 days for mothers who delivered by caesarean section and 11 days for mothers who delivered by vaginal delivery. However, there is an



arrangement with the obstetrics ward to prolong hospitalisation of mothers of babies hospitalised in the neonatal ward as much as it is allowed. Those hospitalisation stays are ultimately not cost-effective for the maternity ward, but the maternity ward aims to counterbalance it by having shorter stays for healthy mothers and babies when possible.

Implementation of NIDCAP is limited by available resources

All four best practices we studied implement NIDCAP, but the routine use depends on the availability of resources. Training neonatal staff in NIDCAP is a big commitment in terms of its cost and length of the training and is, therefore, less frequently applied. Usually a big proportion of the neonatal care providers are educated in the IFCDC principles. Neonatal care providers in the best practices see it as their duty to be well trained in the IFCDC. To meet financial constraints, in most best practices, less intensive developmental training programs are also offered to staff via FINE tier 1 and 2. In some best practices, these FINE training programs are even offered to staff that does not belong directly to the neonatal care team (such as radiologists or obstetricians).

6. TOWARDS ADEQUATE IFCDC IMPLEMENTATION IN BELGIAN NEONATAL CARE

This project has focused on the implementation of IFCDC for premature newborns. However, it is important to note that IFCDC implementation in neonatology should not be limited to this target group only, but can be extended to all neonates hospitalised in this ward. Based on the results of this study, we identified six focal points concerning IFCDC implementation in Belgian neonatal care services.

6.1. Separation of the preterm newborn infant from his/her family can have long-term consequences and must be avoided as much as possible

Separation early in life between newborns and parents can have a significant impact on the child's development later in life.¹⁻³ Babies are biologically programmed to look for the physical proximity of an adult that responds to the baby's need for protection. However, the quality of his/her attachment varies according to the responses of the environment. Therefore, it is imperative that these responses are adequate, leading to the ability of the baby to use attachment as a safe and secure base.^{4, 5} But the concept of attachment is not a one-way street: it is a reciprocal motivation between the child and its parents. By expressing their attachment needs, babies stimulate their parents to offer them closeness, tenderness and comfort. Therefore, one of the best ways to support both parenting and the development of the newborn is to minimise the separation between the newborn and his/her parents at birth and promote the quality of the parental response. These issues are particularly crucial for preterm babies, who often must stay in hospital - sometimes for several months - while their mothers can go home. The importance of non-separation is also been illustrated in several international charters and standards.¹²⁻¹⁴

Many hospitals focus on IFCDC implementation as a means to avoid separation of the parent-newborn dyad and increase parent-newborn attachment and bonding. However, this is still far from being systematically



offered across Belgian hospitals. The current COVID-19 pandemic and previous precautionary measures also affected accessibility of neonatal wards and parental presence. These precautionary measures sometimes felt inhuman and had a big impact on the parents. GLANCE (the global initiative of EFCNI) developed in this respect a long-term campaign: “Zero separation. Together for better care! Keep preterm and sick babies close to their parents”.¹⁵ The campaign’s goal is to raise awareness for the benefits of zero separation of preterm and sick babies and their parents in NICU in times of COVID-19-precautions. However, the non-separation measures should take into account the bearing capacity of parents. Although parents are generally very eager to be with their child as much as possible, the ‘as much as possible’ varies between parents. This nuance emerged from the focus groups with neonatal staff, but not from the interviews with parents. This might be explained by a social desirability bias in parents’ responses, or a biased sample underrepresenting parents who faced barriers that withheld them from being with their child. In addition, multimedia tools or applications can be used to ease the pain caused by the separation in certain circumstances (for instance during COVID-19 restrictions, unavailability of parents because of work or siblings). Important to keep in mind is that these multimedia tools should mainly remain an additional facility as they are not the ideal substitute for being physically present.

Paternal leave can have an influence on the availability of the parents during the hospitalisation of preterm newborns, leading to early separation. Mothers are entitled to at least nine weeks of compulsory postnatal leave or maternity rest in Belgium. In case the newborn is hospitalised longer than seven days, mothers receive an extension of the postnatal leave (equalling the days of hospitalisation, capped at a maximum of 24 weeks). In addition, fathers or co-parents are currently entitled to 15 days of paternity or birth leave (this will be increased to 20 days from 1 January 2023). There is no extension of the paternity or birth leave in case of hospitalisation of the newborn.

6.2. Adequate IFCDC implementation cannot rely on isolated interventions, but requires a comprehensive integrated action plan

The majority of the Belgian neonatal care providers are aware and convinced of the importance of IFCDC and its principles and try everything in their power and with the available resources to provide it to all parents and family members of preterm newborns in Belgian neonatal care. Yet, neonatal care providers call the current situation and organisation of neonatal care “schizophrenic”: on the one hand staff can follow IFCDC-based trainings, while on the other hand, it is not possible to implement IFCDC systematically and universally in everyday practice.

In this context, interviewed neonatal care providers also highlighted the issue of the current organisation and financing of neonatal wards. There are several unintended consequences of this financing that hampers IFCDC implementation: e.g. financing of N* based on the number of deliveries in the maternity ward, intrauterine referrals (although good practice) are disadvantageous for N* financing, few technical acts on N* wards, fewer back referrals to N* when NIC occupancy is low, etc. These unintended consequences lead to insufficiently efficient use of financial means, insufficient staffing levels to carry out IFCDC and insufficient means to allow staff to follow IFCDC trainings. Therefore, during the focus groups, reference was made several times to the need for a profound redesign of the Belgian neonatal landscape including long-term planning to enable all neonatal services to systematically implement and develop IFCDC. However, this reform of neonatal care should ideally be embedded in a comprehensive vision on the perinatal organisation taking into account previous recommendations from other KCE reports (e.g. KCE report 323 on organisation of maternity care in Belgium).



6.3. IFCDC implementation requires sufficient staffing levels

Implementation IFCDC in daily care for preterm newborns and their families takes more time than standard care. However, in order to spend sufficient time, sufficient staff is required. Neonatal care providers mentioned that this is a real bottleneck in the current organisation of neonatal care, mainly due to some consequences of the financing of neonatal services. We have already dealt with these consequences briefly in 6.2.

Neonatal care providers try to implement IFCDC principles as much as possible with the available resources. Nevertheless, the actual implementation of IFCDC depends on the workload. If the workload is too high in relation to the available staff, IFCDC moves to the background. This creates frustration among neonatal care providers, they have the feeling they cannot do their job properly and that quality of care is compromised. Understaffing also leads to the fact that few neonatal care providers can be freed for IFCDC training. In this respect, interviewed neonatal care providers also referred to the importance of leadership engagement of the hospital management.

6.4. Outdated infrastructure or architecture undermines IFCDC implementation

The design of neonatal wards should accommodate the central role that families take in the care and enable individualisation of the environment for each newborn.²⁷ Several standards recommend the availability of single-family and couplet care rooms, family support spaces (e.g. lounge area and family education areas) and transition rooms (i.e. intermediate space between highly medicalised NICU environment and discharge). In addition, the infrastructure should also provide adequate stimuli in the sensory environment of newborn infants (e.g. adjustments of the care environment in terms of light and sound), families and staff and meet personal, professional and administrative needs of the staff by installing staff-support spaces.

However, the current infrastructure and architecture of neonatal wards are often inadequate for IFCDC implementation, mainly due to a lack of space. Especially rooming-in possibilities for parents of preterm newborns hospitalised at neonatal wards is limited to this lack of space and comfort. There is a big scarcity of individual rooms, leading to the fact that staff members have to decide who benefits most from an individual room. In addition, the lack of comfort in neonatal facilities is sometimes very high: for instance, lack of privacy, sanitary facilities, family rooms to rewind or to see siblings, etc. This lack of comfort hinders parental presence in the neonatal ward. The existing infrastructure cannot keep up the pace of evolutions in neonatal care. Changing infrastructure takes time, while new evolutions in neonatal care follow each other in rapid succession.

Furthermore, parents of preterm newborns highlighted that although access can theoretically be free and unlimited, in practice parents experience organisational and practical barriers: such as doors that are locked, elevators, being dependent on others to gain or ask access, distance between maternity ward and neonatal ward, etc.

It is important to highlight that hospitals and neonatal care providers try to offer a wide range of creative solutions to overcome barriers (e.g. offering a hotel function) and these are appreciated by the parents. However, these solutions are usually isolated to specific situations and on their own initiative. They are not a systematic universal approach, because they usually clash with the current hospital organisation and financing.



6.5. Parents of preterm newborn infants must be able to rely on sufficient support during hospitalisation of the newborn and beyond

The hospitalisation of a preterm newborn infant brings much uncertainty and stress to the family. This translates into an increased need for psychosocial and instrumental support. In general, parents of preterm newborns are really impressed and appreciate the availability and support of neonatal care providers. They are very available to answer questions (day and night, even after discharge), repeat information or translate it to lay language. Although, some points of attention were mentioned during the interviews with parents.

Usually, the parents understand the limited framework in which neonatal care providers currently work. It is important to note that, given this current limited framework, parents really appreciate the small gestures and flexibility of the neonatal staff. For instance, acknowledge mothers in their role by asking questions about their newborn baby, even if he/she is not present in her room or offer care to the mother in the neonatal ward to allow non-separation between the newborn and her/his mother.

Nevertheless, the impressive availability and support of the neonatal care providers are not always sufficient to meet all needs of parents. Several neonatal wards offer psychological care to parents of preterm newborns. However, these psychologists are usually not attributed full-time to the neonatal ward and are only available during office hours, which means they are not always available when needed. In addition, some peer-to-peer interventions between parents of preterm newborns have been suspended due to the COVID-19 pandemic. It is important for parents to continue to engage in this peer-to-peer support because friends and family cannot always understand where they are going through, it is not a lived experience for them. Peers are going (or went) through the same experience, which makes it more tangible and understandable. Several parents we interviewed developed close friendships and stayed in contact with peers, even after hospitalisation.

Family and friends are also important providers of practical support (e.g. preparation of meals, picking siblings from school). However, this is not always sufficient (especially during long hospitalisation periods) and is more difficult for parents who do not have a broad support network. Siblings

complicate and decrease the ability of parents to be with their preterm newborn, especially in combination with siblings being denied access to the neonatal ward as an infection control measure during the COVID-19 pandemic. Interviewed parents suggest offering childcare solutions for siblings (e.g. childcare at home, childcare centres or at the hospital). Flemish parents mentioned they received much help from the maternity assistance service (i.e. kraamhulp), but this is usually limited in time and duration, so it is not always sufficient.

6.6. IFCDC implementation requires additional attention during transfer moments

Parents sometimes experience a difference in information dissemination or attitudes between neonatal care providers, neonatal wards, or hospitals due to number of staff or organisational limitations. The information or attitudes do not always support IFCDC principles, making it difficult for parents to know what is expected from them. This difference was mainly mentioned when the preterm newborn was transferred between different levels of neonatal care or different hospitals. For instance, most parents had the feeling that they were well supported when the baby was hospitalised in NICU (because usually there was an adequate number of staff to take sufficient time to support breastfeeding, skin-to-skin contact, be available for questions, etc). However, they had the feeling this was less the case in N* wards of other hospitals. It is therefore important that, across hospitals, neonatal wards and neonatal care providers, attention is paid to the IFCDC principles during these transition moments.

In addition, transition to home is also identified as a key transitory moment. The importance of IFCDC does not stop at the door of the hospital and the family should be well prepared to make this transition. In this context, parents of preterm newborns referred to the importance of rooming-in to prepare the baby's discharge. However, as we mentioned above, the availability of rooming-in possibilities is subjected to some limitations (see 6.4).



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