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## **Towards increased understanding of integrated Youth Care: a qualitative evaluation of facilitators and barriers for professionals**

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# **TOWARDS INCREASED UNDERSTANDING OF INTEGRATED YOUTH CARE**

**A qualitative evaluation  
of facilitators and barriers  
for professionals**

Laura Anne Nooteboom





## **Towards increased understanding of integrated Youth Care**

A qualitative evaluation of facilitators and barriers for professionals

**Laura Anne Nooteboom**

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*A qualitative evaluation of facilitators and barriers for professionals*  
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**Towards increased understanding of integrated Youth Care**  
A qualitative evaluation of facilitators and barriers for professionals

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# 1 General introduction

## BACKGROUND

Families with multiple needs across life domains often deal with a multitude of professionals from various organizations, resulting in fragmented support (Brooks, Bloomfield, Offredy, & Shaughnessy, 2013; Tausendfreund, Knot-Dickscheit, Schulze, Korth, & Grietens, 2016). In theory, integrated care is considered the ultimate solution to overcome this fragmentation (World Health Organization, 2016). However, in practice, providing integrated care is way easier said than done. Consequently, professionals, organizations, and policy makers struggle to implement an integrated approach. It is becoming increasingly clear that integrated care requires more than merging organizations or establishing multidisciplinary teams (Goodwin, 2013). Many scholars claim that it is a necessity to evaluate integrated care in real-life settings, and thereby unravel facilitators and barriers for professionals (Richardson, McCarty, Radovic, & Suleiman, 2017; Sunderji, Ion, Ghavam-Rassoul, & Abate, 2017). This dissertation aims to increase understanding of facilitators and barriers for professionals to provide integrated care from various perspectives: a systematic literature review, semi-structured interviews with professionals and parents, and an action-based research study in integrated care teams in the Netherlands. With the outcomes of this dissertation, clinical and research practices will be better informed about the complexity of integrated care on a professional level. Moreover, practical recommendations will guide practice and policy makers to improve integrated care for the families who need it the most.

### Families with multiple needs

For a small group of families with multiple (often severe and enduring) problems across life domains, their needs exceed the expertise and possibilities of a single professional, service, or organization (Brooks et al., 2013). For example, these families need support for mental disorders, cognitive impairments, problems with alcohol and drugs, parental stress, child abuse, or socioeconomic problems (Kolko & Perrin, 2014; Tausendfreund et al., 2016). If unaddressed, these problems can have lifelong consequences on psychosocial functioning



and lead to a reduced quality of life (Sellers et al., 2019). To support these families, there is often a variety of professionals from a broad range of Youth Care services involved. Youth Care can be defined as all psychosocial support for children (aged 0–25) and their families. In the Netherlands, Youth Care consists of a broad range of services in four domains: (1) universal and preventive support (e.g., basic care and universal pedagogical provisions), (2) primary care (e.g., child health care, general social work, parenting support), (3) secondary care (e.g., Youth Care services, specialized mental health care, child protection), and (4) tertiary care (e.g., high intensive psychiatric support, residential Youth Care).

Ideally, professionals and organizations in Youth Care collaborate to provide support in a timely and adequate manner, across domains, and tailored to families' multiple needs. However, all too often support for these families is fragmented, due to a lack of interprofessional collaboration, a focus on single problems, restricted treatment programs, separated services, limitations in access to services, and distinct funding streams (Forman-Hoffman et al., 2017; Hawkins, 2009; Kodner, 2009; Tausendfreund et al., 2016). This fragmented support not only leads to suboptimal clinical outcomes and reduced family satisfaction, but also to increased health care costs and pressure on Youth Care professionals (Kolko & Perrin, 2014; Wissow et al., 2008). Difficulties in support for families with multiple needs are longstanding and complicated issues of concern for policy makers, organizations, and professionals in Youth Care.

### **Integrated care: theory**

To improve support for families with multiple needs, integrated care is globally considered as the solution (Grone & Garcia-Barbero, 2001; World Health Organization, 2016). There is strong evidence that integrated care can lead to increased (cost-)effectiveness of care processes, improved clinical outcomes, and enhanced satisfaction with support by families (Gilbody, Bower, & Whitty, 2006; Glied, Herzog, & Frank, 2010; Patel et al., 2013). However, integrated care is a broad concept, with a variety of definitions and applications in different contexts



(Armitage, Suter, Oelke, & Adair, 2009; Peek & The National Integration Academy Council, 2013). For example, integrated care can refer to models, programs, collaborative agreements, working approaches, and specific interventions. Common examples of integrated care include joint funding streams, interdisciplinary networks, case management, multidisciplinary care teams, and co-location of services (World Health Organization, 2016). The contextual ambiguity of integrated care hampers general understanding and successful application of integrated care in practice (Kodner, 2009). In this thesis, integrated care is defined as coherent, continuous, and coordinated support, organized across services, and wrapped around families' needs (Kodner, 2009; Peek & The National Integration Academy Council, 2013; World Health Organization, 2016).

Leading theories describe integrated care as a dynamic process. According to the conceptual framework of Valentijn and colleagues (2013), integrated care can take place on three complementary levels: organizational, professional, and clinical. First, the organizational level refers to integration of sectors, systems, and organizations. It is about forming networks across organizational boundaries and sharing the responsibility to ensure continuity of care. Second, the professional level refers to partnerships between professionals, who are responsible to provide coherent and continuous support. Moreover, the professional level is about professionals' behavior, attitudes, and expertise warranted to address a broad range of problems, ensure interprofessional collaboration, and share values, mission, and culture. The intensity of integrated care on a professional level can vary (Leutz, 1999): from linkage (e.g., being aware of the existence of other professionals and inform when needed), to coordination (e.g., separated services offered simultaneously or sequentially in a coordinated way), to full integration (e.g., joint commissioning and care provision from multidisciplinary teams). Third, the clinical level refers to person-centered care. It is about providing tailored support to individual needs in a single process across time, place, and discipline. In this dissertation, we focus on integrated care on a professional level.



### **Integrated care in the Netherlands: decentralization**

To organize integrated support for families with multiple needs, there has been a global trend of reforming health care systems. The characteristics of these top-down restructurings differ across countries in, for example their scope (national or regional), the level of integrated care (organizational, professional, or clinical), and the intensity of integrated care (Dates, Lennox-Chugani, Pereira, & Tedeschi, 2018). In line with this trend of reforming systems, there has been a major decentralization of the Youth Care system in the Netherlands in 2015. Before 2015, the Youth Care system was split into three levels: the local level (municipalities, responsible for universal and preventive services), regional level (twelve provinces, responsible for primary care and secondary care), and the national level (national government, responsible for specialized mental health care). Families with multiple needs often had to deal with a multitude of professionals from different organizations that barely collaborated, due to for example different funding streams and a lack of coordination. As a result, support was often fragmented, leading to some families receiving duplicated support, whereas others experienced a lack of access and gaps in service provision (Werkgroep Toekomstverkenning, 2010).

To overcome these deficiencies, a new Youth Act came into force in the Netherlands in 2015. By adopting this new Youth Act, municipalities were given the authority and responsibility to organize Youth Care on a local level, including preventive services, primary, secondary, and tertiary care (Ministerie van Volksgezondheid, Welzijn en Sport & Ministerie van Veiligheid en Justitie, 2013). The decentralization in the Netherlands shares many characteristics with reformed health care systems in the Nordic countries (Strandberg-Larsen & Krasnik, 2009). By decompartmentalization of budgets and the local responsibility to organize Youth Care, the aim of this decentralization was to facilitate integrated care in families' own environment (Ministerie van Volksgezondheid, Welzijn en Sport & Ministerie van Veiligheid en Justitie, 2013).



### **Multidisciplinary Youth Teams**

Currently, all municipalities in the Netherlands are responsible for the local organization of Youth Care. At the core of the reconstructed Youth Care system are local, multidisciplinary teams, operative in almost all municipalities (Van Arum & Van den Enden, 2018). These so-called Youth Teams are the linking pin between universal services and secondary care. They operate within a primary care setting as the first point of contact for families in need of support (Hilverdink, Daamen, & Vink, 2015). Youth Teams aim to provide coordinated support, in close collaboration with local services such as general practitioners, schools, services for adult mental health care, financial support, and preventive services. Each Youth Team consists of eight to twelve professionals representing a broad range of expertise: social work and education, specialized mental health care, infant mental health, support for youth with (mild) mental retardation, parenting support, and child protection (Hilverdink et al., 2015). Although the organization and team composition slightly differ between municipalities, Youth Teams often consist of primary care providers, psychologists, family counselors, school counselors, and social workers. To support families with a broad variety of needs, professionals operate with a generalist view on the entire family's welfare, and a specialist focus on specific needs. They can provide short-term, ambulatory support to families with a broad variety of psychosocial, stress-related, and socio-economic problems, and refer to secondary or tertiary support if needed.

### **Transformation: a different approach**

The decentralization of the Youth Care system was an attempt to establish integrated care on an organizational level. However, as we know from existing integrated care initiatives, top-down organizational reforms tend to overlook the dynamic process and complexity of providing integrated care in practice (Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). A bottom-up approach is considered vital to accomplish effective integrated care, with an emphasis on evaluation, reflection, and collaborative learning (Tsasis, Evans, Rush, & Diamond, 2013). Therefore, alongside organizational changes, the aim of the renewed Youth Care system was also to ensure another working





approach to improve practice, called 'the transformation'. To facilitate the transformation, the Dutch government formulated the following transformation goals: (1) organize integrated care in close collaboration with families, with a focus on effective interprofessional collaboration, cross-domain continuity of care, and coordinated support; (2) shift to prevention and active contribution of families in their own care process by focusing on families' capacities, strengths, responsibilities, and their social network; (3) stimulate participation and focus on normal functioning instead of a disease-driven focus; (4) provide demand-driven support if needed: timely, adequate, and close to home; (5) reduce regulatory pressure for professionals and increase professional autonomy (Ministerie van Volksgezondheid, Welzijn en Sport & Ministerie van Veiligheid en Justitie, 2013).

However, the transformation of professionals' working approach was not a straightforward process. Soon after the decentralization in 2015, professionals, organizations, and parents reported that a transformation required more than mere organizational changes (Kinderombudsman, 2016). Although the transformation goals were set, it remained unclear how exactly professionals should work differently to achieve integrated care and the other transformation goals. It became increasingly clear that integrated care was an abstract concept for professionals, with many different understandings and approaches in practice. Insight in facilitators (i.e., components enabling/improving integrated care) and barriers (i.e., components hindering/limiting integrated care) of integrated care on a professional level was limited, and knowledge based on the experience of other countries with implementing integrated care on such a large scale was scarce (Henderson et al., 2017). This lack of knowledge and guidance posed significant challenges for professionals, their organizations, and policy makers. Better understanding of facilitators and barriers to integrated care on a professional level was needed to support professionals in providing integrated care and to improve quality of care for families in Youth Care.



## Dissertation

The general aim of this dissertation was to identify facilitators and barriers to integrated Youth Care on a professional level. The additional aim of this dissertation was to guide professionals in Youth Teams in improving evaluation, reflection, and collaborative learning; vital aspects to provide integrated care. The decentralized Youth Care system was considered the ultimate setting to study actual experiences with integrated care in practice, facilitators, and barriers. To investigate the aims, a qualitative and participatory research approach was adapted: an open, narrative, and systematic analysis of international literature (chapter 2), perspectives of parents (chapter 3), and actual experiences of professionals (chapter 4) with integrated care. Moreover, an action research study was conducted (chapter 5) to guide professionals in improving evaluation and reflection.

The studies described in this dissertation were part of the Academic Workplace 'Gezin aan Zet' [English: Family's Turn], a collaborative initiative in the Netherlands, funded by The Netherlands Organization for Health Research and Development (ZonMw; 70-73700-98-006). In an Academic Workplace, parents, professionals, policy makers, academia, and researchers collaborate to solve practice-based problems. This approach has a strong focus on improving current practice, with active involvement of representatives from practice, families, research, education and policy (Migchelbrink, 2007; Abma et al., 2017). To inform researchers about the issues in practice prior to this study, representatives were prospectively asked about their perspectives on the decentralization and a successful transformation of the Youth Care system. Families indicated that they wanted more control over their own care processes and described coordinated support as a major point of improvement. Professionals described the need of guidance in supporting families with multiple needs, with a focus on collaborative learning on the job. Policymakers indicated that after finalizing the organization of Youth Teams, there was a need to consequently evaluate facilitators and barriers in practice, with the aim to learn and develop an integrated approach.



Facilitators and barriers to integrated care on a professional level were identified by: (1) analyzing current literature on integrated care in Youth Care, (2) observations of multidisciplinary team discussions in Youth Teams, and (3) semi-structured interviews with professionals, parents, and policy makers. In total, six Youth Teams from two regions in the Netherlands, Holland Rijnland and The Hague, participated in the research project of the Academic Workplace 'Gezin aan Zet'. In general, the six teams had similar compositions and tasks. Each multidisciplinary team consisted of eight to twelve professionals, that held the responsibility to provide local (ambulatory) support to families in Youth Care. Preliminary results of the qualitative studies were systematically evaluated during learning sessions with professionals from Youth Teams and during project team meetings with representatives from practice, policy, and families. The idea behind these action-focused learning activities was that they would stimulate and accelerate a cyclic learning process in practice. The participative, qualitative approach of this dissertation enabled us to analyze integrated care as a multicomponent and context dependent process in practice from various perspectives (Smith & Firth, 2011; Strauss & Corbin, 1999), leading to a rich description of facilitators and barriers professionals can encounter when providing integrated care.

## **Outline**

In chapter 2, the complexity of integrated care on a professional level and gaps in current knowledge are introduced. A systematic review with the aim to identify facilitators and barriers for professionals in Youth Care was conducted. In total, 55 studies to integrated care from a broad variety of settings and with diverse methodologies, populations, and types of integrated were included and systematically appraised. A thematic analysis was conducted to find common understanding of facilitators and barriers among different contexts and professional disciplines in Youth Care. Quality of individual studies was critically appraised using standardized checklists and an objective ranking system. A strength of evidence rating was calculated for each subtheme by assessing the quality, size of evidence, context, and consistency of findings.



To provide integrated care responsive to the needs of families, it is essential to incorporate parental perspectives into clinical practice. Therefore, chapter 3 describes a qualitative study to parental perspectives on integrated care. This study set two objectives: first, to identify what parents considered key components of integrated care, and second, to describe facilitators and barriers according to parents. Semi-structured interviews were administered to 21 parents of children receiving support from a Youth Team, based on a topic list that was formulated in advance. Qualitative content analysis was conducted by means of a grounded theory approach, resulting in key components of integrated care according to parents.

In addition to parental perspectives, chapter 4 examines actual experiences and perspectives of 24 professionals who worked in one of the six participating Youth Teams. By means of semi-structured interviews, the aim of this study was to identify facilitators and barriers professionals encounter when providing integrated care. Axial coding took place after applying a theory-driven framework analysis to identify facilitators and barriers, leading to themes that covered the broad variety of facilitators and barriers. Then, recommendations with implications for professionals, their organizations, researchers, and governmental policy makers were formulated.

Chapter 5 is the result of a four-year action research study of the Academic Workplace 'Gezin aan Zet'. In this study, researchers collaborated with six Youth Teams during their weekly Multidisciplinary Team Discussions (MTDs). While following these teams, we found out that there was a need to improve learning in practice, to stimulate the transformation process, and to improve the quality of integrated care. Moreover, evaluation and reflection during these MTDs seemed fundamental to stimulate learning, and thereby improving quality of integrated care. Although Youth Teams do have time for evaluation and reflection during their weekly held MTDs, professionals were often dissatisfied by the ineffective and lengthy discussions. The aim of this study was therefore to guide professionals in improving evaluation and reflection in practice. This study's action research cycle consisted of a




qualitative component to identify facilitators and barriers in evaluation and reflection during MTDs by means of observations and semi-structured interviews with professionals, parents, and policy makers. Concurrently, practical recommendations were iteratively formulated and implemented in Youth Teams.

In chapter 6, facilitators and barriers from chapter 2, 3, and 4 are summarized in a comprehensive overview. Implications of all studies from this dissertation are discussed, considering current developments in the organization of integrated care, five years after the decentralization of the Youth Care system in the Netherlands. Finally, strengths, limitations, and recommendations for practice, education, policy, and future research are discussed.










# 2 Towards integrated Youth Care: A systematic review of facilitators and barriers for professionals



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**ABSTRACT**

To overcome fragmentation in support for children and their families with multiple and enduring problems across life domains, professionals increasingly try to organize integrated care. However, it is unclear what facilitators and barriers professionals experience when providing this integrated care. Our systematic review, including 55 studies from a broad variety of settings in Youth Care, showed that integrated care on a professional level is a multi-component entity consisting of several facilitators and barriers. Findings were clustered in seven general themes: 'Child's environment', 'Preconditions', 'Care process', 'Expertise', 'Interprofessional collaboration', 'Information exchange', and 'Professional identity'. The identified facilitators and barriers were generally consistent across studies, indicating broad applicability across settings and professional disciplines. This review clearly shows that when Youth Care professionals address a broad spectrum of problems, a variety of facilitators and barriers should be considered.



## INTRODUCTION

It is challenging for professionals in Youth Care to support children and their families with multiple and enduring problems across life domains (e.g., home, school, in the community; Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016). Although a small group, these children and their families experience a broad variety of problems, including psychosocial, emotional, cognitive, and stress-related impairments, problems with alcohol and drugs, parental stress, child abuse, and socioeconomic disadvantages (Kolko & Perrin, 2014; Tausendfreund et al., 2016). If left unaddressed, these problems can hinder normal child development and cause impairment that can endure into adulthood (Sellers et al., 2019). To timely and adequately address families' needs, services in Youth Care encompass a wide range of support, including universal and preventive services, community centers, special education, specialized mental health care, child protection, social work, and residential treatment (Hilverdink, 2013). However, the needs of families often exceed the expertise and possibilities of a single professional, service, or organization (Brooks, Bloomfield, Offredy, & Shaughnessy, 2013). As a result, multiple professionals from a broad range of services with various expertise in Youth Care are involved in a family's care process (e.g., psychiatrists, psychologists, primary care providers, family counselors, school counselors, and social workers).

Ideally, professionals in Youth Care collaboratively address multiple problems across life domains, while tailoring support to families' needs (Hilverdink, 2013; Krueger, 2002). The number of professionals and type of professional expertise involved in a care process varies and depends on families' needs. However, due to specific limitations in the access to services and fragmentation in terms of financing, there is often a mismatch between service delivery, professional culture, and the needs of families with multiple problems across life domains (Henderson et al., 2017; Kodner, 2009). Consequently, professionals typically operate within their own specialty, while focusing on a restricted number of problems (Kodner, 2009; Peek & The National Integration Academy Council, 2013). A critical issue when focusing on a



restricted number of problems is that the interrelatedness of the often co-occurring and exacerbating problems can be overlooked (Hawkins, 2009; Tausendfreund et al., 2016). Moreover, a lack of coordination and collaboration in a care process can lead to fragmentation in support (Forman-Hoffman et al., 2017; Hawkins, 2009; Tylee, Haller, Graham, Churchill, & Sanci, 2007). Such fragmented care not only reduces client satisfaction and jeopardizes successful treatment outcomes (e.g., improved child and family functioning), it also increases service use and costs of Youth Care organizations (Kolko & Perrin, 2014; Wissow et al., 2008).

To overcome fragmentation, there has been an increased focus on organizing integrated care in the last decade (World Health Organization, 2016). A problem with integrated care is its conceptual ambiguity: integrated care is organized in different ways and related to a broad variety of terms, including health services integration, care coordination, family-centered care, collaborative care, co-located care, and shared care (Armitage, Sutel, Oelke, & Aidar, 2009; Peek & The National Integration Academy Council, 2013). Integrated care can refer to models, programs, collaborative agreements, working approaches, or specific interventions like case management, co-location, multidisciplinary care teams, and joint funding (World Health Organization, 2016). A common feature in models and terms is that integrated care seeks to improve quality of care for families. The goal is to ensure well-coordinated services around families' needs, by incorporating services, ensuring collaboration, and overcoming fragmentation (Kodner, 2009; Wodchis, Dixon, Anderson, & Goodwin, 2015). To ensure common understanding and improve conceptualization, we based our definition on three principal components of integrated care according to the World Health Organization (2016): the delivery of coherent, coordinated, and continuous support, through different levels and sites within the care system (e.g., from universal services and primary care, through specialized mental health care centers), tailored to the needs of children and their families across several life domains.



Organizing integrated care has been deemed a complex and multi-component process. Integrated care can vary in intensity, spanning a continuum ranging from ad hoc linkage, over structured coordination, to full integration (Leutz, 1999). Furthermore, organizing integrated care is more than forming networks, adding services, or providing multiple treatments alongside one another (Goodwin, 2013). It requires processes on different complementary levels: organizational, clinical, and professional (Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). The organizational level refers to relationships between services, coordinated policies, and activities to maintain networks. The clinical level refers to the primary process of care delivery to an individual: person-centered care in a single process across time, place, and discipline. The professional level refers to the delivery of integrated support: a professional's behavior, attitudes, and expertise warranted to provide integrated care in collaboration with other professionals (Valentijn et al., 2013). Hence, integrated care on a professional level requires broad assessment of problems and needs, clear clinical pathways, and collaboration between professionals (Cooper, Evans, & Pybis, 2016; Kolko et al., 2014).

Previous reviews comparing models of integrated care have indicated that integrated care can improve the perceived quality of care and increase client satisfaction (Baxter et al., 2018; Cooper et al., 2016). However, evidence from these studies is mixed and emphasizes the importance of customized interventions or models to serve a specific population, setting, or context (Baxter et al., 2018; Patel et al., 2013). Various studies have sought to understand facilitators (i.e., components improving/enabling integrated care) and barriers (i.e., components limiting/obstructing integrated care) for professionals to integrated care in a specific context or to a specific population. For example, previous studies suggested that integrated care on a professional level requires timely identification of problems by means of adequate assessment of problems across life domains and monitoring progression during a care process (Bower & Gilbody, 2005; Kolko et al., 2014), interprofessional collaboration (Cooper et al., 2016), and a flexibility to respond to the organizational differences across diverse settings (Ho, Yeung, Ng, Chan,



2016). Other facilitators that were identified in general health care practice included clearly defined roles and responsibilities, a shared understanding of integrated care, and shared decision making on the intensity and type of support (Axelsson & Axelsson, 2009; Cohen et al., 2015; Valentijn et al., 2013).

Notwithstanding that this previous research has furthered our understanding on aspects of integrated care, these studies were often conducted on a small-scale, limited to specific settings, or focused solely on one aspect of integrated care. Hence, the complexity of integrated care on a professional level remains understudied (Shaw, Rosen, & Rumbold, 2011; Sunderji, Waddell, Gupta, Soklaridis, & Steinberg, 2016). Various scholars claimed that a deepened understanding of what professionals need to provide integrated care is essential to further improve support for children and their families (Richardson, McCarty, Radovic, & Suleiman, 2017; Sunderji, Ion, Ghavam-Rassoul, & Abate, 2017). Unfortunately, a systematic and comprehensive overview of facilitators and barriers for Youth Care professionals to provide integrated care has not been conducted yet. To fill this knowledge gap, the current systematic literature review aims to identify facilitators and barriers Youth Care professionals may encounter when providing integrated care across settings. A comprehensive review is of indisputable importance to formulate recommendations and guide Youth Care professionals and their organizations to organize and deliver integrated care (Grant & Booth, 2009).

## **METHOD**

Our aim was to perform an extensive systematic literature review with rigorous analysis of facilitators and barriers for professionals to provide integrated care from a variety of settings, models, and populations seen in Youth Care. This approach was intentionally broad in order to find common understanding among different contexts, leading to facilitators and barriers that offer practical guidance across settings and professional disciplines. A research protocol to guide this review was prospectively registered in the International Database of Prospectively



Registered Systematic Reviews in Health and Social Care (PROSPERO, registration number CRD42018084527). The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were followed to guide the review process and transparently report findings stemming from this review process (Liberati et al., 2009). The literature review did not need approval from the Medic Ethics Review Committee (METC).

### **Search strategy**

An extensive search strategy was designed in collaboration with an experienced medical research librarian from the Leiden University Medical Center. Due to terminological variability, a set of search terms was formulated focusing on the following topics: integrated care, problems seen in Youth Care, and children/families. Search terms for integrated care included integrated care, family-centered care, co-located care, collaborative care, and shared care (Armitage et al., 2009; Peek & The National Integration Academy Council, 2013). To account for the fact that Youth Care deals with families who display various (co-occurring) problems, we applied search terms referring to a broad variety of psychosocial, emotional, or cognitive problems, stress- and substance-related problems, socioeconomic disadvantages, and child abuse (Tausendfreund et al., 2016). To include a broad range of services in Youth Care, search terms encompassed child and youth (health) services, primary (health)care, child protective services, specialized mental health, and juvenile justice settings (Hilverdink, 2013). To identify studies that focused on children and their families, we applied search terms such as child, pediatric, adolescents, families, and youth. To reduce the number of irrelevant studies, exclusion terms based on the eligibility criteria were added to the search strategy (e.g., internal medicine, elderly). Based on a preliminary screening, no potential relevant studies were missed when applying these exclusion terms. The detailed search strategy including the search terms can be found in Appendix A.

A computerized literature search was conducted in following electronic databases: PubMed, The Cochrane Library, Web of Science, Medline,



and PsychINFO. The search was supplemented with literature obtained from the evidence-based Integrated Care Search from the International Foundation of Integrated Care ("Integrated Care Search", no date). All identified studies were collected in the bibliographic reference manager Endnote®. Moreover, reference lists of studies selected for data extraction were screened for potential relevant publications that we might have missed during the computerized search.

### **Eligibility criteria**

To be included, studies had to meet the following eligibility criteria:

- Focus on Youth Care: the support for children aged 0–18 and their families who experience a broad variety of problems across life domains, including psychosocial, emotional, cognitive, and stress-related impairments, problems with alcohol and drugs, parental stress, child abuse, and socioeconomic disadvantages. Youth Care services included universal and preventive services, community centers, special education, specialized mental health care, child protection, social work, residential treatment, and juvenile justice settings.
- Respondents: professionals in Youth Care (YC practitioners), including psychiatrists, psychologists, pediatricians, primary care providers, social workers, family counselors, school counselors, and juvenile justice workers. Studies were also eligible for inclusion when they included a combination of Youth Care professionals and other respondents such as managers or parents.
- Focus on integrated care: any model, intervention, or working approach with a focus on overcoming fragmentation and promoting coherent support tailored to families' needs. Integrated care includes the delivery of coherent, coordinated, and continuous support through different levels and sites within the care system, by increasing for example common cause, vision, and strategy, joint funding or service delivery, and quality of support (Goodwin 2013; WHO 2016).
- Include outcomes as the result of an original study, review, or program evaluation, described as a facilitator (i.e., component



identified as improving/enabling integrated care) or barrier (i.e., component identified as limiting/obstructing integrated care) for professionals.

Since research on integrated care comprises a variety of study designs spanning both quantitative and qualitative research methods, we aimed to include a broad range of original research articles (e.g., interviews, focus groups, case studies, action research, RCT's, reviews). In that, we controlled for the source of evidence (e.g., whether the information came directly from professionals or other respondents) and paid specific attention to study quality by standardized quality appraisal. We searched for studies between January 1, 2002 and January 1, 2018 based on the increased focus on organizing integrated Youth Care services since the beginning of the 21th century (Shaw et al., 2011). Additionally, manuscripts had to be in English, peer-reviewed, and available as a full-text article.

To improve the transferability of results, non-western studies were excluded, since there are major differences in the organization of Youth Care across western and non-western cultures (Office of the Surgeon General Center for Mental Health Services, 2001). Also, studies focusing on adults, solely on internal hospital settings, and publications such as conference abstracts or position papers were excluded from this review.

### **Data extraction and synthesis**

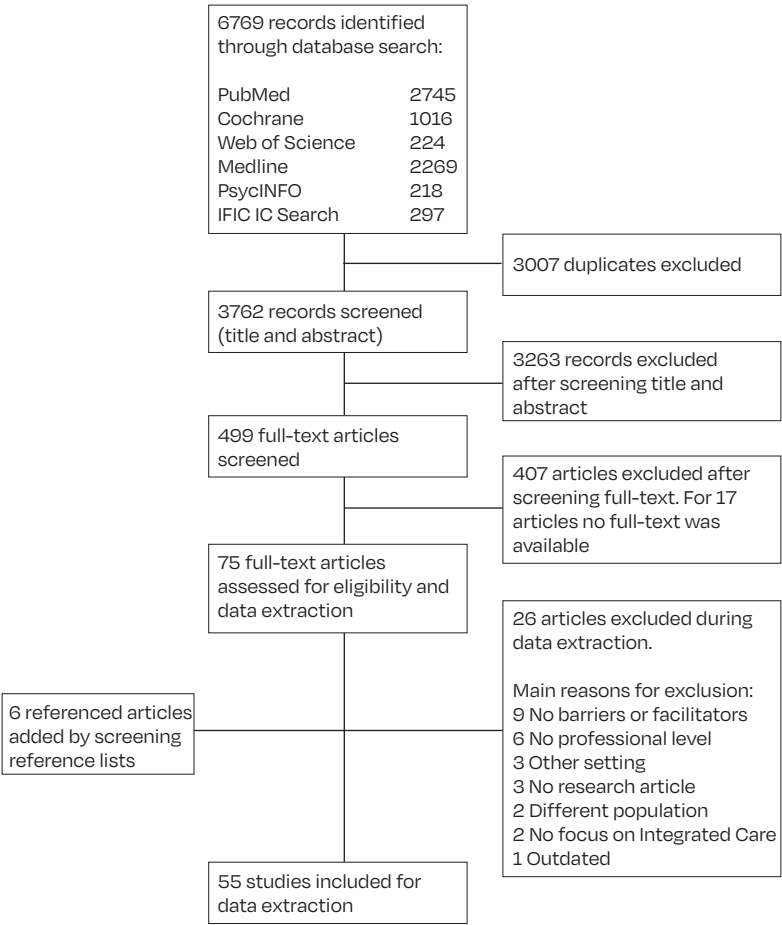
Study selection took place in several phases, summarized in a PRISMA flow diagram (see Figure 1). Studies were independently reviewed by two researchers (LN and LK) based on the eligibility criteria. After studies were included, we derived first, second, and third order interpretations from the full-text manuscripts (Britten et al., 2002). The phases of data extraction and analysis were carefully prepared by the first author (LN) under supervision of two experienced qualitative researchers (CK and EM), by developing a standardized extraction form and plan for the thematic data synthesis. The first author extracted and analyzed the data, and three researchers (EM, CK, and RV) verified data extraction,





thematic analysis, and strength of evidence appraisal by several audit trails and reflexive meetings. Preliminary interpretation was discussed during these meetings to avoid bias.

**Figure 1.** PRISMA flow chart



All manuscripts were loaded in the qualitative data analysis software program Atlas.ti (version 7). First-order interpretation was derived by means of open coding of the facilitators and barriers directly from the manuscript. Open coding is a common method in qualitative research and can be described as an interpretive process to gain new insights (Strauss & Corbin, 1990). Open coding was conducted by conceptual labeling (coding) of identified fragments in the manuscripts and comparing these fragments during further analysis. During the process of open coding, no additional codes were conceptualized for the last seven articles, indicating data saturation and completeness of our findings (Saunders et al., 2018). An a priori developed and pilot-tested standardized extraction form based on the Cochrane Data Extraction Template and the National Institute of Health and Clinical Excellence universal template (NICE) was used to register main outcomes from the open coding (facilitators and barriers); the second-order interpretation. This extraction form also included study characteristics (bibliographic information, aim, participants, study design, setting, and target population), source of evidence, a description of the integrated care process, and the level of integration (Leutz, 1999). Furthermore, a third-order evaluation summary of the main outcomes was registered on the extraction form. For each study, the template was completed by the first author (LN) and verified by the research team (EM, RV, and CK). The use of a standardized extraction template enabled us to register comparable information from each study. To avoid publication bias, all studies were controlled for repeated sample use. However, none of the included studies used repeated samples.

Thematic data synthesis was applied based on the open coding of facilitators and barriers. Using both inductive and deductive strategies, axial coding took place by analyzing and combining the coded fragments (Van Staa & Evers, 2010). Facilitators and barriers were listed per theme to explore patterns in data and to create a conceptual model of themes and subthemes (Bearman & Dawson, 2013). After summarizing these individual study outcomes, thematic descriptions were deductively compared with the initial study reports to limit possible adverse effects of prejudices and interpretation bias.



### Quality appraisal

Quality of individual studies was critically appraised using standardized checklists developed by the Joanna Briggs Institute (2017). These checklists were available to assess a variety of study methods, including case reports, qualitative research, quasi-experimental studies, randomized controlled trials, and systematic reviews. With these forms, methodological quality of each study and possible bias in design, conduct, and analysis were rigorously appraised to inform synthesis and interpretation of the results. An objective ranking system was formulated in advance by the authors to assess the study quality based on the checklist. The quality ranking system included three categories: high (more than 8 items checked), medium (6–8 items checked), or low quality (less than 6 items checked). An overview of study characteristics and critical appraisal scores can be found in Appendix B.

To assess strength of evidence of each subtheme, individual study outcomes were listed per subtheme. Critical appraisal was one of the main elements on which we based strength of evidence assessment. The first author labeled each facilitator and barrier with the quality label based on the critical appraisal (high, medium, or low). Then, to guide practice recommendations, strength of evidence was calculated for each subtheme by assessing (Harbour & Miller, 2001; Ryan & Hill, 2016):

- Quality of studies based on critical appraisal of individual studies: high (+; over 75% of the studies appraised as high quality), medium ( $\pm$ ; 25–75% of the studies appraised as high quality), or low (–; under 25% of the studies appraised as high quality).
- ‘Size of evidence’: the number of studies within a subtheme. Since a golden standard for the number of studies was not available, size of evidence was based on a priori set standards: large (+; over 20 individual studies), medium ( $\pm$ ; between 10 and 20 individual studies), or small (–; less than 10 individual studies).
- Context, categorized into global (+; a variety of studies from multiple contexts) and specific (–; all studies reported findings within the same specific context).



- Consistency of findings: assessed as consistent (+; all studies point to identical or similar conclusions), inconsistent (-; one or more studies directly refutes the findings of another study, in the same context or under the same conditions), or mixed ( $\pm$ ; studies have produced results that contrast with those of other studies in different contexts or under different conditions).

Subsequently, strength of evidence was assessed based on the scores for each subscale, resulting in the following categories: very strong (++++), strong (+++), medium (++), limited (+), or no evidence (-). An overview of strength of evidence assessment for each subtheme can be found in Appendix C.

## RESULTS

### Study selection

Our database search identified 6.769 studies, resulting in 3.762 non-duplicate publications that were collected in the bibliographic reference manager (Endnote® X9). Study selection was conducted independently by two researchers (LN and LK) to reduce risk of bias and ascertain validity. Title and abstract were screened based on the eligibility criteria. In this round, we excluded studies solely focusing on medical conditions, adult populations, conference abstracts, position papers, and non-peer reviewed manuscripts. In case the two reviewers did not agree, the full-text was reviewed. In total, 499 studies were selected for full-text screening, leading to 75 studies eligible for data extraction. Main reasons for exclusion of these 424 articles were a lack of focus on professionals in Youth Care or integrated care (n=129), lack of barriers or facilitators on a professional level (n=127), no full-text available (n=17), no research article (n=87), different target population (n=35), different setting (n=29). The study selection inter-rater agreement as measured by Cohen's Kappa was 0.70 for this round of inclusion, indicating substantial agreement between the two reviewers (Landis & Koch, 1977). In four studies, disagreement was resolved through discussion and counselling by a third independent researcher (EM), who searched for consensus. In the other studies,



reviewers solved their disagreement by collaboratively assessing the full-text articles. During the extraction phase, another 26 studies were excluded, mainly due to a lack of focus on facilitators or barriers on a professional level. After hand searching reference lists of the included studies, another 6 studies were eligible for inclusion. In total, 55 studies were included in this review.

### **Study characteristics**

Of the 55 included studies selected within the span of 2002–2018, more than half ( $n=33$ ; 60%) were published after 2011. The included studies covered multiple settings in Youth Care. Specifically, all studies took place in primary care ( $n=33$ ) or in specialized mental health care settings ( $n=22$ ), in combination with for example educational ( $n=6$ ), child welfare ( $n=3$ ), juvenile justice ( $n=4$ ), substance abuse treatment ( $n=2$ ), or child protection ( $n=3$ ) settings. Most studies focused on mental health problems of children ( $n=32$ ), often in combination with child maltreatment, substance abuse, and psychosocial support of family members. Integrated care models and approaches varied widely across studies, and the level of integration spanned a continuum ranging from ad hoc linkage, over structured coordination, to full integration (Leutz, 1999). Examples of integrated care models or approaches included in our study sample were collaborative screening, care coordination, shared referral, service networks, collaborative training, multidisciplinary teams, and co-location.

In 43 studies, Youth Care professionals were the primary respondents, including psychologists, parent support workers, child psychiatrists, pediatric nurses, social workers, special education workers, and primary care providers. Study methodology varied across studies, including questionnaires, interviews, focus groups, observations, literature reviews, case descriptions, action research, or a combination of these methods. Based on critical appraisal of individual studies, 30 studies were appraised of high quality (e.g., based on clear and comprehensive report of research methodology), 7 studies of medium quality, and 18 studies of low quality. The low-quality studies were often small-scale program evaluations, lacking a clear design or reported methodology. A



complete overview of individual study characteristics and the critical appraisal can be found in Appendix B.

## **Outcomes**

The aim of this review was to identify facilitators and barriers for professionals to provide integrated care. Since the identified facilitators (e.g., sufficient time) were often the opposite of barriers (e.g., lack of time) and vice versa, we chose for a thematic clustering of facilitators and barriers that were identified during the open coding. The thematic clustering resulted in seven overarching themes and 24 subthemes (see Table 1 for a description of each subtheme, Figure 2 for an overview of themes and subthemes). The coded facilitators and barriers were listed to explore patterns by means of axial coding, leading to a conceptual model of subthemes (Bearman & Dawson, 2013). The conceptual model circulated in the research team for verification. The final themes and subthemes were formulated during reflexive meetings (LN, EM, CK, and RV). This approach led to a variety of (interrelated) themes that offer practical guidance for professionals to provide integrated care. Strength of evidence was rated for each subtheme based on our rating scheme and varied from medium to very strong. This is an indication that all subthemes can be interpreted with confidence. Most subthemes included a high number of studies with medium quality. In all subthemes, the context was assessed as 'general'. Sixteen subthemes were rated as 'consistent', the other eight were 'mixed', indicating that the subthemes are applicable for professionals in a variety of settings in Youth Care. Detailed findings of strength of evidence appraisal and presence of individual studies within each subtheme are listed in Appendix C. To improve readability, studies presented in the result section received a study number.

### ***Theme 1: Child's environment***

The theme 'Child's environment' was divided into two subthemes with barriers and facilitators: family-centered focus (17 studies) and fragmentation (5 studies).



**Table 1.** Themes and subthemes based on barriers and facilitators

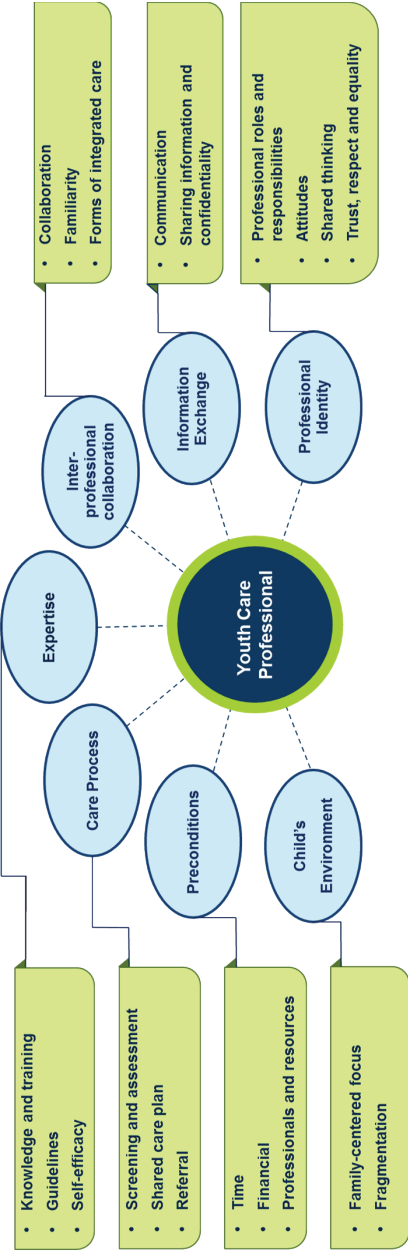
Theme	Subthemes	Subtheme description	Number of studies	Strength of evidence
Child's environment	Family-centered focus	A holistic approach on a family's welfare	17	Medium - Strong
	Fragmentation	Collaboration between education and health care systems	5	Strong
	Time	Time to address a broad spectrum of problems and for interprofessional collaboration	25	Strong - Very strong
Preconditions	Financial	Financial support and funding streams	7	Strong
	Professionals and resources	Availability of professionals and services	28	Strong
	Screening and assessment	Broad assessment of problems and the use of screening tools	21	Strong
Care process	Shared Care plan	Several perspectives and goals in a comprehensive care plan	5	Medium - Strong
	Referral	Transition between care providers	9	Medium - Strong
	Knowledge and training	Extending knowledge by means of training	37	Strong
Expertise	Guidelines	The use of evidence-based guidelines to support professionals	13	Strong
	Self-efficacy	Confidence and comfort of professionals to provide integrated care	15	Strong
	General aspects of collaboration	The importance of interprofessional relationships	10	Medium - Strong



Theme	Subthemes	Subtheme description	Number of studies	Strength of evidence
	Familiarity with other professionals	Knowing and understanding other professionals' expertise	16	Strong – Very strong
	Forms	Co-location	19	Strong
		Multidisciplinary meetings	13	Strong – Very strong
		Meetings where professionals share knowledge, highlight concerns, and reflect on care processes		
		Consultation	18	Strong
		Care coordination	6	Medium
		Professional with the specific task to coordinate a care process		
Information exchange	Communication	A shared language and motivation to communicate	22	Strong – Very Strong
Professional identity	Sharing information and confidentiality	Content and frequency of information exchange, shared medical records and legal guidelines for sharing information	27	Strong
	Professional roles and responsibilities	Clarity and expectations about professional roles, sharing responsibility	27	Strong
	Attitudes	Attitudes and commitment towards integrated care and collaboration	16	Strong
	Shared thinking	A shared foundation in thoughts, aims, priorities, and values	22	Strong – Very Strong
	Trust, respect, and equality	Mutual trust, respect for other professionals and perceived equality	20	Strong



**Figure 2.** Thematic overview of facilitators and barriers for Youth Care professionals to provide integrated care



### *Family-centered focus*

A holistic focus with both a generalist view on the entire family's welfare and a specific focus on individual needs was reported as a facilitator in nine studies (6, 11, 22, 29, 34, 42, 47, 49, 50). To accomplish a balance between a generalist view and a specialist approach of problems, professionals should be able to accurately prioritize problems and decide on the focus of support when considering different life domains (22, 32). Other reported facilitators were being aware of the other professionals' context and being able to respond competently to various situations (44, 45, 54).

A reported barrier for professionals was to maintain a holistic focus while at the same time prioritize problems, especially for children with severe problems (25, 51). Studies suggested that the feasibility of combining a specialist and generalist approach was complicated by the unpredictable and episodic nature of problems, incompatible needs of multiple family members, or concerns about a child's safety (22, 53). Other reported barriers were differences in perspectives on the primary client within one family, and the perception that other professionals solely pay attention to their own individual client or field of expertise (11, 53, 54).

### *Fragmentation*

The gap in collaboration between professionals working in the educational system (e.g., teachers) and professionals from other settings in Youth Care was reported as a major barrier in various studies (8, 11, 23, 36, 39). These studies suggested that differences in focus, culture, and procedures lead to disconnection and fragmentation between the two systems, hampering Youth Care professionals to provide integrated care.

## **Theme 2: Preconditions**

Facilitators and barriers of the theme 'Preconditions' were described in three subthemes: time (25 studies), financial (7 studies), and professionals and resources (28 studies).



### *Time*

Reported facilitators were flexible schedules, sufficient time for interprofessional team development, reflection on collaboration, and clinical discussions (10, 22, 37, 39, 45, 47, 49). On the other hand, a lack of time during regular visits to address a broad spectrum of problems was reported as a major barrier (5, 8, 17, 27, 36, 39, 42, 45, 46, 49). Also, interprofessional collaboration was described as time consuming (22, 24, 35, 37, 45, 47), with inflexible schedules of professionals, a lack of time for communication, and leaving collaboration to chance as reported barriers (2, 12, 19, 21, 23, 51, 52, 54, 55).

### *Financial*

A lack of financial support for collaborative activities, separate funding streams, and differences in reimbursement rates for various health codes or diagnoses were reported barriers for professionals (2, 5, 21, 33, 39, 42, 47).

### *Professionals and resources*

Reported facilitators were the availability of professionals and adequate resources such as specific intervention programs (2, 7, 48, 50). Hiring additional staff was also described as a facilitator, under the condition that new staff has a notably distinct role or expertise (1, 2, 3, 7, 27, 28, 41, 46). Estimating the adequate number of professionals needed to provide integrated care was stressed as complex, due to the fluctuating demands and specific needs of families at various times (2, 39, 53). Reported barriers in availability of professionals were related to frequent turnover of professionals (24), high clinical demands (33), and a lack of transparency in the availability of services (39, 51, 54). Other barriers included specific demands of services (i.e., a focus on single problems that caused refusal of children and families with interrelated problems) and a shortage of trained professionals for assessment, treatment, or care coordination (1, 6, 13, 19, 32, 49, 52). Also, the lack of availability of specialist services was identified as a barrier, often leading to long waiting lists and gaps in service provision (9, 11, 17, 24, 29, 39, 50).



### ***Theme 3: Care process***

This theme was divided into three general aspects of care processes in Youth Care: broad assessment and the use of screening tools (21 studies), the use of a shared care plan (5 studies), and the referral process (i.e., the transition between care providers; 9 studies).

#### *Screening and assessment*

Reported facilitators for broad screening and assessment were joint assessment (i.e., professionals with supplementary expertise jointly assess children and families; 50) and the use of validated screening tools to identify risks and strengths across multiple life domains (1, 8, 12, 15, 17, 26, 27, 28, 29, 32, 38, 41, 46, 49). Screening tools deemed important in multiple studies, because they seemed to increase the capacity and confidence of professionals to assessing a broad spectrum of problems (35), discussing strengths and weaknesses with families (51), and sorting out diagnostic criteria and comorbidities (17). However, the following barriers to the implementation of screening tools were identified: difficulties in (timely) application of tools, interpretation of test results, formulating a follow-up plan based on the screening results, and reporting the screening results to families (11, 17, 21, 27, 33, 41, 49, 52).

#### *Shared care plan*

Five studies reported a shared care plan as a facilitator: a mutually understood and agreed upon care plan, including an overview of a families' needs and goals (7, 25, 38, 39, 50). The plan should be flexible and adjustable to the needs of families at any time.

#### *Referral*

Identified facilitators in the referral process (i.e., the transition between care providers) were: clear referral pathways, warm handoffs between professionals, and shared intervention planning (2, 13, 29, 38, 41, 52). On the contrary, reported barriers were a lack of sharing information and miscommunication between professionals at transition points, leading to a discontinuity of care (24, 50, 51).



### **Theme 4: Expertise**

The theme 'Expertise' was divided into three subthemes with barriers and facilitators, that were often mentioned in relation to each other: knowledge and training (37 studies), the use of guidelines (13 studies), and self-efficacy (15 studies).

#### *Knowledge and training*

A broad range of knowledge concerning problems seen in Youth Care was a reported facilitator for professionals (21, 44). Multiple studies indicated that training expands knowledge of this broad range of problems, resulting in improved self-efficacy of professionals to provide integrated care (5, 13, 18, 20). Also, (joint) training in interprofessional collaboration was a reported facilitator (16, 17, 18, 20, 25, 29, 30, 33, 41, 50), described in several forms: multidisciplinary training, working alongside a professional with different expertise, and interdisciplinary education curricula (2, 4, 10, 14, 19, 30, 32, 35, 38, 46). Studies suggested that study material should be available after training to keep knowledge up to date (25, 39, 49).

A frequent reported barrier was a professional's lack of knowledge, for example regarding triaging and referring to other services (1, 4, 5, 11, 15, 18, 21, 24, 25, 27, 46, 51, 53, 54). Also, studies yielded mixed evidence on the objectives of training. In fact, it remains unclear whether the focus of training should be on enhancing broad knowledge of a spectrum of problems (1, 5, 11, 24, 26, 32, 38, 46, 52), or on enhancing elaborated knowledge of specific problems (10, 12, 15, 18, 27, 35, 54). Also, findings concerning whether training should be on the job were inconsistent (35, 41, 46). Professionals can experience difficulties in prioritizing training due to high work demands, a lack of time, or little motivation (3, 17, 25). Moreover, evidence regarding the effect of training on a professional's self-efficacy was inconsistent: one study described that despite training, professionals still experienced a lack of knowledge and confidence to provide integrated care (39).



### *Guidelines*

A reported facilitator was the presence of evidence-based practice guidelines or protocols for interprofessional collaboration (3, 7, 8, 19, 23, 25, 27, 30, 37, 38, 39, 42, 50). These reported guidelines supported professionals in the recognition and treatment of problems, and in interprofessional collaboration by describing standardized processes for sharing information, decision making, and treatment planning.

### *Self-efficacy*

Feeling comfortable and competent (i.e., self-efficacy) to assess a broad spectrum of problems and collaborate with various professionals was often mentioned as a facilitator in relation to a professional's knowledge (9, 17, 20, 30, 49, 53). Self-efficacy was found to be improved by a professional's perception of empowerment (i.e., the validity to act and the feeling of control over their work), and positive feedback from families (17, 45). Reported barriers were interprofessional challenges and addressing a broad spectrum of severe problems, driving professionals out of their comfort zone and thereby leading to a lack of self-efficacy (9, 15, 17, 20, 24, 27, 29, 33, 35, 51).

## **Theme 5: Interprofessional collaboration**

Facilitators and barriers of the theme 'Interprofessional collaboration' (i.e., working across organizational and professional boundaries) were described in three subthemes: general aspects of interprofessional collaboration (10 studies), familiarity with other professionals (16 studies), and various forms of interprofessional collaboration (19 studies on co-location, 13 on multidisciplinary meetings, 18 on consultation, and 6 on care coordination).

### *General aspects of collaboration*

Reported facilitators to collaboration were concrete objectives and conditions for collaboration, timely involvement of other professionals during early stages of care, and sharing information. Other facilitators were investing in team development and the creating of supportive relationships with other professionals that are based on mutual respect (3, 22, 29, 34, 39, 40, 42, 45). Studies indicated that both structural



collaboration in fully integrated care teams, and flexible collaboration on a case level can facilitate integrated care (19, 29). When forming these multidisciplinary care teams, it is important to be aware of the size of a care team: involving too many professionals was described as a barrier (37, 39).

#### *Familiarity with other professionals*

Familiarity with other professionals was reported as a facilitator, by adequately incorporating different perspectives, and understanding other professionals' contributions and day-to-day practice (3, 6, 11, 12, 23, 32, 33, 37, 42, 46, 50, 53). Familiarization can be improved by sharing brief bibliographical information, evaluate strengths or limitations in collaboration, and regular clinical case discussions (12, 14, 23, 53). Being unfamiliar with other professionals' care systems, services, language, and protocols were reported barriers that led to frustration and underutilization of services (22, 29, 33, 37, 45, 50).

#### *Forms of integrated care*

Co-location and multidisciplinary meetings seemed to broaden the scope of care provided, increase information exchange, and improve opportunities for learning (6, 16, 19, 21, 33, 37, 39, 46, 47, 48, 50, 52, 53). Also, co-location and multidisciplinary meetings were described as leading to more frequent contact moments and warm handoffs (4, 10, 28, 29, 41, 42, 52), positive perception of interprofessional collaboration (16, 43), more appropriate assessment or referral (22, 31, 33), and eventually time saving (30). Consultation of other professionals was a reported facilitator that led to a feeling of support, improved staff wellbeing, and increased self-efficacy in supporting families (1, 7, 10, 12, 15, 17, 22, 29, 32, 38, 41, 50, 52). A care coordinator was described as a facilitator to integrated care by stimulating interprofessional communication, and having a complete overview of families' needs and the availability of support (7, 10, 29, 42, 50, 55). Although all forms of integrated care were reported as facilitators, one study pointed out that it is not necessarily the physical proximity of professionals that influences integrated care, but the level of communication (23). Reported barriers concerning various forms of integrated care were a



shortage of specialized professionals available for consultation or to work at co-located sites (15, 35, 51), a shortage of time and workspace (16, 21), and inflexible schedules of professionals to participate in meetings (33, 48). Other barriers were a lack of structure or coordination during multidisciplinary meetings (48) and a lack of support and financial compensation for consultation activities (20, 24, 29, 40, 50).

### ***Theme 6: Information exchange***

This theme was strongly related to the theme 'Interprofessional collaboration', as it is about the frequency and consent of sharing information between professionals. The theme 'Information exchange' was divided into two subthemes: communication (22 studies), and sharing information and confidentiality (27 studies).

#### *Communication*

Reported facilitators were clear and transparent communication between professionals (9, 27, 32, 38, 50, 53). Specifically, a shared language, being available for contact, electronic reminders for communication, and acknowledging the importance of clear and transparent communication, facilitated clear and transparent communication (6, 12, 23, 24, 30, 37, 38, 39, 45, 53). Other facilitators were: collaboratively defining expectations for the content, frequency, and timing of communication, evaluation of communication processes, understanding differences in communication styles, and effective oral and written communication skills (9, 12, 23, 26, 34, 38, 42, 46, 48). Reported barriers in communication included a perceived unavailability or unwillingness to communicate, inadequate timing, a lack of reciprocity, and a lack of shared terminology (9, 11, 25, 36, 42, 44, 50, 53).

#### *Sharing information and confidentiality*

Sharing accessible and comprehensible information with other professionals was reported as leading to role expansion and shared knowledge, both facilitators to integrated care (19, 26, 28). Also, shared medical records (e.g., bidirectional system for sharing information, advice, and feedback) were identified as facilitators, by reducing





service duplication, improving regular communication and shared understanding of families' needs (9, 12, 14, 21, 23, 27, 30, 32, 33, 36, 38, 41, 47, 48, 51). Professionals' perception that their input contributed to a care process was deemed important in sharing information (16). Also, discussing the importance of sharing information or possible confidentiality issues with families was described as a facilitator (38, 46, 47). Reported barriers were a lack of information exchange, unawareness of the content of information that other professionals needed, and a failure to understand the provided information (16, 23, 29, 33, 34, 53). Also, misunderstanding of confidentiality requirements across disciplines was a barrier for professionals in sharing information (21, 29, 32, 37, 38, 42, 46, 50, 54).

### **Theme 7: Professional identity**

Facilitators and barriers of the theme 'Professional identity' were described in four subthemes: professional roles and responsibilities (27 studies), attitudes (16 studies), shared thinking (22 studies), and trust, respect, and equality (20 studies).

#### *Professional roles and responsibilities*

Clear professional roles, realistic expectations of other professionals, and being aware of professionals' own boundaries and responsibilities were identified as facilitators (14, 21, 22, 26, 29, 30, 38, 42, 48, 53). Other facilitators were being able to recognize and take responsibility during a care process (45), and the feeling of shared responsibility over complex cases (29, 30, 33, 34, 37). Some studies reported that roles and responsibilities should be discussed and set in advance (29, 41). Yet, other studies described flexible roles and responsibilities as facilitators to integrated care, enabling professionals to respond to the changing needs of families (19, 22, 45, 53). Reported barriers were unclear or competing roles and unrealistic expectations of other professionals, that often led to confusion and conflicts among professionals (6, 11, 22, 23, 29, 36, 37, 39, 42, 44, 45, 50, 53, 54, 55). Other barriers were disagreement over responsibilities, confusion about legal liability, and a perceived lack of reciprocity in collaboration, leading to different feelings of ownership, unclear allocation of tasks, and finger-pointing (6, 24, 29, 48, 50, 51, 54, 55).



### *Attitudes*

Reported facilitators were positive attitudes and commitment towards integrated care or interprofessional collaboration (12, 17, 19, 22, 23, 24, 29, 44, 45, 55). In contrast, reported barriers were a lack of commitment, lack of appreciation of other professionals, and negative experiences with collaboration (4, 14, 17, 19, 22, 23, 33, 34, 42, 54).

### *Shared thinking*

Reported facilitators were integrating viewpoints of other professionals in comprehensive care plans (38, 53) and a shared foundation in thoughts, values, knowledge, and working styles (3, 12, 14, 26, 30, 40, 45, 47). Reported barriers were competing work demands, differences in priorities, various explanatory models, and different (hierarchical) relations between professionals and families (6, 9, 11, 14, 19, 25, 34, 37, 40, 42, 50, 52, 53, 54, 55).

### *Trust, respect, and equality*

Mutual trust, respect, appreciation of the diversity of professional backgrounds, and equality between professionals were found to facilitate integrated care (6, 19, 26, 29, 35, 37, 38, 42, 44, 45, 47, 50, 54). Reported barriers included a lack of trust and respect, perceived inequality between professionals, concerns about confidentiality, and a lack of commonality in the approach of families and other professionals (11, 16, 19, 24, 29, 33, 34, 40, 44, 45, 48, 50, 54).

## **DISCUSSION**

In this systematic review, we aimed to identify facilitators and barriers for professionals to provide integrated care from a broad variety of studies. We included studies with diverse methodologies, populations, settings in Youth Care, and types of integrated care to find common understanding among different contexts and professional disciplines. The current review identified seven themes and 24 subthemes of barriers and facilitators for Youth Care professionals to provide integrated care. Despite the diversity in studies included, the strength of evidence rating showed that the barriers and facilitators were



generally consistent across studies and thereby applicable in a variety of settings.

Overall, the broad variety of facilitators and barriers clearly shows that providing integrated care is a multicomponent and complex process. An important aspect of integrated care is that it is not limited to, or focused on one specific setting or individual, but that it is provided throughout the entire continuum of care. Whether professionals work in universal services or specialized mental health centers, integrated care is influenced by multiple facilitators and barriers on a professional level that require interprofessional collaboration and the addressing of a broad variety of problems. As described in previous research (Curry & Ham, 2010), the variety of studies and integrated care approaches suggest that there is no single approach or model to integrated care that can be applied universally. Hence, different approaches might be needed to fit local and individual needs.

Reflecting upon the themes and subthemes, we conclude that facilitators and barriers regarding interprofessional collaboration were most frequently reported (e.g., time for interprofessional team development, training in interprofessional collaboration, several forms of collaboration, sharing information with other professionals). This finding is consistent with prior work that studied integrated care for children and adolescents with mental health problems (Cooper et al., 2016; Richardson et al., 2017). In addition, findings reported in the themes 'Child's environment', 'Care process' and 'Expertise' suggest that broad assessment of problems and timely identification of the intensity and type of care a family needs are other important aspects of integrated care.

Echoing prior work, our review indicates that the organization of integrated care is substantially influenced by processes on a professional level (Goodwin, 2013; Valentijn et al., 2013). We suggest that when further developing the concept of integrated care, the focus should be on the professionals involved in integrated care on a day-to-day-basis, instead of solely considering interprofessional collaboration



at organizational level (Stein, 2016; World Health Organization, 2016). In the following section, we reflect upon our findings in depth and formulate implications for practice, education, and further research.

### **Specialist versus generalist approach**

Various studies emphasized the importance of expanding knowledge and skills of Youth Care professionals. Echoing prior recommendations (Sunderji et al., 2016), there is a need for role changes and advanced competences for professionals in attaining both a generalist view of a family's welfare, and a specialist's approach on specific needs of each individual family member. However, studies that focused on the knowledge professionals should possess yielded mixed findings (see Theme 1 'Child's environment' and Theme 4 'Expertise'). Specifically, it remains unclear whether this knowledge should be broad (generalist), in depth (specialist), or a combination of both. Although the importance of diverse knowledge can be inherent to the broad spectrum of problems seen in Youth Care, it seems unrealistic that one individual professional can learn and apply all available knowledge in its day-to-day practice. As long as there is no consensus on the basic knowledge and skills a Youth Care professional should possess, it remains unclear whether expanding professionals' knowledge facilitates integrated care (Armitage et al., 2009; Kodner, 2009). Moreover, previous research suggested that working in multidisciplinary teams can expand the scope of care provided when supporting families in Youth Care (Anderson-Butcher, Lawson, & Barkdull, 2002; Golding, 2010; Nolan, Walker, Hanson, & Friedman, 2016). To efficiently compose these multidisciplinary teams, we strongly recommend to further examine what disciplines, knowledge, and skills are needed in a multidisciplinary team to provide integrated support in Youth Care.

Moreover, working alongside a professional with different expertise and collaboratively reflecting on multidisciplinary care processes, can expand a professional's knowledge and skills (see Theme 4, 'Expertise'). Future studies must examine the effectiveness of several forms of interprofessional learning in integrated care. For example, previous studies suggested that active involvement in a continuous



learning cycle with a focus on improving professionals' competences, interprofessional team development, and clinical case discussions facilitates professionals in expanding their knowledge and skills (Langins & Borgermans, 2015; Stein, 2016). When developing learning methods for interprofessional collaboration in Youth Care, the high work demands and difficulties in prioritizing learning activities should be considered. Therefore, we recommend to engage professionals in collaboratively developing learning methods, since this might lead to increased applicability and validity in practice.

### **Assessment and prioritizing of problems**

Broad assessment of problems and timely identification of the intensity and type of care a family needs are important aspects of integrated care (see Theme 1 'Child's environment', Theme 3 'Care process', and Theme 4 'Expertise'). Yet, issues that emerged when reflecting upon these themes were difficulties in prioritizing problems, leading to problems in determining the focus of support. These difficulties seemed related to the interaction of problems within one individual or between different family members. Specifically, the needs of family members can conflict, and professionals can have different perceptions about the primary client within one family. Also, previous research stated that professionals can experience difficulties in incorporating clients' viewpoints in decision-making processes (Simmons, Coates, Batchelor, Dimopoulos-Bick, & Howe, 2018). To enhance professionals' skills in prioritizing problems and shared decision making, we recommend to frequently discuss priorities with families and thereby incorporate their perspectives in the care process. Moreover, our findings in the subtheme 'Guidelines' support the recommendation of the World Health Organization (2016), namely that the use of practice-based guidelines facilitates professionals in prioritizing and decision-making processes. However, details on the implementation and effectiveness of evidence-based practice guidelines were not reported in the studies included in this review. As we know from previous research, adherence to guidelines in applied settings improves when paying specific attention to a structured and tailored implementation in collaboration with the end-users (Fisher, Lange, Klose, Greiner, & Kraemer, 2016).



### **Professional roles and responsibilities**

It is often difficult for professionals to define clear roles in interprofessional collaboration and to share responsibility over a care process (Cooper et al., 2016). Studies in this review indicated that clear roles and responsibilities that are set in advance facilitate interprofessional collaboration (see Theme 7 'Professional identity'). However, other studies reported that roles and responsibilities must be flexible when responding to the changing needs of families in Youth Care. This apparent inconsistency (e.g., fixed versus flexible roles) can be attributed to the variety of professional disciplines involved in care processes and the different needs across families. In line with previous research (Valentijn et al., 2013), we suggest that it is crucial to continuously evaluate roles and responsibilities during a care process, with all stakeholders involved. Yet, it remains unclear how and how often professionals should hold these evaluative meetings. Also, previous research reported a lack of structure during these meetings as a barrier (see Theme 5 'Interprofessional collaboration'). Hence, to guide professionals in organizing these evaluative meetings, future research should study the effectiveness of various forms of evaluative meetings in practice, for example by means of action-research.

### **Time to invest in integrated care**

Supporting families with various needs and interprofessional collaboration are time-consuming processes (see Theme 2 'Preconditions'). Based on the reviewed studies, we suggest that when trying to optimize integrated care processes and eventually save time, it is necessary to invest in prolonged visit times, time for interprofessional team development, and evaluative meetings. However, since a lack of time is a well-known problem in Youth Care, investing time in interprofessional team development and case discussions is limited. Therefore, it is important that professionals are supported in effectively organizing and prioritizing these activities, for example by their management or by practice-based guidelines.

Additionally, it is challenging to estimate the amount of time and number of professionals that are needed in a single care process (see



Theme 2 'Preconditions'). For example, needs differ between families, and fluctuate over time within a family. As we already suggested, more work needs to be done in determining patterns in families' needs, to establish a better estimation of the required time, disciplines, and number of professionals. We also recommend examining the long-term effects of integrated care by setting up a continuous routine monitoring system (see also: Tsiachristas, Stein, Evers, & Rutten-van Molken, 2016). Such a system could, for example, track families' needs and goal attainment, service utilization, and costs of integrated care.

### **Attitudes, skills and competences**

Providing integrated care requires specific attitudes, skills, and competences of professionals, including: (i) positive attitudes and commitment of Youth Care professionals towards integrated care and interprofessional collaboration, (ii) the ability to incorporate viewpoints of several professionals into a comprehensive care plan, and (iii) acknowledgement of the importance of communication and effective communication skills. Previous research demonstrated that it is not necessarily the physical proximity of professionals, but the level of communication that influences integrated care (Greene, Ford, Ward-Zimmerman, Honigfeld, & Pidano, 2016). This indicates that interprofessional communication skills are important to consider when organizing integrated care and must be part of training and education programs for (future) professionals.

Moreover, multiple studies in our review showed that professionals in Youth Care should be able to timely and adequately estimate when and what additional expertise is needed in a care process (see Theme 2 'Preconditions' and Theme 4 'Expertise'). Although this was beyond the scope of our review, we suggest that there might be differences in professionals' perspectives on what expertise is needed, at what time, and to what extent. This is an important issue for future research, since there is often a broad variety of professional disciplines involved in a care process. We recommend the use of qualitative research methods to examine what professionals need in deciding the focus of support and the expertise required to tailor support to families' needs.



### **Strengths and limitations**

This review has several strengths. First, by prospectively registering our review protocol in PROSPERO we kept track of any unexpected differences during the review process that, fortunately, did not occur. Thereby we reduced the risk of reporting bias. Second, our review covered relevant literature regarding facilitators and barriers for Youth Care professionals, due to our extensive search strategy and rigorous analysis. Third, to increase the applicability and generalizability of the results, we included studies of a broad range of settings within the field of Youth Care (i.e., mental health care, primary care, education, child welfare, juvenile justice, substance abuse settings, and child protection). The consistency of reported facilitators and barriers across settings indicate broad applicability across settings and professional disciplines.

Of course, our results should be interpreted in the context of various limitations. Since there was no common approach to measure outcomes across studies, it was difficult to provide an overall comparative analysis of the impact of barriers and facilitators identified in the studies. By means of an a priori developed and pilot tested standardized extraction form, we registered main outcomes for each included study, a working approach that facilitated the collection of comparable information (Burau, 2012). Studies were analyzed by means of open coding, followed by axial coding to explore patterns in coded fragments (Strauss & Corbin, 1990). Data saturation was reached when coding the results, an indication that our review provides an extensive overview of facilitators and barriers from existing literature. Due to the conceptual ambiguity of integrated care (Armitage et al., 2009; Peek & The National Integration Academy Council, 2013), our search terms were broadly defined. However, the definition of integrated care slightly differed across the included articles. We intended to control for these differences by rating the intensity of integrated care and extracting a description of integrated care directly from the included studies on a standardized extraction form. Moreover, we limited our search to English, peer-reviewed articles, with both qualitative and quantitative





research designs and program evaluations. Adversely, we might have missed some relevant information from reports or other gray literature.

We intended to control for quality by critically appraising the quality of individual studies and assessing the strength of evidence per subtheme. However, we did include 18 studies of low quality, for example studies with uncontrolled or unclear designs, and small or unclear samples. We aimed to control for these low-quality studies by including quality of studies in our strength of evidence appraisal. Most of the included studies did not report any effect sizes, hence it was not possible to estimate to what extent facilitators and barriers affected practice. Likewise, the study design did not allow to scrutinize if the distilled themes interacted with each other. As a result, barriers and facilitators are separated in themes that might be interrelated. These limitations have been mentioned in previous reviews in the field of integrated care (Cooper et al., 2016; Richardson et al., 2017), stressing that there is a need for high quality studies to the effects of integrated care in practice (e.g., randomized controlled trials). However, since integrated care is such a context-dependent and multi-component process on several levels, conducting a randomized controlled trial is challenging. In line with previous research (Wisdom, Cavaleri, Onwuegbuzie, & Green, 2012), we therefore suggest that mixed method research, using both quantitative and qualitative research methods is needed to further our understanding of integrated care on a professional level.

## CONCLUSION

Overall, this review clearly shows that providing integrated care is a multi-component and complex process, hallmarked by various facilitators and barriers for professionals. With our review, it was possible to identify barriers and facilitators that were generally consistent from a variety of studies, indicating broad applicability across settings and professional disciplines in Youth Care. The identified barriers and facilitators were related to interprofessional collaboration, including various forms of interprofessional collaboration, efficient information exchange, flexible professional roles, and sharing responsibilities.



We also identified facilitators and barriers for professionals in the assessment of a broad spectrum of problems, timely identification of problems, and prioritizing the needs of families.

Currently, the major focus when organizing integrated care is at an organizational level (Goodwin, 2013). This review demonstrated that considering various aspects of integrated care on a professional level is critical to organize integrated care in practice. Moreover, in education and training for (future) professionals, attention should be paid to various aspects of integrated care like interprofessional communication, the application of practice-based guidelines, and evaluation and reflection on roles and responsibilities. Importantly, a consensus on the general knowledge and skills Youth Care professionals should possess, and disciplines that should be involved in a care process are needed to improve integrated care in practice and develop curriculum methods for future professionals in Youth Care.

## Appendix A. Search strategy

The search strategy was developed in collaboration with the Walaeus Library of the Leiden University Medical Center. The search strategy was originally developed for the PUBMED electronic database, but was adapted for other electronic databases, depending on the database and available filters.

### *Pubmed Search Strategy*

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(((((("Delivery of Health Care, Integrated"[Mesh] OR "Integrated Delivery of Health Care"[tw] OR "integrated Health Care"[tw] OR "integrated HealthCare"[tw] OR "integrated Care"[tw] OR "Collaborative Care"[tw] OR "patient-centered healthcare"[tw] OR "patient-centered health care"[tw] OR "patient-centered care"[tw] OR "patient-centred healthcare"[tw] OR "patient-centred health care"[tw] OR "patient-centred care"[tw] OR "coordinated healthcare"[tw] OR "coordinated health care"[tw] OR "coordinated care"[tw] OR "co-located healthcare"[tw] OR "co-located health care"[tw] OR "co-located care"[tw] OR "colocated healthcare"[tw] OR "colocated health care"[tw] OR "colocated care"[tw] OR family centered[tw] OR family centred[tw] OR familycentered[tw] OR familycentred[tw] OR person centered[tw] OR person centred[tw] OR personcentered[tw] OR personcentred[tw] OR child centered[tw] OR child centred[tw] OR childcentered[tw] OR childcentred[tw] OR ((integrated[ti] OR integration*[ti] OR collaborative[ti] OR shared[ti] OR patient-centered[ti] OR patient-centred[ti] OR coordinated[ti] OR co-located[ti] OR colocated[ti])) AND (care[ti] OR healthcare[ti] OR "health care"[ti]))) AND ("Mental Health"[Mesh] OR mental[tw] OR "behavioral health"[tw] OR "behavioural health"[tw] OR "behavioral healthcare"[tw] OR "behavioural healthcare"[tw] OR "behavioral health care"[tw] OR "behavioural health care"[tw] OR "Psychiatry"[Mesh] OR psychiatry[tw] OR psychiatr*[tw] OR psychol*[tw] OR depression[tw] OR depressive[tw] OR "substance abuse"[tw] OR autism[tw] OR autistic[tw] OR adhd[tw] OR attention deficit[tw] OR psychotrauma*[tw] OR posttrauma*[tw] OR "post trauma"[tw] OR "post traumatic"[tw] OR intellectual disabl*[tw] OR intellectual disabl*[tw] OR mental retard*[tw] OR child protection*[tw]
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OR "social work"[tw] OR psychosocial[tw] OR "psycho social"[tw] OR aggression[tw] OR selfinjur\*[tw] OR self injur\*[tw] OR oppositional behav\*[tw] OR anxiety[tw] OR mood disorder\*[tw] OR learning problem\*[tw] OR problem behav\*[tw] OR eating disorder\*[tw] OR anorex\*[tw] OR bulimi\*[tw] OR OCD[tw] OR obsessive compuls\*[tw] OR neurodevelopmental disorder\*[tw] OR "neuro developmental disorder"[tw] OR "neuro developmental disorders"[tw] OR stress[tw] OR stressor\*[tw] OR tic[tw] OR tics[tw] OR personality disorder\*[tw] OR Substance-Related Disorder\*[tw] OR addict\*[tw] OR psychiatr\*[all fields] OR Socioeconomic disadvantage\*[tw] OR financial problem\*[tw] OR youth care\*[tw] OR youthcare\*[tw] OR "Child Protective Services"[Mesh] OR Child Protective[tw] OR child protection\*[tw] OR "Child Abuse"[Mesh] OR Abuse[tw] OR Abuses[tw] OR neglect\*[tw] OR maltreat\*[tw] OR primary care[tw] OR primary healthcare[tw] OR primary health care[tw] OR "Child Health Services"[Mesh] OR "Child Welfare"[Mesh] OR Child Welfare[tw] OR child care[tw] OR child health care[tw] OR child healthcare[tw] OR "Adolescent Health Services"[Mesh] OR Adolescent Health Service\*[tw] OR Adolescent care[tw] OR Adolescent health care[tw] OR Adolescent healthcare[tw] OR youth health service\*[tw] OR youth health care[tw] OR youth healthcare[tw]) AND ("child"[mesh] OR "Pediatrics"[MESH] OR "Neonatology"[MESH] OR "child"[tw] OR "children"[tw] OR "childhood"[tw] OR "infant"[tw] OR "infants"[tw] OR "pediatric"[tw] OR "pediatrics"[tw] OR "paediatric"[tw] OR "paediatrics"[tw] OR "baby"[tw] OR "babies"[tw] OR "toddler"[tw] OR "toddlers"[tw] OR "newborn"[tw] OR "newborns"[tw] OR "postnatal"[tw] OR "postneonatal"[tw] OR "neonatal"[tw] OR "neonate"[tw] OR "neonates"[tw] OR "suckling"[tw] OR "sucklings"[tw] OR "teen"[tw] OR "teens"[tw] OR "juvenile"[tw] OR "juveniles"[tw] OR "adolescent"[tw] OR "adolescents"[tw] OR "puberty"[tw] OR "youngster"[tw] OR "youngsters"[tw] OR "boy"[tw] OR "boys"[tw] OR "girl"[tw] OR "girls"[tw] OR "schoolchild"[tw] OR "schoolchildren"[tw] OR "stepchild"[tw] OR "stepchildren"[tw] OR youth\*[tw])) NOT ("Asia"[Mesh] OR "Africa"[Mesh] OR "South America"[Mesh] OR "Aged"[Mesh] OR "Viruses"[Mesh] OR "Palliative care"[Mesh] OR "Internal Medicine"[Mesh] OR "Respiratory Tract Diseases"[Mesh]) NOT ("Adult"[Mesh] NOT "child"[mesh]).

Filters: **Publication date from 2002/01/01 to 2018/01/01**



**Appendix B. Study characteristics**

<b>Study Number</b>	<b>Study</b>	<b>Design (method)</b>	<b>Setting</b>	<b>Principal problem or diagnosis</b>	<b>Respondents (n)</b>	<b>Intensity of integrated care</b>	<b>Quality</b>
1	Acri et al. (2016)	Descriptive (Unclear)	Primary care	Mental health problems	YC practitioners (n=unclear)	Fully-integrated	Low
2	Adams, Hinojosa, Armstrong, Takagishi, and Dabrow (2016)	Descriptive (Questionnaire)	Primary care	Broad range of problems	YC practitioners (n=8)	Coordinated	Medium
3	Anderson-Butcher, Lawson, and Barkdull (2002)	Descriptive (Action research)	Child Welfare	Vulnerable families	YC practitioners (n=70)	Fully-integrated	High
4	Bunik et al. (2013)	Descriptive (Questionnaire)	Primary care	Mental health problems	Policy makers and managers (n=57)	Varying	Medium
5	Burka, Van Cleve, Shafer, and Barkin (2014)	Descriptive (Questionnaire)	Primary care; Mental health care	Mental health problems	YC practitioners (n=30)	Fully-integrated	High

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
6	Callaly, von Treuer, van Hamond, and Windle (2011)	Descriptive (Focus groups and interviews)	Primary care	Mental health problems	'Stakeholders' (n=unclear)	Fully-integrated	Low
7	Campo et al. (2005)	Descriptive (Case study)	Primary care	Mental health problems	Unclear (n=unclear)	Fully-integrated	Low
8	Carbone, Behl, Azor, and Murphy (2010)	Descriptive (Focus Groups)	Mental health care	Autism Spectrum Disorder	YC practitioners (n=9)	Fully-integrated	High
9	Campbell et al. (2017)	Descriptive (Questionnaire)	Primary care and mental health care	Mental health problems	YC Practitioners (n=123)	Varying	High
10	Carlson et al. (2012)	Descriptive (Questionnaire)	Early childhood system	Mental health problems, socioemotional wellbeing and children at risk of childhood expulsion	YC Practitioners (n=unclear)	Fully-Integrated	Low

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
11	Collins and McCray (2012)	Descriptive (Interviews)	Social care, Education and primary care	Broad range of problems	YC Practitioners, education workers (n=20)	Coordinated	High
12	Dayton et al. (2016)	Descriptive (Unclear)	Primary care and mental health care	Trauma	YC Practitioners, parents and youth (n=unclear)	Coordinated	Low
13	Eapen and Jairam (2009)	Descriptive (Literature review)	Primary care and mental health care	Mental health problems	Unclear (n=unclear)	Unclear	Low
14	Erickson (2012)	Descriptive (Literature review)	Juvenile Justice and mental health care	Mental health problems, criminal behavior	Unclear (n=unclear)	Coordinated	Low
15	Fallucco et al. (2017)	Descriptive/Pilot study (Questionnaire)	Primary care	Depression, Anxiety or ADHD	YC Practitioners (n=25)	Linkage	High

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
16	Friedman et al. (2007)	Longitudinal (focus groups)	Juvenile Justice, Child care and Child protection services	Family violence	YC Practitioners (n=varying from 25 to 51 participants in 6 different focus group rounds)	Fully integrated	High
17	Gadomski et al. (2014)	Descriptive (Interviews)	Primary care	Mental health problems	YC Practitioners (n=40)	Fully integrated	High
18	Gaines, Missiuna, Egan, and McLean (2008)	Descriptive (Questionnaire and focus groups)	Primary care	Developmental Coordination Disorder	YC Practitioners, occupational therapists (n=147)	Linkage	High
19	Garcia et al. (2014)	Descriptive (literature review)	Child welfare, child protection services	Child maltreatment	YC Practitioners, law enforcement agencies (n=unclear)	Varying	Low



Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
20	Garfunkel, Pisani, leRoux, and Siegel (2011)	Quasi Experimental (Questionnaire)	Mental health care	Mental illness	YC Practitioners (n=147)	Fully integrated	High
21	Godoy et al. (2017)	Descriptive (Case description)	Primary care and pediatric hospital	Mental health problems, psychosocial stressors	YC Practitioners, managers and policy makers (n=unclear)	Fully integrated	High
22	Golding (2010)	Descriptive (Case description, literature review)	Mental health care, education	Mental health problems	YC Practitioners, (n=unclear)	Fully integrated	High
23	Greene, Ford, Ward-Zimmerman, Honigfeld, and Pidano (2016)	Quasi Experimental (Survey, observation)	Mental health care and primary care	Mental health problems	YC Practitioners, (n=39)	Coordinated	High

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
24	Guevara et al. (2005)	Descriptive (Focus groups)	Primary care, mental health, education	ADHD	YC Practitioners (n=varying from 4-10 participants per focus group, 13 focus groups)	Linkage	High
25	Hawkins (2009)	Descriptive (Literature Review)	Substance abuse, Mental health care	Co-occurring mental health and substance abuse disorder	YC Practitioners (n=unclear)	Varying	Medium
26	Hoffses et al. (2016)	Descriptive (Focus groups)	Primary care	Broad range of problems	YC Practitioners (n=unclear)	Unclear	Low
27	Hyman and Johnson (2012)	Descriptive (Literature review)	Primary care	Autism Spectrum Disorder	YC Practitioners and Parents (n=unclear)	Fully integrated	Low



Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
28	Hyter, Atchison, Henry, Sloane, and Black-Pond (2002)	Descriptive (Case description, literature review)	Multi-disciplinary care center for trauma	Trauma	Unclear (n=unclear)	Fully integrated	Low
29	Janssens, Peremans, and Deboutte (2010)	Descriptive (Focus groups)	Mental health care	Mental health problems	YC Practitioners (n=56)	Linkage	High
30	Kirby and Thomas (2011)	Descriptive (Literature review)	Child and youth care services, education	Comorbid developmental disorders	Unclear (n=unclear)	Coordinated	Medium
31	Kolko et al. (2014)	Randomized controlled trial (Questionnaire)	Primary care	ADHD or Disruptive Behavior Disorder	YC Practitioners (n=74)	Coordinated	High
32	Kolko and Perrin (2014)	Descriptive (Literature review)	Primary care	Broad range of problems	Unclear (n=unclear)	Varying	Low

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
33	Levy et al. (2017)	Descriptive (Interviews)	Primary care and mental health care	Mental health problems	YC Practitioners (n=37)	Fully integrated	High
34	Liff and Andersson (2011)	Descriptive (Interviews and observations)	Mental health care	Mental health problems	YC Practitioners (n=73)	Linkage	Medium
35	Lubman, Hides, and Elkins (2008)	Descriptive (Case description and literature review)	Alcohol and other drugs sector	Alcohol problems and co-morbid mental health problems	Unclear (n=unclear)	Fully integrated	Low
36	Lynch, Cho, Ogle, Sellman, and Dosreis (2014)	Descriptive (case study, interviews)	Primary care	ADHD	YC Practitioners (n=11)	Coordinated	High
37	Nadeau, Jaimes, Johnson-Lafleur, and Rousseau (2017)	Descriptive (Interviews)	Primary care	Mental health problems	YC Practitioners, parents and youth (n=15)	Fully integrated	High



Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
38	Njoroge, Williamson, Mautone, Robins, and Benton (2017)	Descriptive (Literature review)	Primary care	Broad range of problems	YC Practitioners (n=unclear)	Fully integrated	Low
39	Nolan, Walker, Hanson, and Friedman (2016)	Descriptive (Focus groups)	Primary care	Autism Spectrum Disorder	YC Practitioners (n=25)	Coordinated	High
40	Ødegård (2006)	Validation study (Questionnaire)	Primary care	Mental health problems	YC Practitioners (n=134)	Coordinated	High
41	Oppenheim et al. (2016)	Descriptive (Interviews, Questionnaire and case study)	Primary care	Broad range of problems	Management of YC practitioners (n=6)	Coordinated	Low
42	Reiss, Greene, and Ford (2017)	Descriptive (Interviews)	Primary care and Mental health care	Mental health problems	YC Practitioners (n=9)	Linkage	High

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
43	Rousseau, Pontbriand, Nadeau, and Johnson-Lafleur (2017)	Descriptive (Questionnaire)	Primary care	Mental health problems	YC Practitioners (n=104)	Coordinated	High
44	Stuart (2012)	Descriptive (Action research auto-ethnography)	Child care, social care, health, justice and education	Broad range of problems	YC Practitioners (n=20)	Fully integrated	Medium
45	Stuart (2014)	Descriptive Action research (interviews, observations, workgroups, system analysis)	Child care, social care, health, justice and education	Broad range of problems	YC Practitioners (n=varying from 11-66 per cycle)	Fully integrated	High
46	Ward-Zimmerman and Cannata (2012)	Descriptive (Questionnaire)	Primary care	Mental health problems	YC Practitioners (n=46)	Coordinated	Low

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
47	Wayne, Alkon, and Buchanan (2008)	Descriptive (interviews, focus groups, computer-based Delphi study)	Early care and education, mental health, parent education and family support	Broad range of problems	YC Practitioners, Policy makers, Parents and Management (focus groups n=910; interviews n=122; Delphi study n=14).	Fully integrated	High
48	Widmark, Sandahl, Pluva, and Bergman (2013)	Descriptive (Interviews)	Child welfare	Anxiety and depression	Parents (n=7)	Linkage	High
49	Wisow, van Ginneken, Chandna, and Rahman (2016)	Descriptive (Literature Review)	Primary care and mental health care	Mental health problems	Unclear (n=unclear)	Fully integration	Low

Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
50	Cooper, Evans, and Pyblis (2016)	Descriptive (Literature review)	Mental health care	Emotional, behavioral and mental difficulties	YC Practitioners, parents, management, policy makers (n=unclear)	Varying	High
51	Davis et al. (2012)	Descriptive (Questionnaire)	Primary care	Behavioral concerns and mental health problems	YC Practitioners (n=70)	Linkage	Medium
52	Briggs, Racine, and Chinitz (2007)	Descriptive (Case description, Questionnaire)	Infant mental health	Mental health problems or developmental problems	YC Practitioners (n=unclear)	Fully-Integration	Low
53	Darlington, Feeney, and Rixon (2005)	Descriptive (Interviews)	Child protection, mental health care	Parental mental health problems, youth mental health problems and child safety concerns	YC Practitioners (n=37)	Varying	High



Study Number	Study	Design (method)	Setting	Principal problem or diagnosis	Respondents (n)	Intensity of integrated care	Quality
54	Darlington, Feeney, and Rixton (2005)	Descriptive (Questionnaire)	Child protection, mental health care	Parental mental health problems, youth mental health problems and child safety concerns	YC Practitioners (n=232)	Varying	High
55	Odegard and Strype (2009)	Descriptive (Questionnaire)	Primary care, mental health care, education	Mental health problems	YC Practitioners (n=134)	Coordinated	High





Appendix C. Summary of findings table

Theme	Subtheme (number of studies) Study numbers	Quality <sup>1</sup>		Context	Consistency	Strength of overall evidence
Child's environment	Family-centered focus (n=17) 6, 11, 22, 25, 29, 30, 32, 34, 42, 44, 45, 47, 49, 50, 51, 53, 54	Facilitators (n=12) High quality: 8 Medium quality: 1 Low quality: 3	Barriers (n=8) High quality: 4 Medium quality: 3 Low quality: 1	General	Mixed	Medium- Strong
	Fragmentation (n=5) 8, 11, 23, 36, 39	Facilitators (n=0) High quality: 0 Medium quality: 0 Low quality: 0	Barriers (n=5) High quality: 5 Medium quality: 0 Low quality: 0	General	Consistent	Strong
Preconditions	Time (n=25) 2, 5, 8, 10, 12, 17, 19, 21, 22, 23, 24, 27, 35, 36, 37, 39, 42, 45, 46, 47, 49, 51, 52, 54, 55	Facilitators (n=8) High quality: 5 Medium quality: 0 Low quality: 3	Barriers (n=19) High quality: 11 Medium quality: 2 Low quality: 6	General	Consistent	Strong- Very strong

<sup>1</sup> Based on critical appraisal of individual studies.



Theme	Subtheme (number of studies)	Study numbers	Quality <sup>1</sup>		Context	Consistency	Strength of overall evidence
Preconditions		Financial (n=7) 2, 5, 21, 33, 39, 42, 47	Facilitators (n=0) High quality: 0 Medium quality: 0 Low quality: 0	Barriers (n=7) High quality: 6 Medium quality: 1 Low quality: 0	General	Consistent	Strong
Preconditions		Professionals and resources (n=28) 1, 2, 3, 6, 7, 8, 9, 11, 13, 17, 19, 21, 24, 27, 28, 29, 32, 33, 39, 41, 46, 48, 49, 50, 51, 52, 53, 54	Facilitators (n=13) High quality: 6 Medium quality: 1 Low quality: 6	Barriers (n=19) High quality: 10 Medium quality: 2 Low quality: 7	General	Mixed	Strong
Care process		Screening and assessment (n=21) 1, 8, 11, 12, 15, 17, 21, 26, 27, 28, 29, 32, 33, 35, 38, 41, 46, 49, 50, 51, 52	Facilitators (n=19) High quality: 6 Medium quality: 1 Low quality: 12	Barriers (n=4) High quality: 3 Medium quality: 0 Low quality: 1	General	Mixed	Strong



Theme	Subtheme (number of studies) Study numbers	Quality <sup>1</sup>		Context	Consistency	Strength of overall evidence
Care process	Shared care plan (n=5) 7, 25, 38, 39, 50	Facilitators (n=3) High quality: 1 Medium quality: 1 Low quality: 1	Barriers (n=2) High quality: 1 Medium quality: 0 Low quality: 1	General	Consistent	Medium- Strong
Care process	Referral (n=9) 2, 13, 24, 29, 38, 41, 50, 51, 52	Facilitators (n=6) High quality: 1 Medium quality: 1 Low quality: 4	Barriers (n=3) High quality: 2 Medium quality: 1 Low quality: 0	General	Consistent	Medium- Strong
Expertise	Knowledge and training (n=37) 1, 2, 3, 4, 5, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 24, 25, 26, 27, 29, 30, 32, 33, 35, 38, 39, 41, 44, 46, 49, 50, 51, 52, 53, 54	Facilitators (n=30): High quality: 11 Medium quality: 4 Low quality: 15	Barriers (n=17): High quality: 9 Medium quality: 4 Low quality: 4	General	Mixed	Strong



Theme	Subtheme (number of studies)	Quality <sup>1</sup>	Context	Consistency	Strength of overall evidence
Expertise	Guidelines (n=13) 3, 7, 8, 19, 23, 25, 27, 30, 37, 38, 39, 42, 50	Facilitators (n=11) High quality: 7 Medium quality: 1 Low quality: 3	General	Consistent	Strong
		Barriers (n=3) High quality: 1 Medium quality: 1 Low quality: 1			
Expertise	Self-efficacy (n=15) 8, 9, 15, 17, 20, 24, 27, 30, 33, 35, 39, 45, 49, 51, 53	Facilitators (n=6) High quality: 4 Medium quality: 1 Low quality: 1	General	Consistent	Strong
		Barriers (n=12) High quality: 8 Medium quality: 1 Low quality: 3			
Inter- professional collaboration	General aspects of interprofessional collaboration (n=10) 3, 19, 22, 29, 34, 37, 39, 40, 42, 45.	Facilitators (n=8) High quality: 7 Medium quality: 0 Low quality: 1	General	Mixed	Medium- Strong
		Barriers (n=3) High quality: 2 Medium quality: 1 Low quality: 0			



Theme	Subtheme (number of studies) Study numbers	Quality <sup>1</sup>		Context	Consistency	Strength of overall evidence
Inter- professional collaboration	Familiarity with other professionals (n=16) 3, 6, 11, 12, 14, 22, 23, 29, 32, 33, 37, 42, 45, 46, 50, 53	Facilitators (n=14) High quality: 9 Medium quality: 0 Low quality: 5	Barriers (n=6) High quality: 6 Medium quality: 0 Low quality: 0	General	Consistent	Strong- Very Strong
	Forms: Co- location (n=19) 4, 6, 12, 15, 16, 19, 21, 23, 29, 30, 31, 33, 37, 39, 43, 46, 47, 50, 52	Facilitators (n=18) High quality: 11 Medium quality: 2 Low quality: 5	Barriers (n=2) High quality: 2 Medium quality: 0 Low quality: 0	General	Mixed	Strong
	Forms: Multidisciplinary meetings (n=13) 10, 16, 19, 21, 22, 28, 29, 33, 41, 42, 48, 50, 53	Facilitators (n=13) High quality: 9 Medium quality: 0 Low quality: 4	Barriers (n=2) High quality: 2 Medium quality: 0 Low quality: 0	General	Consistent	Strong- Very Strong



Theme	Subtheme (number of studies)	Study numbers	Quality <sup>1</sup>	Context	Consistency	Strength of overall evidence
Inter- professional collaboration	Forms: Consultation (n=18)	1, 7, 10, 12, 15, 17, 20, 22, 24, 29, 32, 35, 38, 41, 50, 51, 52, 54	Facilitators (n=13) High quality: 5 Medium quality: 0 Low quality: 8	General	Consistent	Strong
			Barriers (n=9) High quality: 7 Medium quality: 1 Low quality: 1			
Inter- professional collaboration	Forms: Care- coordination (n=6)	7, 10, 29, 42, 50, 55	Facilitators (n=6) High quality: 4 Medium quality: 0 Low quality: 2	General	Consistent	Medium
			Barriers (n=0) High quality: 0 Medium quality: 0 Low quality: 0			
Information exchange	Communication (n=23)	6, 9, 11, 12, 23, 24, 25, 26, 27, 30, 32, 34, 36, 37, 38, 39, 42, 44, 45, 46, 48, 50, 53	Facilitators (n=19) High quality: 10 Medium quality: 2 Low quality: 7	General	Consistent	Strong- Very Strong
			Barriers (n=9) High quality: 8 Medium quality: 1 Low quality: 0			






Theme	Subtheme (number of studies)	Study numbers	Quality <sup>1</sup>	Context	Consistency	Strength of overall evidence
Information exchange	Sharing information/ confidentiality (n=27)	9, 12, 14, 16, 19, 21, 23, 26, 27, 28, 29, 30, 32, 33, 34, 36, 37, 38, 41, 42, 46, 47, 48, 50, 51, 53, 54	Facilitators (n=20) High quality: 8 Medium quality: 2 Low quality: 10	Barriers (n=14) High quality: 11 Medium quality: 1 Low quality: 2	General	Mixed
						Strong
Professional identity	Professional roles and responsibilities (n=27)	6, 11, 14, 19, 21, 22, 23, 24, 26, 29, 30, 33, 34, 36, 37, 38, 39, 42, 44, 45, 48, 50, 51, 53, 54, 55	Facilitators (n=14) High quality: 7 Medium quality: 2 Low quality: 5	Barriers: (n=17) High quality: 14 Medium quality: 2 Low quality: 1	General	Mixed
						Strong



Theme	Subtheme (number of studies)	Quality <sup>1</sup>	Context	Consistency	Strength of overall evidence
Professional identity	Attitudes (n=16)	Facilitators (n=11)	General	Consistent	Strong
	4, 12, 14, 17, 19,	High quality: 8			
	22, 23, 24, 29, 33,	Medium quality: 1			
Professional identity	34, 42, 44, 45, 54,	Low quality: 2	General	Consistent	Strong
	55				
	Shared thinking (n=22)	Facilitators (n=10)			
Professional identity	3, 6, 9, 11, 12, 14,	High quality: 5	General	Consistent	Strong- Very Strong
	19, 25, 26, 30, 34,	Medium quality: 1			
	37, 38, 40, 42, 45,	Low quality: 4			
Professional identity	47, 50, 52, 53, 54,		General	Consistent	Strong
	55				
	Trust, respect and equality (n=20)	Facilitators (n=12)			
Professional identity	6, 11, 16, 19, 24,	High quality: 6	General	Consistent	Strong
	26, 29, 33, 34, 35,	Medium quality: 1			
	37, 38, 40, 42, 44,	Low quality: 5			
Professional identity	45, 47, 48, 50, 54		General	Consistent	Strong







# 3 What do parents expect in the 21st century? A qualitative analysis of integrated Youth Care

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**ABSTRACT**

To provide integrated Youth Care responsive to the needs of families with multiple problems across life domains, it is essential to incorporate parental perspectives into clinical practice. The aim of this study is to advance our understanding of key components of integrated Youth Care from a parental perspective. Semi-structured interviews were administered to 21 parents of children receiving Youth Care from integrated care teams in the Netherlands. Qualitative content analysis was conducted by means of a grounded theory approach following qualitative reporting guidelines. Parental perspectives were clustered into six key components: a holistic, family-centered approach; addressing a broad range of needs in a timely manner; shared decision making; interprofessional collaboration; referral; and privacy. Parents emphasized the importance of a tailored, family-centered approach, addressing needs across several life domains, and active participation in their own care process. However, they simultaneously had somewhat opposing expectations regarding these key components, for example, concerning the changing roles of professionals and parents in shared decision making and the value of involving family members in a care process. Professionals should be aware of these opposing expectations by explicitly discussing mutual expectations and changing roles in decision making during a care process. To enable parents to make their own decisions, professionals should transparently propose different options for support guided by an up-to-date care plan.



## INTRODUCTION

Sustainable change in Youth Care can only be achieved in cooperation with all parties involved, especially parents and their children (Welling, 2015). Previous studies have shown that client perspectives demonstrate low convergence with quality indicators based on clinicians, research, and policy (Bröcking, 2016; Luther et al., 2019). Clients often value functional outcomes in the context of everyday living and quality of life over control of their illness (Adams & Drake, 2006; Davis, Claudius, Palinkas, Wong, & Leslie, 2012). Moreover, incorporating client perspectives into clinical practice is associated with improved working alliance, increased satisfaction with services, and autonomy support (Luther et al., 2019). Thus, to provide integrated Youth Care responsive to the needs of families, it is essential to incorporate parental perspectives into clinical practice (Miller et al., 2009). Therefore, this study aims to advance our understanding of key components of integrated Youth Care from a parental perspective.

Youth Care encompasses the support for children aged 0–23 years and their families who need support from a variety of services, including preventive health services, youth mental health support, and specialized (mental health) care (Hilverdink, Daamen, & Vink, 2015). Families in Youth Care with multiple needs often deal with a plurality of (enduring) co-occurring psychosocial problems in various areas of life (Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016). It is difficult to support these families due to the interactions between problems, the varying needs of families, the organization of care focusing on single needs, and a lack of coordination between the multiple care services involved (Appleyard, Egeland, van Dulmen, & Sroufe, 2005; De Jong et al., 2015; Tausendfreund et al., 2016). If left untreated, these problems adversely affect a child's development and family functioning, leading to an increased burden on social, familial, and academic functioning that tend to persist into adulthood (Wang et al., 2005). For example, unsupported mental health problems can eventually lead to social isolation, poor educational achievement, emotional dysregulation, and parental distress (Sellers et al., 2019; Sunseri, 2019).



To meet the needs of these families, Youth Care professionals seek to promote coherent, continuous, and coordinated care across several life domains, also defined as integrated Youth Care (Kodner, 2009; Tausendfreund et al., 2016). The aim of integrated Youth Care is to coordinate services around families' needs and improve quality of support by incorporating services, and ensuring collaboration between professionals (Kodner, 2009). Providing this integrated Youth Care has increasingly been recognized as a necessity by professionals, policy makers, researchers, youth, and parents as it can be effective to improve the care process and families' satisfaction with care (Campo, Geist, & Kolko, 2018; Davis et al., 2012; Kodner, 2009; Patel, 2013). Although evidence on the effectiveness of integrated Youth Care is promising (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015; Baxter et al., 2018), there is a gap between empirical support for the effectiveness of integrated approaches and the efficacy of these models in actual practice (Sunderji, Ion, Ghavam-Rassoul, & Abate, 2017).

Following the principles of Evidence Based Practice to organize high-quality care, it is crucial to combine client perspectives, clinical experiences, and evidence from research (Kuiper, Munten, & Verhoef, 2016). As previous research to youth engagement in the organization and policy of services suggested, it is important to engage children and their families in developing integrated care, since this can increase service uptake, engagement in-, and control over their care process, and satisfaction over services (Hasall et al., 2019; Hawke et al., 2019; Henderson, Hawke, & Relihan, 2018; Hetrick et al., 2017). These studies recommend to organize accessible and welcoming locations with minimal waiting times, where youth feel valued and respected. Also, co-location of services, offering walk-in sessions, and meeting youth at a location of their choice can increase accessibility (Hasall et al., 2019; Hetrick et al., 2017). However, these recommendations cannot be generalized to parental perspectives, since youth perspectives do not necessarily align with those of parents.

Moreover, a limited number of studies have attempted to determine key components to integrated Youth Care from a parental perspective.



For example, a small qualitative study focusing on a specific population (parents of children with anxiety and depression), demonstrated that the presence of a care coordinator enabled parents to focus on their child, instead of coordinating the care process among multiple professionals (Widmark, Sandahl, Piuva, & Bergman, 2013). Also, this study found that integrated Youth Care was hindered by a lack of clarity with respect to allocation of responsibilities and confidentiality issues between professionals (Widmark et al., 2013). Studies on integrated care in other fields of interest, for example, general health care and adult services, have found that from a client perspective, timely access to services, smooth transitions between health care providers, adequate exchange of information, and co-location of services are important aspects of integrated care (Kodner, 2009; Sunderji et al., 2017). However, integrated care has been deemed a highly context-dependent process and there is no single example or best practice applicable to all settings (Busetto, 2016; Lyngso, Godtfredsen, & Frolich, 2016; Widmark et al., 2013).

An important issue in integrated Youth Care is determining the focus of support. One of the leading principles of decision making in integrated Youth Care is shared decision making, in which clients and professionals collaborate to make decisions about a care process (Bunn et al., 2017; Smits & Jukema, 2016). Although shared decision making can lead to improved client satisfaction and self-support skills, implementing shared decision making across settings is intricate (Bunn et al., 2017). Particularly in integrated Youth Care, shared decision making can be complicated by difficulties in prioritization of needs, sequencing of services, conflicting needs of family members, and a large number of professionals involved in a care process (Bunn et al., 2017; O'Brien, Crickard, Rapp, Holmes, & McDonald, 2011; Shaw, Rosen, & Rumbold, 2011). Previous research demonstrated that parents and youth might need support for their role in decision making (Kokanovic et al., 2018). Moreover, Youth Care professionals often experience difficulties incorporating multiple perspectives into a comprehensive care plan (Davis et al., 2012; Simmons, Coates, Batchelor, Dimopoulos-Bick, & Howe, 2018). Disagreement between youth, parents, and professionals





concerning the form and intensity of support also hinder shared decision making (Kuiper et al., 2016; O'Brien et al., 2011).

Yet, despite the importance of incorporating client perspectives into clinical practice, little attention has been paid to parental perspectives on integrated Youth Care and decision-making processes (Bröcking, 2016). Parents are crucial in children and young persons' life's and their recovery process (Levasseur, Roeszler, Den Besten, & Pinkoski, 2019). Also, they are, especially in young children, the first point of contact with professionals and play an important role in treatment participation (Smith, Linnemeyer, Scalise, & Hamilton, 2013). Therefore, this qualitative study sets two objectives: (1) to identify what parents consider key components of integrated care, and (2) to describe facilitators and barriers of integrated Youth Care according to parents. The objectives are to advance the understanding of integrated Youth Care from a parental perspective, to eventually enable professionals to tailor integrated Youth Care to the needs of families with multiple needs. Also, the results of this study might encourage services and policy makers to include quality indicators that reflect integrated Youth Care from a parental perspective.

## **METHODS**

### **Setting**

This study is part of the research project of the Academic Workplace 'Gezin aan Zet' (translated: Family's Turn), a collaborative initiative in the Netherlands, involving stakeholders from practice (youth and parents, professionals), academia, policy, and education. The current study focusses on parents receiving support from full-integrated, multidisciplinary care teams (Leutz, 1999), the so-called Youth Teams that operate in almost all municipalities in the Netherlands (see also Text Box 1 for the context of Youth Teams; Van Arum & Van den Enden, 2018). Each Youth Team consists of eight to twelve professionals with different expertise (e.g., social work and education, specialized mental health care, infant mental health, (mild) mental retardation, coaching, parenting support, and child protection; Hilverdink, 2013). Youth Teams



support families as much as possible within their own environment and operate within a primary care setting as a linking pin between universal services and specialized care (Hilverdink et al., 2015). If necessary, they provide short-term, ambulatory support or refer to more specialized Youth Care, following a matched- or stepped-care approach (Bower & Gilbody, 2005; Leloux-Opmeer, Kuiper, Swaab, & Scholte, 2017). In total, six Youth Teams from two regions in the Netherlands (Holland Rijnland and The Hague) participated in the overall research project.

**Text Box 1:** The context of Youth Teams

In 2015, there has been a decentralization of the Youth Care system in the Netherlands. Currently, municipalities are responsible to organize and provide Youth Care on a local level, including preventive support, primary care, specialized mental health care, and child protection. Arguments for this decentralization were reported deficiencies concerning an increased use of care, pressure on specialized care, fragmentation of support, and a lack of interprofessional collaboration. Municipalities aim to provide accessible, integrated care within families' own environment by decompartmentalization of budgets and organizing local support for children and their families with a variety of psychosocial, stress-related, and socio-economic needs.

In almost all municipalities in the Netherlands, multidisciplinary care teams (i.e., Youth Teams) are operative to organize and provide integrated Youth Care on a local level. All professionals in Youth Teams have a broad range of tasks to ensure high quality support for children and their families, with a focus on empowerment, strengthening the capacities of families, involving the social network of families, and provide early detection and support. Although specific tasks and team composition of a Youth Team varies depending on local needs, professionals generally have four major functions: (i) accessible support by means of



consultation, advice and basic diagnostics to identify needs, (ii) a linking pin between universal services and specialized Youth Care, (iii) coordinate support in collaboration with other (local) services, and (iv) provide ambulatory support if needed.

Since professionals in Youth Teams provide support to families with a broad variety of needs, they operate with a generalist view on the entire family's welfare, and a specialist focus on specific needs (e.g., specialized mental health care, parental support, child protection). Professionals in Youth Teams are responsible to preserve their specialism by means of training and supervision. Due to its multidisciplinary character, Youth Teams can provide a broad range of services, leading to increased access of support. Also, professionals can learn from each other's expertise, by closely collaborating in care processes. To improve collaboration, professionals in Youth Teams meet every week to discuss cases and team functioning. Moreover, as a linking pin between universal services and specialized mental health care, Youth Teams closely collaborate with local general practitioners, schools, services for adult mental health support, financial support, and preventive services.

### Participants

Parents were invited to participate in a semi-structured interview by an email from their Youth Team professional. As we aimed to prevent convenience sampling bias, professionals were encouraged to approach all parents in their caseload (Etikan, Musa, & Alkassim, 2016). The email contained a description of the project and the process of interviewing (audio-taping, confidentiality, and the right to withdraw at any moment). A parent representative (BH) supported the researchers in formulating comprehensible content to ensure that parents understood the information. After parents expressed their interest, they were called by a student of the Leiden University of Applied Sciences, who worked under the supervision of the researchers (LAN



and JE). From the 22 parents who were approached, one parent refused to participate due to a lack of time.

To guarantee parental perspectives were based on actual experiences, we purposively included parents who had at least three meetings with a Youth Team professional (Teddlie & Yu, 2007). There were no further criteria for in- or exclusion, since we aimed to involve a heterogeneous group of parents, representing the diverse population of families in Youth Care. After parents agreed to participate, the interview was scheduled at a place of their choice, mostly at home. All parents gave written informed consent prior to the interview. The researchers had no prior knowledge of the participants and vice versa. All parents except one mother filled in a demographic survey, her data was listed as missing. The Medical Ethics Review Board of Leiden University Medical Center concluded that the research project was not subject to the Medical Research Involving Human Subject Act (WMO) and complied with the Netherlands Code of Conduct for Research Integrity. The Consolidated criteria for Reporting Qualitative Research (Tong, Sainsbury, & Craig, 2007) were applied to promote transparency and ensure clear and comprehensive reporting of the study methods.

### **Data collection**

To shed light on the complex process of integrated care and allow parents to express their experiences, semi-structured interviews were conducted (Shaw et al., 2011). A topic list with open-ended questions was formulated in advance based on previous studies of client perspectives on integrated care (Sunderji et al., 2017; Widmark et al., 2013). The topic list was supplemented with input from a reflexive meeting of the authors (LAN, JE, EAM, CHZK) and two Youth Team professionals. Subsequently, the topic list was pilot tested on a parent representative (BH) and minor linguistic adjustments were made. Next to general questions on the support of a Youth Team and overall satisfaction, the topic list included questions on: (i) a family-centered focus (e.g., experiences with the involvement of family members and the social network in a care process), (ii) collaboration between professionals and parents (e.g., attitudes and communication of professionals towards



parents), (iii) parental involvement in shared decision making (e.g., how parents experienced their roles in decision making processes, experienced freedom to adapt treatment plans), (iv) interprofessional collaboration and joint meetings (e.g., parental experiences with joint meetings and collaboration between professionals involved in the care process), (v) experiences with a shared care plan (e.g., whether there was a care plan, and the role parents played in formulating the care plan), (vi) availability of care (e.g., time between application for support and first meeting, availability of specific support), and (vii) privacy-issues (e.g., confidentiality of information and communication between professionals).

The interviews were conducted between February and June 2017 by two students (one male and one female) of the Leiden University of Applied Sciences, accompanied by a researcher experienced in interviewing and qualitative data analysis (LAN or JE, both female). Field notes were obtained during each interview. A reflexive meeting to evaluate the interview process and discuss new insights between the student and one of the researchers (LAN or JE) took place after each interview. All parents were assigned a study number to guarantee anonymity. Each interview was audio-recorded and transcribed (verbatim) afterwards. Parents were asked if they wanted to comment on the transcripts, however, no parent was interested in doing so. The presented quotes have been translated from Dutch to English by three researchers (LAN, SvdD, PJR). Due to the verbatim transcription, the quotes presented in our results section contain literal wordings and therefore, might not be completely fluent.

### **Analysis**

All transcripts were imported into ATLAS.ti (version 7), a computer program for labelling and organizing text content. In analyzing the transcripts, we applied a triangulation approach by using both inductive and deductive strategies (Van Staa & Evers, 2010). A coding tree was developed and applied based on the topic list, supplemented with codes that arose from open coding based on the grounded theory approach (Corbin & Strauss, 1990). Two researchers (LAN and JE) discussed each



coded transcript to resolve differences in coding. No additional codes were added after coding approximately 15 out of the 21 interviews, an indication that saturation was reached and no supplemental interviews were needed (Saunders et al., 2018). Second, axial coding took place by further analysis and merger of the coded fragments, resulting in six key components (Saldaña, 2015). During reflexive meetings, the researchers (LAN, JE, EM) and parent representatives (BH and CdK) discussed the interpretation of the codes and components. Subsequently, the first author (LN) deductively compared the themes that emerged from the thematic analysis by re-reading the transcripts. By applying this bracketing method, we have limited possible adverse effects of prejudices that may have affected the research process (Tufford & Newman, 2010).

## RESULTS

### Demographics

In total, 21 parents were interviewed, 17 mothers and 4 fathers, all from different families. The interview duration ranged from 31 to 92 minutes ( $m=53$  minutes). Eleven parents provided information regarding their child's age, that ranged from 3 to 21 years ( $n=17$ ,  $m=11.23$ ). Although the diagnosis of the child and type of familial problems were not explicitly asked, all parents had received support from professionals of Youth Teams, supplemented with other services such as specialized mental health-, mediation-, or financial support services. This is an indication of multiple needs across several life domains. For an overview of demographic characteristics of the parents, see Table 1.

### Findings

Parents described integrated Youth Care as a process where multiple professionals collaborate to provide adequate care for the entire family. Overall, parents were satisfied with the support of local multidisciplinary Youth Teams. Despite the heterogeneity of the participants, our results show a high consensus between parents in their perspectives on integrated Youth Care. Based on the open coding of the interviews, six key components were formed, displayed in Table 2. These components will be further explained in the following section.



**Table 1.** *Demographic characteristics of the parents*

<b>Variable</b>	
Gender	
Male [n(%)]	4 (19.1%)
Female [n(%)]	17 (80.9%)
Age in years	
Mean age in years (SD)	43.75 (8.47)
Age range in years	26-57
Cultural Background	
Western [n(%)]	17 (85.0%)
Non-Western [n(%)]	3 (15.0%)
Highest Educational Level	
Primary Education [n(%)]	2 (10.0%)
Intermediate Vocational Education [n(%)]	8 (40.0%)
Higher Vocational Education [n(%)]	7 (35.0%)
University [n(%)]	3 (15.0%)
Marital Status	
Two-parent household [n(%)]	10 (50.0%)
Divorced [n(%)]	9 (45.0%)
Single-parent household [n(%)]	1 (5.0%)
Total number of Children	
One child [n(%)]	5 (25.0%)
Two or more children [n(%)]	15 (75.0%)

Note. n=21.

### ***Holistic, family-centered approach***

All parents emphasized the importance of a holistic, family-centered approach in integrated Youth Care: a focus on a families' welfare across several life domains, instead of solely addressing the needs of the child with the most explicit problem behavior. Parents' main argument for a family-centered approach was that the problems of one family member often influence the entire family's well-being. Addressing the welfare of all family members was experienced as having a positive effect on a family's capacity to addressing their needs.



**Table 2.** *Components of integrated Youth Care according to parents*

Component	Description	Codes from coding scheme
Holistic, family-centred approach	A holistic approach of needs and strengths of all family members	Family-centred focus Broad focus on needs Social network
Addressing a broad range of needs in a timely manner	Timely support across several life domains, tailored to a family's needs	Timely signalling Prevention Access to care Scale up/down Visibility of professionals
Shared decision making	Parental involvement in decision making processes	Shared care plan Shared decision making Freedom of choice Point of view parent versus professional
Interprofessional collaboration	Collaboration between professionals with different expertise, or from different organizations	Communication professionals Collaboration professionals Co-location Coordination Multidisciplinary meetings
Referral	Transition from one care provider/organization to another	Referral End of a care trajectory Evaluation of a care process
Privacy	Privacy of family members during information exchange	Privacy Trust

*“When a single person has a problem, this in turn also has its effect on the rest of the family. So, it is great to start together in the assessment phase, and to continue individually during the care process.”*

- Parent 3.1.

To facilitate a complete overview of families' functioning, various parents described that professionals should incorporate all family





members' perspectives on needs and strengths, supplemented by the perspectives of teachers and other professionals like general practitioners. According to most parents, discussing the various perspectives with families led to new insights into needs and strengths, which in turn resulted in a feeling of empowerment and positively influenced the care process.

*"And I can tell my story, but I see it from one direction. I want an extra pair of eyes that look at the situation from different angles. In the end, that went very well, because of the open communication with school and the general practitioner:"*

- Parent 1.1.

A barrier in mapping the entire families functioning was that some parents experienced uneasiness the moment a professional asked questions about family functioning across several life domains, without explicitly mentioning the importance of asking these questions. To illustrate, one parent was confused that a professional asked about her/his family's financial situation, while the initial application for support was based on a child's externalizing behavioral problems at school.

*"The reason why they actually want to know so much about us, while I only asked a question about my son or daughter. And when an explanation is given, then you think 'all right, on the one hand it makes sense, so it's a plan for the whole family, the functioning of the whole family'. I do understand that:"*

- Parent 2.1.

Alongside the family-centered approach, Youth Team professionals often proposed to involve a family's personal social network for informal support. By drawing a visual overview of the social network, parents reported that they gained more insight in the people whom they can ask for informal support. A facilitator in involving the social network was that parents chose by themselves who they approached, this was



not dictated by professionals. Some parents experienced that involving grandparents, friends, or neighbors as support resulted in more energy and strength to face problems. Importantly, not all parents felt the need to involve their personal social network in the care process. Barriers in involving the social network were cultural and generational differences in talking about problems and a social network that was already overburdened.

*"My mother is from a different generation, and she says: 'these kinds of problems you have to solve yourself, do not air your dirty laundry.'"*

- Parent 1.7.

### ***Addressing a broad range of needs in a timely manner***

In integrated Youth Care, addressing the needs of all family members in a timely manner was reported as essential. However, parents emphasized that an integrated approach does not mean that all needs should be addressed simultaneously. In fact, too many treatment goals at the same time resulted in overburdening of families, hindering the care process. Jointly prioritize needs and decide on the focus of support was described as a facilitator, while focusing on a family's needs instead of a supply-oriented approach.

*"I like the fact that not everyone is placed inside a box of 'that is how you function, and we are going to solve it in the following standard ways.' No, they really assessed our individual needs."*

- Parent 3.2.

All parents reported long waiting lists, often for specialized services as a major barrier to addressing needs in a timely manner, leading to insufficient support, stagnation of the care process, an increase in needs, and difficulties in interprofessional collaboration. Nevertheless, parents differed greatly in their perceptions of waiting times. This variety seemed related to the severity of problems: the more severe the problems, the more urgent the need for help, and the longer the



perceived waiting time. Furthermore, a lack of clarity of services and specific demands of organizations (e.g., refusing family members with comorbid problems) were described as barriers in integrated Youth Care. Parents emphasized the need of transparent communication about waiting times and the type of services offered by organizations.

*“Because [organization] is not always clear in what they can provide and can’t provide, the Youth Team cannot adapt to this. So, the communication and the care offered were not always clear. So sometimes it is not entirely clear what one party does and what the other party does. And the communication is just rigid, making it very difficult to coordinate things.”*

- Parent 4.2.

### **Shared decision making**

Multiple examples of shared decision making in integrated Youth Care were described in the interviews: the need for jointly assessing priorities during the care process, the value of making their own decisions on the type and intensity of care, and the increased motivation parents experienced due to the involvement during all stages of care. Freedom of choice and transparent communication about different options for support were reported as facilitators by parents to make their own decisions.

*“No, the decisions are coming from me and my husband. But the coach gave us advice, just for the decision. But we made the decision. We can accept these advices, but we also can just say no.”*

- Parent 2.2.

An up-to-date care plan, shared with families and professionals promoted a transparent overview of the care process and gave insight in current and future goals and actions, facilitating shared decision making, and leading to an increased consensus on the focus of support. Generally, a professional took the lead in formulating the care plan,



by inventorying families' needs and formulating goals. Importantly, parents expressed that they should always participate in this process, by formulating their own goals or adjusting the goals formulated by a professional.

*"They gave us the feeling of being heard, leading to feelings of security, safety, and positivity, and increasing feelings that you can work on something."*

- Parent 1.3.

Frequent evaluation is necessary to maintain an up-to-date and flexible care plan, which is responsive to the changing needs of families. These evaluations should be initiated by professionals, and parents thought it is a professional's responsibility to keep the care plan up to date. Some parents explicitly mentioned an increased feeling of involvement in the care process when developing or evaluating a care plan in collaboration with a Youth Team professional.

There were also barriers in shared decision making reported by parents. First, differences in the local organization of Youth Care, for example, between two adjacent regions, led to perceived disparities in access to services, and most importantly a perceived limited freedom of choice. Second, different views on adequate support, for example between professionals and parents, were experienced as having a negative effect on shared decision making. These differences were particularly problematic, since parents trust and value a professionals' expertise, but on the contrary, they are experts on their own family situation. Third, in some cases the perceptions of the most appropriate support for families differed between various professionals involved, leading to confusion for parents. In case of differences in perceptions or a perceived limited freedom of choice, a parent suggested that professionals should transparently discuss all options with families.

*"Professionals stated that he was better off at [organization]. I said, 'yes but that is an organization you have a contract with, that is cheaper for*



*you, but not appropriate for my son'. And then you get into a conflict (...). What I found most painful was that they did not look at my son's needs, but what was financially appropriate for them."*

- Parent, 3.2.

### ***Interprofessional collaboration***

Beside the support of a Youth Team, all parents also received support from professionals of other services, like specialized mental health care centers or financial support services. Although many parents preferred support from one single professional or organization, they understood the importance of interprofessional collaboration to provide a broader range of support. Specifically, schools and general practitioners were mentioned as important collaborative partners, since they have known families for a longer period and are involved in their daily lives.

Multiple examples of facilitators and barriers in interprofessional collaboration were reported. For example, familiarity between professionals, frequent communication, and accessibility of professionals were mentioned as facilitators. Also, parents emphasized the importance of clear allocation of tasks and responsibilities, especially when there were multiple family members and professionals involved. Interprofessional collaboration, by ensuring clear communication and coordinated support, should be initiated by professionals, but always with parental consent.

*"I think we were heard, but I think the problem is just the structure. There is just not one person with the final responsibility within the specialized mental health care, who consults our coach. There were all super competent people, but one is about diagnostics, the other one about autism treatment, the other is the psychiatrist.... But there is not one person who says: 'I will take the lead!'"*

- Parent 3.2.



Co-location of services, multidisciplinary care meetings, and a care coordinator were forms of interprofessional collaboration described by parents. Co-location was experienced to have a positive effect on the accessibility of care, by reducing the threshold of seeking help for a broad range of problems. Furthermore, parents experienced that co-located professionals were more familiar with the other professionals' services, leading to increased interprofessional communication, reduced fragmentation of services, and early support. Overall, parents reported to be more satisfied with interprofessional collaboration between professionals from one Youth Team compared to collaboration between professionals from different organizations. Due to the multidisciplinary organization of Youth Teams, parents felt that diverse expertise was easily accessible, increasing the efficiency of the care process. Moreover, parents experienced that Youth Teams had short lines of communication with universal services like schools, general practitioners, and child healthcare centers in the neighborhood. For example, Youth Team professionals were frequently co-located at visible locations, like schools or police stations, leading to an increased accessibility of care and early support.

All interviewed parents had participated in multidisciplinary care meetings. During these meetings, the care process was discussed among the family, the professionals involved, and sometimes the personal social network of the family. Although parents described these meetings as valuable to create an overview of the care process and to reduce fragmentation in support, parents stressed that the meetings were sometimes burdensome. Sufficient preparation facilitated multidisciplinary meetings, both for professionals and the parents, for example by formulating an agenda beforehand. Moreover, parents found it essential that professionals adjusted their pace and language during multidisciplinary meetings, and that there was someone (a professional or someone from a family's network) available to support parents expressing their needs.



*"And also, in response to large meetings, where 17 people were sitting around the table. I felt so alone. There were 17 people around the table and I needed someone to stand by me, who, together with me, stood up for my child."*

- Parent 6.2.

A reported barrier in organizing multidisciplinary meetings was the lack of availability of professionals. Some parents noticed that it was not always a necessity to organize or participate in a face-to-face meeting to come to an agreement. Discussions by phone or email would also have been sufficient and easier to organize, as long as there is transparent reporting to parents afterwards.

A care coordinator, described as a professional with the formal task to maintain an overview of the care process and to stimulate interprofessional collaboration, was reported as an important facilitator to interprofessional collaboration. In fact, a lack of care coordination led to fragmentation of support, a major barrier in integrated Youth Care. Another reported barrier was the high turnover rate of professionals. Due to this turnover rate, parents had to tell their stories repeatedly and form relationships with several professionals, leading to resistance and overburdening of families. Also, the changing composition of a care team led to indistinct responsibilities and a lack of communication between professionals.

*"It would have been great if there was just one professional that supported our family."*

- Parent 1.5.

### **Referral**

Many parents were referred from one organization to another, mostly from local Youth Teams to more specialized mental health care services. To facilitate the referral process professional should have knowledge of local services and the skills to efficiently identify the



needs of families. During referral, parents were often requested to provide personal information. Although most parents understood the importance of sharing this information, some felt uncomfortable sharing personal information with unfamiliar professionals or organizations. Warm handoffs were mentioned as facilitating the referral process, described as the transition from one care provider to another, in which a professional supported parents with sharing relevant information. Parents often had to wait for available support, a barrier in the referral process. During this transition phase, it is essential that there is a contact person for questions and if necessary, a minimum of support available.

*"The professional continued to support [me] until the care was handed over, which was very nice. She joined us to the consultation where the diagnosis and treatment were discussed with the psychiatrist. And she says, you know, if you'd like, I could come along. I could coordinate what [organization] will do and what I'll do."*

- Parent 4.5.

### **Privacy**

Parents emphasized two elements of privacy that were of importance during an integrated care process. First, professionals should consider the privacy of all family members. Specifically, professionals cannot presume that all family members involved in a care process can receive all information reported by other family members. For example, during meetings with the entire family, caution is needed when sharing information that was discussed in previous, individual support sessions. A reported strategy to ensure the privacy of all family members was a discussion of the information that can be shared with other family members beforehand.

According to parents, the second element of privacy was the exchange of information between professionals. All parents understood the importance of information exchange between professionals to adjust support. However, a barrier to integrated care was that professionals





sometimes exchanged information without parental consent. This led to distrust and confidentiality issues, negatively influencing the integrated care process. To facilitate information exchange, professionals should always explain the importance and content of the information that will be shared and explicitly ask for permission to do so.

*"The professional did not go behind my back to call my daughters school and inform on how she was doing. No, she did not do that and that was good. In advance, she asked whether I had any problems with her going to my daughter's school."*

- Parent 1.2.

## DISCUSSION

Thus, what do parents expect from integrated Youth Care in the 21st century? In this qualitative study we identified six key components of integrated Youth Care according to parents: (1) a holistic, family-centered approach, (2) addressing a broad range of needs in a timely manner, (3) shared decision making, (4) interprofessional collaboration, (5) referral, and (6) privacy. Parents described several facilitators, including: transparent communication, involvement in the care process, freedom of choice, comprehensive and up-to-date shared care plans, and clear allocation of tasks and responsibilities between professionals. Unfortunately, a perceived lack of access to services, long waiting lists, and difficulties in interprofessional collaboration hindered integrated Youth Care. When comparing these results to previous findings from studies on integrated care from the perspective of youth, we conclude that there are similarities in themes identified (Hasall et al., 2019; Hawke et al., 2019; Henderson et al., 2018; Hetrick et al., 2017). Both parents and youth stressed the importance of accessible support with minimal waiting times, co-location of services, and engagement in decision making.

In this study, we explicitly studied parental perspectives. Parents stressed the importance of addressing a broad range of needs



across several life domains. However, an integrated approach does not mean that all needs should be addressed simultaneously since this can lead to overburdening of families. Parents value a tailored, family-centered approach, which addresses needs across several life domains and requires active participation in a care process of both parents and professionals. However, they also held somewhat opposing expectations regarding these key components. In the following section we reflect on our findings and provide implications for practice, policy, and future research.

A holistic, family-centered focus was the first component of integrated Youth Care, which focusses on the welfare of the entire family across several life domains. Confirming previous research, parents emphasized that a family-centered approach strengthened a family's capacity to identify and address needs, leading to increased feelings of empowerment, ownership of, and involvement in a care process (Swanson, Raab, & Dunst, 2011). Professionals should explicitly stress the importance of a holistic, family-centered approach, since some parents experienced uneasiness and confusion during broad assessment of all family members on several life domains. Furthermore, although some parents valued the involvement of their personal social network in the care process, there were also parents who did not want to involve their network, especially when they considered their network as overburdened. This is problematic, since families with multiple needs are a population from which we expect to benefit most from a supportive, informal social network (Varda & Talmi, 2018). There is a need for increased efforts of Youth Care professionals to organize informal support for these families, for example by introducing peers or experienced experts as support (Farkas & Boevink, 2018). Including these experienced experts in integrated care has also been identified as a facilitator in previous research to integrated care from youth perspectives (Hawke et al., 2019).

A major barrier in addressing a broad range of needs in a timely manner, the second key component of integrated Youth Care according to parents, was a lack of access and availability of services. According



to parents, this was due to long waiting times and a lack of clarity concerning the type of services offered by organizations. A lack of access and availability negatively influences the care processes, for example by lowering attendance for appointments (Gallucci, Swartz, & Hackerman, 2005; Hasall et al., 2019). Moreover, parental perceptions of waiting times differed greatly by severity: the more severe the problem, the more urgent the need for support and the longer the perception of the waiting time. In line with previous research on youth perspectives (Hasall et al., 2019), parents emphasized that transparent communication about availability of services positively influenced the perceived waiting time. This in turn had a positive effect on the care process, since parental expectations were more aligned with the actual situation. In improving transparency of availability of services, future research should focus on creating innovative (digital) systems with up-to-date information on the availability of services.

Regarding shared decision making, the third component of integrated Youth Care, most parents highlighted the importance of making their own decisions about the type and intensity of care. Multiple parents suggested that the brunt of the responsibility in shared decision making should be with families, and that a professional's main task is to inform parents about the options for support. This finding seems somewhat contradictory to the principles of shared decision making, namely that professionals and families share responsibility over a care process, discuss multiple options for support, and make joint decisions (Bunn et al., 2017; Ten Brummelaar, Knorth, Post, Harder, & Kalverboer, 2016). The focus on the word 'own' seems in line with the worldwide trend of growing participation of clients in health care decisions and health consumerism, in which clients have increased responsibility in their own care trajectories, but also place high demands on immediate, personalized services (Yang, 2019).

Particularly when perspectives on the most appropriate focus of support differ between parents, youth, and professionals, it is unclear who decides in shared decision making. Is a professional with expertise on child development and sequencing of services most



suited to make a final decision, or the family, as an expert on their own situation? A complicating factor is that the extent of a family's involvement in shared decision-making changes over time and often gradually develops during a care process (O'Brien et al., 2011). This finding implicates that during a care process, responsibility for choices might shift from professionals to families. A possible explanation for these changing roles in shared decision making that we can draw from our study, is that families gain more insight in their needs and strengths during a care process, leading to increased feelings of empowerment, ownership, and involvement in decision making processes. Although we did not explicitly ask for the roles of youth in decision making, it might be possible that decision-making power shifts from parents and professionals to children and youth as they grow older (Beacham & Deatrick, 2013). In line with previous research (Kokanovic et al., 2018), we advocate that professionals must be aware of changing roles of families in shared decision making and discuss these roles over time. In that, professionals must consider (cognitive) capabilities of families, the age of children, and always discuss families values and preferences (Mejia, Smith, Wicklund & Armstrong, 2019). Unfortunately, to date there are few guidelines applied by professionals to discuss multiple perspectives and preferences in integrated care (Davis et al., 2012). In our study, we found three major facilitators in shared decision making according to parents: (1) transparent communication, (2) an up-to-date care plan including an overview of the care process and goals for support, and (3) frequent evaluation of this care plan. Future research is warranted to further examine the roles and responsibilities of parents, professionals, and youth in shared decision making. In that, we recommend to consider eventual differences between parents and youth in their perspectives on the roles of children and youth in decision making processes, and under which conditions it is justified to disengage a professional, parent, or youngster from a decision-making process.

Concerning interprofessional collaboration, the fourth key component of integrated Youth Care, parents emphasized the importance of collaboration between schools and care professionals. However,



collaboration between the two systems is fragmented due to differences in culture and language, but also in policy, roles, and tasks (Greene, Ford, Ward-Zimmerman, Honigfeld, & Pidano, 2016). Since this collaboration is of such an indisputable importance for families in Youth Care, we strongly recommend professionals and policy makers to invest in collaborative care initiatives, focused on improving familiarity and communication between Youth Care professionals and schools.

A barrier regarding referral, the fifth key component of integrated Youth Care, was that due to turnover of professionals, parents had to tell their stories repeatedly, leading to resistance and overburdening of families. Previous research stressed that many transitions to other care professionals harm a care process, since it leads to difficulties in forming trusting relationships and reduces the likelihood of appropriate support being sought by the parents (Golding, 2010). In line with previous research (Widmark et al., 2013), parents from our study emphasized the importance to have a professional available for questions and, if necessary, to support transitions between organizations. This can be a professional in the role of a care coordinator, who supports a family during the entire care process and stimulates interprofessional collaboration. Future research should pay attention to the function of a care coordinator (e.g., psychologist, general practitioner, social worker) and its role, for example whether this coordinator should also provide ambulatory support directly to the family.

The sixth key component was the importance of privacy, both within families and between professionals. This component is strongly linked to the other key components, such as a family-centered approach, interprofessional collaboration, and referral. According to parents, professionals should always explain the importance of sharing information, and discuss beforehand what information will be shared with other family members or other professionals.

When reflecting on the setting we studied, we conclude that overall, parents were positive about the support from local, multidisciplinary Youth Teams, especially regarding interprofessional collaboration within



a Youth Team. Furthermore, Youth Team professionals were visible in the neighborhood because of co-location in schools and health care centers, leading to increased accessibility and early support. In line with previous research, we state that centrally and co-located services that facilitate accessibility of integrated support are preferable (Halsall et al., 2019; Hawke et al., 2019). On the other hand, parents also mentioned several disadvantages of organizing Youth Care on a local level (e.g., local differences in organization of care, long waiting lists, and limited access of specialized services). Since measuring the effectiveness and efficiency of Youth Teams was beyond the scope of this study, we cannot conclude whether forming full-integrated teams on a local level is the most efficient way to provide integrated Youth Care. Future studies should focus on the type of services and expertise needed on a local level to effectively meet the needs of families with multiple needs across several life domains.

Our findings should be interpreted in the light of several strengths and limitations. By applying the Consolidated criteria for Reporting Qualitative Research (Tong et al., 2007), we promoted transparency and ensured comprehensive reporting of our study. A unique aspect of this study was the continuous and intensive involvement of parent representatives. The reflexive meetings with both parents and researchers limited potential negative effects of prejudice and helped the researchers to approach parents in an understandable way. We deliberately chose semi-structured interviews as our research method, to shed light on the complex process of integrated Youth Care and to allow parents to express their viewpoints (Shaw et al., 2011). However, a mixed-methods approach would also have been valuable to measure to what extent the key components influenced the actual care process (Creswell, Plano Clark, Gutmann, & Hanson, 2003). Although we aimed to prevent convenience sampling bias, all parents we spoke to had generally positive experiences with the support from a Youth Team. For future studies it might be interesting to compare parents with positive and negative experiences with integrated support, to see whether there are characteristics that predict successful treatment outcomes and satisfaction with support. Furthermore, the relatively



small number of participants and lack of geographic spread across the country might have negatively influenced the transferability of results to other contexts or situations (Tracy, 2010). Moreover, we lack specific information regarding the children's age, type of needs, and intensity of support that families received. It would have been interesting to combine this specific information with the parental perspectives, perspectives of youth, and perspectives of the professionals involved, to study whether these components influence effectiveness and perspectives on integrated care. Also, for this study we included parents based on the assumption that most Youth Team professionals are in contact with the biological parents of children in care. In future studies, perspectives of alternate caregivers and other family members can be investigated further, since they might have other perspectives.

## CONCLUSION

The parental perspectives on integrated Youth Care in this study emphasize that parents have a strong desire for a family-centered approach and active participation in decision making over their own care process. However, since parental expectations regarding these key components of integrated Youth Care are somewhat opposing, professionals should be aware of potential confusion and explicitly discuss mutual expectations during a care process. Furthermore, since parental involvement in shared decision making is not fixed, professionals should frequently evaluate family's roles and responsibilities with the help of an up-to-date care plan and transparently propose different options for support. There is a need for guidelines on how to discuss and decide in integrated care, specifically when there are multiple conflicting perspectives and preferences. Despite the organization of integrated care in local Youth Teams, parents still perceive a lack of access, long waiting lists, and difficulties in interprofessional collaboration. Therefore, it is crucial that both professionals and policy makers invest in collaborative care initiatives, for example between schools and Youth Care. Also, innovative ways to organize integrated Youth Care on a local level for families with multiple needs should be explored further.











# 4

## An integrated approach to meet the needs of high-vulnerable families: a qualitative study on integrated care from a professional perspective

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**ABSTRACT**

To meet the needs of high-vulnerable families with severe and enduring problems across several life domains, professionals must improve their ability to provide integrated care timely and adequately. The aim of this study was to identify facilitators and barriers professionals encounter when providing integrated care. Experiences and perspectives of 24 professionals from integrated care teams in the Netherlands were gathered by conducting semi-structured interviews. A theory-driven framework method was applied to systematically code the transcripts both deductively and inductively. There was a consensus among professionals regarding facilitators and barriers influencing their daily practice, leading to an in depth, thematic report of what facilitates and hinders integrated care. Themes covering the facilitators and barriers were related to early identification and broad assessment, multidisciplinary expertise, continuous pathways, care provision, autonomy of professionals, and evaluation of care processes. Professionals emphasized the need for flexible support across several life domains to meet the needs of high-vulnerable families. Also, there should be a balance between the use of guidelines and a professional's autonomy to tailor support to families' needs. Other recommendations include the need to improve professionals' ability in timely stepping up to more intensive care and scaling down to less restrictive support, and to further our insight in risk factors and needs of these families.



## BACKGROUND

It is a major challenge for professionals in Youth Care to timely and adequately meet the needs of high-vulnerable families (Sunderji, Ion, Ghavam-Rassoul, & Abate, 2017). Although a small group (e.g., 3–5% of all families in the Netherlands; Van den Berg & De Baat, 2012), these families are in need of support from multiple services due to severe and enduring, co-occurring problems across several life domains (e.g., mental health, parenting, financial or housing, somatic health, criminal activities, substance abuse; Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016). While providing integrated support has been recognized as a necessity (World Health Organization, 2016), the support of high-vulnerable families is often complicated by the chronic, unpredictable nature of co-occurring and interacting problems in multiple family members (both child and parental factors), and by families' reoccurring crisis situations (Tausendfreund et al., 2016). If left unsupported due to a lack of treatment, interventions, or assistance, these problems and situations cause distress and impairment with life-long consequences on psychosocial functioning in children, their families, and the community (Sellers et al., 2019). Furthermore, feeling unable to support these families can lead to work-related stress, poor well-being, and an increased risk of burnout in professionals (Johnson et al., 2018).

Currently, support for high-vulnerable families in Youth Care is performed by multiple professionals from different organizations, for example professionals from community centers, (special) education, specialized mental health care, child protection, parenting support, social work, and residential treatment. Youth Care is defined as the support for children aged 0–25 and their families including a wide range of services: from universal and preventive services to specialized care (Hilverdink, Daamen, & Vink, 2015). Previous studies stressed that interprofessional collaboration is at present, however all too often characterized by fragmentation of (costly) services, resulting in a lack of coherence and coordination in the care process (Cooper, Evans, & Phylis, 2016; Hoffses et al., 2016). Subsequently,



high-vulnerable families can present resistance to the support from Youth Care professionals. It is unclear whether these families actively resist support due to their negative experiences with prior support or difficulties in forming therapeutic alliance (Almqvist & Lassinantti, 2018) or whether they do not receive the support they need. To overcome these difficulties, there is a need to substantially improve professionals' ability to support these families in an integrated way.

In integrated care, professionals aim to collaboratively address a wide variety of problems at different levels and sites within the continuum of care in a coordinated, coherent, and continuous way (World Health Organization, 2016). As reported in previous research (Cooper et al., 2016; Hermens, Muntingh, Franx, Van Splunteren, & Nuyen, 2014; Janssens, Peremans, & Deboutte, 2010), a necessity to meet the needs of families is to align available support throughout the entire continuum of care (e.g., from primary care to highly specialized mental health care). According to leading approaches, integrated care provision can be simultaneous, with varying intensity tailored to families' needs (matched care), or sequential by increased intensity of support (stepped care). In matched care, families are allocated ('matched') to support based on the assessment of individual needs, risk factors, characteristics, and values (Linton, Nicholas, & Shaw, 2018; Van Straten, Hill, Richards, & Cuijpers, 2015). Since support is tailored to individual needs, it varies across clients regarding intensity, setting, and type of services (Van Straten et al., 2015). The alternative approach, stepped care, is about offering the least restrictive support that is still likely to yield significant health gain, and 'step up' to more intensive support if needed by a predefined evidence-based sequence of options for support (Benett-Levy, Farrand, Christensen, & Griffiths, 2010; Bower & Gilbody, 2005; Meeuwissen, 2018). Stepped care is self-correcting, meaning that progress and response to support are reflexively monitored and systematically evaluated by professionals and clients to assess if support must be altered (Firth, Barkham, & Kellett, 2015; Meeuwissen, 2018; Richards, 2012). For clients with single problems, stepped care was found to be effective in terms of clinical outcomes, cost-effective allocation of resources, and efficiency of support



(Bower & Gilbody, 2005; Firth et al., 2015; Ho, Yeung, Ng, & Chan, 2016; Van Straten et al., 2015).

Theoretically, matched and stepped care seem distinct. However, in clinical practice these approaches are difficult to distinguish and often applied interchangeably in an unthoughtful way. Moreover, in both matched and stepped care there is a lack of predefined criteria and guidelines for monitoring, evaluating, and applying the most appropriate and available support based on families' multiple needs (Van Straten et al., 2015). Furthermore, guidelines rarely consider decision making for families with multiple interacting problems and do not take social circumstances or individual preferences into account (Raine et al., 2014). This can lead to intuitive decision making by professionals and inadmissible variations in support due to different values, perspectives, and expertise of professionals (Meeuwissen, 2019; Van Straten et al., 2015). The interaction and unpredictable nature of the broad variety of co-occurring problems complicates the matching of individual family members to the most suitable and available support (Van Straten et al., 2015). As a result, some families may receive excessive support, while others are insufficiently supported, leading to inappropriate care provision and inefficient allocation of resources (Lovell & Richards, 2000). Furthermore, a difficulty with sequencing in stepped care reported in previous studies (Cross & Hickie, 2017; Henderson et al., 2017; Repetti, Taylor, & Seeman, 2002) is the individual and disease-specific focus, overlooking the interaction of problems and leading to fragmented support offered by multiple professionals and organizations. Another difficulty in stepped care is that failure of the least restrictive support can negatively affect families' motivation, eventually leading to resistance of families to support and high risks of drop out (Seekles, Van Straten, Beekman, Van Marwijk, & Cuijpers, 2011).

Altogether, these difficulties often result in inappropriate, delayed, or prolonged trajectories, or no care provision at all. Consequently, problems exacerbate, leading to further impairment in functioning of high-vulnerable families (Wang et al., 2005), increased costs, and



burden on the relatively scarce professionals and services such as specialized mental health care (Gilbody, Bower, & Witty, 2006; Smith & Smith, 2010). In addition to governmental policy concerns and changes at organizational level by forming networks and aligning services, there is a need to substantially improve professionals' ability to support these families in an integrated way (Sunderji et al., 2017; Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). Therefore, this qualitative study aims to identify facilitators and barriers professionals encounter when providing timely and adequate integrated care to these families. Actual experiences and perspectives of professionals in the field of Youth Care that work in integrated care teams will be translated into insights and recommendations for professionals, their organizations, researchers, and governmental policy makers.

## **METHODS**

### **Setting**

This study is part of a larger research project which focusses on integrated care teams for children and their families in the Netherlands. In the Netherlands, municipalities are responsible and have the authority to organize Youth Care on a local level, including preventive services, youth mental health care services, and specialized Youth Care (Hilverdink et al., 2015). The presumed improvement of organizing Youth Care on a local level is that integrated care can be provided at an earlier stage, within the family's own environment, and with easy access to various local services. In almost all municipalities, so called Youth Teams operate within a primary care setting, as a linking pin between preventive services and specialized mental health care (Hilverdink et al., 2015). Youth Teams are multidisciplinary teams consisting of eight to twelve professionals with different expertise (i.e., social work and education, specialized mental health care, infant mental health care, support for youth with (mild) mental retardation, coaching, parenting support, and child protection). Youth Team professionals can coordinate a care process and provide short-term support if needed. They operate following both matched and stepped care approaches: professionals tailor support based on families' needs and characteristics ('matched



care'), and if needed, they refer to appropriate support in steps of increased intensity ('stepped care'), starting with the least restrictive as possible.

### **Participants**

Professionals were invited to participate in semi-structured interviews by one of the researchers (LN) during their weekly team meetings. To obtain a representative and complete sample of Youth Team professionals, we aimed to include at least three professionals from each of the six participating Youth Teams. There were no further inclusion or exclusion criteria, since we intended to target a heterogeneous group of Youth Team professionals with diverse expertise (e.g., (infant) mental health, social work and education, (mild) mental retardation, child protection, and parenting support). Convenience sampling was applied based on availability since all professionals were capable of providing adequate information about their experiences in integrated Youth Teams (Etikan, Musa, & Alkassim, 2016). None of the participants refused to participate after application for the interview. There was some degree of acquaintance between participants and the researcher because of their participation in the overall research project. However, the students who conducted the interviews under supervision had no prior knowledge of the participants. Interviews were scheduled at the professionals' work place in a separate room. Participants were verbally informed of the study aims and interview procedures, and subsequently provided written informed consent. Participants were asked to fill in a demographic questionnaire after each interview.

The Medical Ethics Review Board of Leiden University Medical Center judged that the overall research project should not be subject to evaluation based on the Medical Research Involving Human Subject Act (WMO) and complied with the Netherlands Code of Conduct for Research Integrity. Reporting of the study methods and results was informed by the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury, & Craig, 2007).





### **Data collection**

Semi-structured interviews were conducted between July and August 2017 by a student of the University of Applied Sciences in Leiden (DN, male or ET, female) under supervision of a trained interviewer (LN or JE, both female). The interviews were guided by a topic list with open-ended questions to facilitate deep understanding of viewpoints and experiences of professionals (Smith & Firth, 2011). The topic list was formulated in advance based on previous reviews on integrated care (Cooper et al., 2016; Sunderji et al., 2017), and supplemented by input from reflexive meetings of the researchers. Subsequently, the topic list was pilot tested on four professionals from different Youth Teams who were involved in the overall research project. The topics focused on: the general working method of professionals, a professional's expertise to support a broad range of problems in Youth Care, early assessment and identification of problems, clinical decision making, interprofessional collaboration within the Youth Team, interprofessional collaboration with other stakeholders, availability of support, and timely step up or scale down to appropriate support. All interviews were conducted in Dutch, audio-recorded, and transcribed verbatim to avoid interpretation bias (Tufford & Newman, 2010). Field notes were obtained during the interviews. No participant expressed interest in commenting on the Dutch transcripts. The presented quotes in the result section were translated literally from Dutch to English by two researchers (LN, SvdD). Hence, the quotes contain literal wordings and might not be completely fluent.

### **Analysis**

All transcripts were imported into the computer program ATLAS.ti (version 7) for coding and analyzing the text content. A framework method was applied to systematically code the transcripts by following a standardized procedure to maintain a transparent audit trail and enhance the rigor of the analytical process (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie, Lewis, Nicholls, & Ormston, 2013). The coding framework (Appendix A) was built by combined qualitative analysis, both deductively and inductively (Gale et al., 2013). First, codes were deductively formulated based on previous literature on



integrated, stepped, and matched care (LN, SvdD, CK). Facilitators were conceptualized as components enabling professionals to provide integrated care. In contrast, barriers were defined as components limiting integrated care in practice. After familiarization with the transcripts, the framework was pilot-tested on two interviews by two researchers independently (LN, SvdD). After resolving uncertainties and differences, the framework was applied on all the interviews by the two researchers. During the coding process, the framework was supplemented with codes generated from inductive, open coding. After five interviews, no new codes were formulated, an indication that we built a comprehensive coding frame. We applied this coding framework on all the following interviews to identify the barriers and facilitators. Subsequently, axial coding took place by further analysis and merger of the coded fragments, resulting in themes that covered the broad variety of facilitators and barriers. The data was interpreted back and forth as an iterative process (Ritchie et al., 2013), supplemented by reflexive meetings (LN, SvdD) in between each interview to discuss the coding and interpretation process. By applying this bracketing method, we aimed to limit possible adverse effects of prejudices (Tufford & Newman, 2010). Inductive thematic saturation was reached after analyzing 17 interviews (Saunders et al., 2018).

## RESULTS

### Demographics

In total, 24 professionals (2 male and 22 female) participated in the interviews, 4 from each Youth Team. This male–female ratio reflects the actual gender representation in Youth Teams in the Netherlands. The interview duration ranged from 39 min to 79 min ( $m=56$  minutes). Participants' education varied, and they held various areas of expertise (e.g., social work and education, specialized mental health care, infant mental health, (mild) mental retardation, coaching, parenting support, and child protection). See Table 1 for an overview of the demographic characteristics of the professionals.



**Table 1.** *Demographic characteristics of the professionals*

Variable		
Gender		
Male [n(%)]	2	(8.3%)
Female [n(%)]	22	(91.7%)
Age in years		
Mean age in years (SD)	39.25	
Age range in years	24-61	(11.04)
Highest Educational Level		
Higher Vocational Education [n(%)]	21	(87.5%)
University [n(%)]	3	(12.5%)
Area of Expertise		
Socio-pedagogical assistance [n(%)]	11	(45.8%)
Pedagogics [n(%)]	6	(25.0%)
Psychology [n(%)]	1	(4.2%)
Social work [n(%)]	5	(20.8%)
Music therapy [n(%)]	1	(4.2%)
Years of work experience		
Mean years of experience (SD)	14.23	(9.67)
Range years of experience	1.5-35	

Note. n=24.

## Findings

Overall, there was a consensus among professionals regarding the reported facilitators and barriers that influenced the provision of integrated care. As a result, the interviews were largely complementary. Based on the thematic analysis of the reported barriers and facilitators, six themes were formulated:

1. Early identification and broad assessment to timely recognize potential risk factors.
2. Multidisciplinary expertise: specialist professionals in a generalist team.
3. Continuous pathways: flexible support throughout the entire continuum of care.
4. Current approaches in integrated care provision: a mix of stepped and matched care.

5. Autonomy of professionals: tailor support and follow guidelines.
6. Evaluation of care processes: discuss progress and alter support if needed.

Results are presented in the following section, starting with general aspects of integrated care and followed by a thematic report of the facilitators and barriers. An overview of facilitators and barriers per theme can be found in Appendix B, the frequency of quotes per code can be found in Appendix A.

### ***General aspects of integrated care***

Most professionals found it difficult to define integrated care. In general, descriptions were related to interprofessional collaboration. Professionals mentioned for example colocation, the presence of a Youth Team professional at schools or other sites in the neighborhood. Professionals also described integrated care as a central access point for multiple services, working towards mutual goals, coordination, and sharing responsibilities. On the other hand, some professionals referred to integrated care as a holistic, family-centered approach, focusing on the needs of all family members across multiple life domains. These professionals emphasized that a family-centered approach is crucial in integrated care, since the problems of one family member often impact the entire family's functioning. To provide integrated care, the aim of most professionals was to look beyond the initial request for support and broadly assess the entire family's functioning.

*"Integrated is of course a very broad concept. That you obtain knowledge on several areas of life: the family level and how they are related to their context, the environment, and those involved. In that way, I understand integrated care for families. That you obtain knowledge of their functioning and that you provide support on those aspects if needed."*

– Professional HR3.3.



Professionals found it challenging to support high-vulnerable families. Most professionals described the combination of (mild) intellectual disability, psychiatric problems, and safety concerns as demanding in view of the chronicity, interaction, and unpredictability of these problems. Collaboration between Youth Team professionals and services focusing on adults was considered a necessity to coherently support the entire family. However, this collaboration was often complicated by fragmentation between youth- and adult services. Another barrier to a family-centered, integrated approach was the resistance of parents the moment professionals attempted to discuss parental problems, particularly when the initial request for support focused on the child's malfunctioning.

***Theme 1: Early identification and broad assessment to timely recognize potential risk factors***

The first theme was timely recognition of (potential) risk and protective factors across several life domains by early identification and broad assessment of problems. To adequately support high-vulnerable families, most professionals did not feel that they had to solve all problems a family encountered, but that their task was to identify families' needs and timely involve other professionals with the required expertise if needed. Reported facilitators to early identification of potential vulnerable families were early consultation, being aware of potential risk factors and intergenerational transmission of problems, enhanced accessibility of support by offering free trainings, and one visible point of entry for families. Early consultation was often established by professionals' colocation at schools, general practitioners' practices, police centers, or at youth health care centers. This requires availability of professionals, an outreaching approach, and familiarity with other systems and their work-flow. A reported barrier to early identification was the risk of providing excessive support to families with minor problems. To prevent professionals from doing so, adequate triaging is needed.

*"By adequately identifying signals and from there, I assess what is needed. I also think that [professionals should possess] general*



*knowledge of the possibilities and which intervention suits best. And then I can see if it is something that I can do myself, or if it is something that I have to refer to specialized mental health care services."*

*- Professional HR1.3.*

Professionals stressed that broad assessment at the beginning of a care process is essential to identify needs across several life domains. Reported facilitators were addressing a broad range of topics and the use of a shared care plan. Professionals described the following topics for broad assessment, complaints and strengths, functioning across several life domains (at home, at school/work, in the community), involvement of previous/current professionals and services, and the informal (social) network of families. Furthermore, formulating a care plan in collaboration with families facilitated an overview of families' functioning across several life domains.

On the other hand, some professionals reported barriers to broad assessment, including a lack of knowledge on a broad range of problems and the burden broad assessment might put on families. Although most professionals felt confident and competent to make an initial assessment of a family's needs, one professional stressed that a lack of knowledge was a barrier to ask about problems that felt outside her field of expertise. Furthermore, broad assessment was often considered as time consuming and burdensome for families, since families had to share detailed personal information at the beginning of a care process while the relationship with their professional was not yet established.

***Theme 2: Multidisciplinary expertise: specialist professionals in a generalist team***

*"It is not that I am an expert in all areas of expertise. But I have general knowledge of most areas of expertise as a generalist, and I have specialists in my team who know the rest."*

*- Professional DH2.1.*



Regarding multidisciplinary expertise, the second theme we identified, professionals emphasized the need of both generalist and specialist expertise to provide integrated care. In that, professionals stressed the importance of being aware of the reach of their own expertise. Specifically, professionals described the importance of recognizing the boundaries of their expertise and timely involving professionals with other expertise if needed. The multidisciplinary character of Youth Teams was described as a facilitator to integrated care since the multidisciplinary teams deployed a broad range of expertise in one place to support families with multiple needs, professionals were able to take different roles towards families during a care process, and it enabled them to learn from another professionals' expertise. To facilitate interprofessional collaboration within a Youth Team, professionals often worked in pairs and held weekly multidisciplinary case discussions with the entire team. To avoid a multidisciplinary team full of generalists, professionals stressed the importance of keeping their expertise up to date. Professionals thought it was the responsibility of organizations to accommodate specialist training and supervision. A reported barrier was the high working demand, forcing professionals to provide support on areas outside their own expertise. This did not only decrease the quality of support for families, but also felt unsafe for professionals.

***Theme 3: Continuous pathways: flexible support throughout the entire continuum of care***

The third theme, continuous pathways, can be described as clear, coherent, and coordinated alignment of support throughout the entire continuum of care. According to most professionals, high-vulnerable families need a flexible provision of support through the continuum of care with varying intensity, that is matched to a family's changing needs. Professionals described various facilitators for continuous pathways:

- Familiarity with other professionals and their working approaches, leading to increased trust and improved interprofessional collaboration. Co-location and joint case discussions were reported facilitators to increasing familiarity.



- Frequent evaluation and long-lasting agreements with all professionals involved in care processes throughout the entire continuum of care.
- Sharing up to date information with other professionals, based on mutual agreements on the content and frequency of sharing information.
- Warm handoff, described as the gradual transfer from one professional or organization to another.
- A care coordinator, described as a professional who maintains an overview of the care process. The care coordinator facilitates communication between professionals involved, and coordinates support in line with families' needs. Whether this care coordinator can also provide ambulatory support to a family remained unclear from the interviews, since professional perspectives varied at this point.

*"That families are being monitored, or no, receive continuous support. The moment it improves, professionals can take a little more distance, and if needed, they can return to support the family."*

*- Professional DH2.2.*

On the other hand, professionals described multiple barriers for continuous pathways. First, coherent and continuous support was often hampered by the complexity and variability of families' problems. In supporting high-vulnerable families, the responsibilities, tasks, and roles of the professionals involved were often unclear, leading to fragmented support and confusion by both families and professionals. Other reported barriers were the high turnover rates of professionals, the time-consuming process of interprofessional collaboration, and specific organizational demands, for example requiring professionals to stay involved in a care process as short as possible. Professionals' unavailability hindered warm handoffs, just as privacy issues were reported as a barrier to sharing information.

Another barrier to form continuous pathways reported by all professionals, was the lack of availability of support often due to long waiting lists. This led to a delay in care provision, sometimes for over





half a year. Consequently, professionals who were already involved in the care process felt responsible or forced to provide inadequate support during these transition times. Besides the risk of increased complaints and drop out of families, this inadequate support also burdens professionals and reduces the quality of support. Alongside the long waiting lists, availability of support also seemed limited for specific ethnic groups such as immigrants and non-native speakers. Professionals described the limited ethnical diversity of professionals employed in Youth Teams and language barriers as reasons for this specific lack of availability.

***Theme 4: Current approaches in integrated care provision: a mix of stepped and matched care***

This fourth theme is about current approaches in integrated care provision: stepped and matched care. Based on the interviews we conclude that professionals offered a mix of matched and stepped care in practice. Professionals reported starting with the least restrictive support as possible and gradually increase intensity of support if needed. On the other hand, professionals described that they tailor support to families' needs and immediately referred families to more intensive support if necessary. In the following section, the application of matched and stepped care in practice is discussed, followed by facilitators and barriers to timely stepping up to more intensive support and scaling down to less restrictive support.

***Matched care***

Matched care was described as tailoring support to families' needs and preferences based on their demands. Matched care was explained as the opposite of a supply-oriented approach which involves allocating support based on services offered by organizations. Professionals intended not only to tailor support based on the severity of problems, but also on families' preferences regarding the location, type of service, and frequency of visits. In that, professionals stressed that families were not completely free in their choices and emphasized the need for shared decision making. Reported facilitators to shared decision making were the provision of different options for support and taking



both the professional's appraisal and families' preferences into account. Professionals emphasized the need to guide parents through the decision-making process by adjusting their pace, offering multiple choices, considering different preferences between family members, and considering cultural differences.

*"Sometimes the mother asks for a psychologist. Yes... but mother can ask all she wants, we do not always offer everything a parent wants. Maybe it is more a general request for help, a cry for a psychologist while all mother really wants is being heard. And when you can ask as much as possible beyond this initial request, the faster you can provide adequate support."*

- Professional DH3.2.

### *Stepped care*

In general, three aspects of stepped care were described by professionals: starting with the least restrictive option for support by involving the social network or volunteers, allocating support by an increased intensity (from preventive to more intensive support), and following a predetermined sequence of steps.

*"Working by a stepped care approach can also just be that you start with groups, and afterwards start an individual trajectory. In this way, you may also ensure a reduction in waiting lists. Because you see people in groups, you can offer support quicker and eventually, perhaps 40% of the people on a waiting list are sufficiently supported by a group training."*

- Professional HR1.3.

According to some professionals, a stepped care approach ensured more effective evaluation of a family's goals and provided structure during a care process. Overall, professionals reported two major barriers to applying a stepped care approach. First, although starting with the least restrictive form of support was sufficient for some families, for



high-vulnerable families this was often inappropriate, increasing the risk of providing insufficient support, drop out, and dissatisfaction. Second, there was often a time-limit for each step based on a protocol that did not match the pace of families (e.g., the number and length of visits). As a result, support was not tailored to families' needs.

#### *Stepping up and scaling down*

Both in matched and stepped care, stepping up to more intensive support and scaling down to less restrictive support were reported as important elements to ensure adequate allocation of support. Multiple professionals described that specific expertise was needed to step up and scale down adequately in collaboration with families. In both stepping up and scaling down, professionals stressed the following facilitators: a future-oriented care plan formulated in collaboration with parents, early involvement of the informal (social) network and schools, and frequent evaluation of a family's progress.

*"I am very much in favor of preventive services to stimulate parents in solving their problems independently and voluntarily. But sometimes that is simply not possible. And if things remain within voluntary support for too long before referring to more intensive, restrictive support... Then so much has been tried and there is so much resistance, that in the restrictive setting things are difficult to change, because parents simply do not want anymore."*

- Professional DH2.1.

In stepping up, professionals were hindered by difficulties in early assessment, a lack of availability of support, and resistance of families. Stepping up too late negatively influenced care processes and resulted, due to exacerbation of problems, in prolonged care processes and a crisis-oriented focus of support. Professionals experienced multiple barriers to scaling down. First, limited attention was paid to scaling down and timely introducing less restrictive support to families during care processes. As a result, intensive support trajectories ended too abruptly or continued for too long. Second, in supporting high-



vulnerable families who are hallmarked by their instability and high risk of relapse, professionals encountered difficulties in objectively assessing families' actual needs, leading to scaling down too late. Other reasons for a delay in scaling down were the experienced sense of responsibility, professionals' personal involvement, and the resistance of families towards less restrictive support, for example provided by volunteers.

***Theme 5: Autonomy of professionals: tailor support and follow guidelines***

The fifth theme was autonomy of professionals: the freedom professionals experienced in their daily practice. Professionals described the autonomy to undertake a variety of tasks and tailor support to a family's needs as a facilitator to integrated care. Professionals reported valuing their autonomy since it led to an increased focus on a professional's competencies and room for personal development. On the other hand, autonomy was reported as a barrier. Some professionals experienced too much autonomy in their work due to unclear tasks and vague responsibilities, leading to feelings of insecurity. Also, professionals stressed that too much autonomy could lead to inadmissible differences in the type of support families with similar problems receive. To reduce this disparity, professionals stressed the importance of discussing the focus of support within their multidisciplinary Youth Team.

*"It is also a bit overwhelming, because as a professional you need boundaries, so you know how to handle certain situations, know what works in a specific situation, based on scientific research. It similarly gives much freedom, although such freedom can be a bit overwhelming."*

- Professional DH3.4.

Professionals reported that they applied a selection of elements from guidelines or protocols in their daily practice based on their own assessment. Many professionals reported that following fixed protocols



or evidence-based guidelines was limiting their autonomy. On the other hand, there were professionals who stressed that guidelines offered structure, extended their expertise, and resulted in more aligned care processes. A small group of professionals mentioned the limited use of guidelines as controversial, since it increases the risk of intuitive decision making, varying working approaches, and might decrease the effectiveness and quality of support.

***Theme 6: Evaluation of care processes: discuss progress and alter support if needed***

The sixth and last theme we formulated was evaluation: keeping track of a care process by monitoring and discussing the progress and timely altering support if needed. Professionals described evaluation on three levels: evaluation of the care process together with families, multidisciplinary case discussions within a Youth Team, and evaluation of collaboration with professionals of other organizations. For all levels of evaluation, systematic monitoring of the care process was reported as a facilitator in keeping track of the care progress. However, professionals described that in practice systematic monitoring was rarely conducted. They emphasized the need of concrete and usable monitoring instruments that facilitate professionals in structuring and keeping track of the care process.

*Evaluation with families*

A reported facilitator was evaluation of the care process with families. Professionals described evaluation as improving families' insight in the care process and positively influencing shared decision making on the type and intensity of support. Also, evaluation with families enabled professionals to keeping track of families' changing needs and timely altering support if needed.

*Multidisciplinary case discussions*

Weekly multidisciplinary case discussions within a Youth Team was a reported facilitator to evaluating care processes. According to professionals, multidisciplinary case discussions served multiple purposes: an objective approach of the care process and insight



in potential blind spots, taking advantage of the broad expertise of the Youth Team, involving multiple perspectives in decision making, sharing responsibility with other professionals, and learning from each other. A barrier to multidisciplinary case discussions was the crisis-oriented focus of the cases discussed, leaving no room for other, less urgent, cases to be discussed. Subsequently, professionals described that this could lead to a lack of focus on scaling down and preventive activities, resulting in a risk of providing excessive support to families. Furthermore, a lack of structure during multidisciplinary case discussions was also stressed as a barrier, leading to inefficient meetings and dissatisfaction of professionals.

*“And that you regularly sit down with your colleagues and discuss ‘now I have done this, that has been achieved, and that does not work, and why does it not work? And what is the reason for trying again, if it has already been done?’ In this way, you stay sharp, I think that has added value.”*

– Professional HR1.4.

#### *Evaluation of collaboration with other professionals*

Frequent evaluation of collaboration with professionals of other organizations was described as a facilitator to integrated care. According to professionals, frequent evaluation resulted in improved agreements on roles, tasks, and working procedures, such as referral and care coordination.

## **DISCUSSION**

To meet the needs of high-vulnerable families with severe and enduring problems across several life domains, professionals must improve their ability to provide integrated care timely and adequately. Based on the analysis of interviews with 24 professionals from multidisciplinary care teams in the Netherlands, we formed six themes covering facilitators and barriers these professionals encounter when providing integrated care. In general, there was consensus among professionals regarding



the facilitators and barriers influencing their daily practice. Hence, the interviews were largely complementary and led to an in-depth thematic description of facilitators and barriers.

To tailor support to the changing needs of high-vulnerable families, professionals in our study stressed the importance of flexible and variable provision of support throughout the continuum of care by timely stepping up and scaling down. In line with previous research, multidisciplinary teams with a broad range of expertise and continuous pathways throughout the continuum of care were reported as facilitators to provide integrated care across several life domains (Hermens et al., 2014; Janssens et al., 2010; Meeuwissen, 2018). The variety of barriers reported in this study highlight the complexity of supporting high-vulnerable families with chronic, unpredictable, and interacting problems across several life domains. As also found in previous studies, difficulties in prioritizing problems, allocating adequate support responsive to the changing needs of families, difficulties in interprofessional collaboration, and a lack of coordination over the care process hinders professionals to providing integrated care (Cooper et al., 2016; Hoffses et al., 2016; Repetti et al., 2002; Van Straten et al., 2015).

Based on the thematic description of facilitators and barriers, we formulated five recommendations with implications for professionals, their organizations, researchers, and governmental policy makers that we believe are needed to address to further improve professionals' ability to provide integrated care.

**Recommendation 1: Enhance knowledge of (potential) risks and needs of high-vulnerable families, to tailor care to family's needs and identify gaps in the availability of support**

As we conclude from the theme 'Early identification and broad assessment' and the theme 'Current approaches in integrated care provision', timely recognition of risks and needs is essential in providing integrated care. Enhancing our knowledge of potential risks and needs can improve insight in the type of expertise and support that



is needed to cover families' broad range of problems across several life domains. Furthermore, with this information, gaps in availability of support through the continuum of care can be identified. Echoing prior recommendations, availability of services throughout the entire continuum of care seems crucial to provide adequate, flexible, and enduring support for these high-vulnerable families (Cooper et al., 2016; Janssens et al., 2010). The lack of availability described in the themes 'Continuous pathways', 'Multidisciplinary expertise', and 'Current approaches in integrated care provision' is currently a major problem for professionals, since it forces them to provide support outside their scope of expertise. Formal agreements on tasks, roles, and responsibilities of professionals and their organizations during transition periods are needed to avoid overburdening of professionals when adequate support for families is unavailable.

**Recommendation 2: Increase professionals' ability to broadly assess (potential) risks and address families' needs, by being aware of their responsibilities as professionals and to timely involve others if needed**

In addition to enhancing our knowledge of (potential) risks and needs, there is a need to increase professionals' ability to broadly assess these risks and timely address families' needs. Professionals in our study stressed that integrated care does not mean that one professional is responsible for solving all problems a family encounters. They described the importance of being aware of their professional responsibility to identify families' potential risks and needs by early identification, broad assessment, and timely involve other professionals if needed. As can be concluded from the themes 'Early identification and broad assessment' and 'Multidisciplinary expertise', professionals need generalist expertise of a broad spectrum of problems, family dynamics, and potential risk factors. Hence, multidisciplinary teams seem to be an important facilitator to integrated care, since the diversity of all specialist expertise within a team leads to a broad range of generalist expertise. Moreover, professionals must be familiar with the broad variety of services in the field of Youth Care. However, it seems unrealistic that one individual professional can be familiar with all services throughout





the continuum of care. Hence, to support professionals we strongly recommend organizations and policy makers to provide an up to date overview of available services on a local level.

**Recommendation 3: Keep professionals' specialist expertise up to date and recognize the boundaries of their own expertise**

Professionals in our study reported that they must keep their specialist expertise up to date to avoid a multidisciplinary team full of generalists. In that, organizations should facilitate the development and preservation of specialist expertise, for example by offering training and supervision. Furthermore, as described in the theme 'Multidisciplinary expertise', professionals should be aware of the reach and boundaries of their specialist expertise to preserve high quality integrated care. Multidisciplinary case discussions were reported as facilitators to increase insight in potential blind spots and learn from the broad expertise represented within the Youth Team. However, previous research on learning activities reported that training, supervision, interprofessional learning, and frequent evaluations were hindered by difficulties in prioritizing, high work demands, or a lack of time (Hawkins, 2009). Therefore, professionals and organizations should collaboratively discuss options for effectively executing these learning activities, for example by scheduling monthly evaluative meetings.

**Recommendation 4: Facilitate professionals in timely stepping up and scaling down by improving systematic monitoring and frequent evaluation of care processes**

As can be concluded from the theme 'Current approaches in integrated care provision', professionals seem to offer a mix of matched and stepped care when providing integrated care. They tailor support to families' needs and preferences, while starting with the least restrictive support as possible, and gradually increase the intensity of support if needed. Professionals reported timely stepping up to more intensive support and scaling down to less restrictive support as a necessity to provide integrated care. Interestingly, professionals often attributed difficulties with stepping up to external factors such as a lack of availability of support, whereas difficulties with scaling down were



attributed to internal factors such as professionals feeling responsible, personal involvement, and the concerns regarding the risk of relapse in high-vulnerable families. Hence, to overcome difficulties in stepping up and scaling down, it is important for professionals to recognize and distinguish these internal and external aspects. In line with previous research, frequent evaluation of the care process was reported as a facilitator to adequately decide on the focus of support and timely alter support if needed by stepping up or scaling down (Firth et al., 2015; Meeuwissen, 2018). However, professionals in our study mentioned that the care process was rarely monitored in practice and evaluations often lacked structure. Furthermore, the crisis-oriented focus during multidisciplinary case discussions led to a lack of focus on scaling down and preventive activities. This is especially critical in supporting high-vulnerable families, since the chronic, unpredictable nature of interacting problems and reoccurring crisis situations requires systematic monitoring and frequent evaluation (Tausendfreund et al., 2016). Besides sufficient resources for evaluation such as time and monitoring instruments, future practice-based studies should focus on identifying facilitators and barriers that professionals encounter during multidisciplinary case discussions to guide professionals in improving these evaluations.

**Recommendation 5: Find balance between the use of guidelines and a professional's autonomy to tailor support to families' needs**

Lastly, as described in the theme 'Autonomy of professionals', a professional's autonomy to undertake a variety of tasks is a facilitator to tailor support to families' needs. However, many professionals were concerned that too much autonomy led to intuitive decision making and varying working approaches, resulting in inadmissible variations in the support of families with similar problems. A remarkable finding was that few professionals mentioned the use of (evidence-based) guidelines in their daily practice, since guidelines can provide structure, focus, and equality in care processes (Van Straten et al., 2015). What professionals did report was that strict guidelines on the duration of support and the number of visits was a barrier to tailor support to families' needs. As we already know from previous research, structured



protocols and guidelines for example used in stepped care, do not always match the pace of families and overlook the interaction of problems that high-vulnerable families encounter (Henderson et al., 2017; Cross & Hickie, 2017). Therefore, we advocate that there is a need to collaboratively improve practice-based and evidence-based guidelines concerning the content of support for high-vulnerable families. For example, these guidelines can support professionals in prioritizing problems, allocating adequate support responsive to the changing needs of families. Importantly, these guidelines should assist professionals in structuring the care process and working effectively by a goal-oriented approach, while similarly leaving a certain degree of freedom and flexibility to tailor support to the needs of families.

### **Strengths and limitations**

An important strength of this study lies in the fact that qualitative research provides a powerful methodology for exploring complex processes and thereby facilitates a deep understanding of professionals' perspectives on integrated care (Smith & Firth, 2011). In total, we interviewed 24 professionals from Youth Teams in The Netherlands. Although professionals were predominantly female, this male–female ratio reflects the usual sex proportions in Youth Teams. The interviews provided complementary information, resulting in a rich description of facilitators and barriers professionals encounter when providing integrated care. By applying the COREQ guidelines (Tong et al., 2007), we ensured systematic and transparent reporting of our study methods and interpretation of the results. The structured analysis procedure, guided by a theoretic framework and open coding, enhanced the comprehensiveness of the results. Also, the iterative process of analysis, the use of subjective expressions of participants (quotes), and the reflexive meetings enabled us to explore the data in depth and decreased the risk of researchers' subjectivism (Ritchie et al., 2013).

On the other hand, several limitations must be considered. The most important limitation lies in the fact that the interviews were conducted during a restrictive period in a highly changing context. Together with



the narrow focus on a group of professionals working in Youth Teams in the Netherlands, this decreases the transferability of the results and complicates the assessment of data rigidly. Therefore, it will be interesting to repeat the interviews at another time or within another population of Youth Care professionals. Moreover, to further our understanding of the extent to which these facilitators and barriers influence clinical practice, there is a need for high-quality mixed-methods research.

## CONCLUSION

Taken together, this qualitative study highlights the need for flexible support across several life domains to meet the needs of high-vulnerable families. To substantially improve professionals' ability to support these families, we formulated five recommendations based on the facilitators and barriers professionals encounter when providing integrated care. First, research should enhance our knowledge of (potential) risks and needs. Then, organizations and professionals should invest in improving professionals' ability to broadly assess these (potential) risks and needs of high-vulnerable families. Also, professionals' specialist expertise should be kept up to date to avoid a multidisciplinary team of generalists. Moreover, to facilitate professionals in timely stepping up and scaling down, systematic monitoring and the evaluation of care processes should be improved in practice. Finally, practice, research, and governmental policy should find a balance between the use of guidelines to structure a care process and a professional's autonomy to tailor support to families' needs.



## Appendix A. Coding Framework

Concept	Category	Code	Frequency of quotes per code	Description	Literature
Integrated care	General principles	Coordinated	40	Coordination in the care process across professional, organizational and system boundaries.	World Health Organization, 2016
		Coherent	11	Coherence in assessment and support, across professionals and in policies.	World Health Organization, 2016
		Continuity	18	Continuous support over time (within and between professionals).	World Health Organization, 2016
		Family focused	42	Addressing the needs of all family members.	Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016
		(Lack of focus on) several life domains	33	(Lack of) focus on several life domains: academic, familial, social and personal.	Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016; Wang et al., 2005
		Interprofessional collaboration (intern or extern)	79 (extern) 46 (intern)	Collaboration between professionals involved in the care process. Intern: collaboration with professionals within the own care team. Extern: collaboration with professionals from other organizations.	Cooper, Evans, & Pyblis, 2016; Hermens et al., 2014; Janssens et al., 2010; Van Straten et al., 2015

Concept	Category	Code	Frequency of quotes per code	Description	Literature
Expertise	Assessment	Generalist/Specialist expertise	50	Broad knowledge and approach of problems (generalist) or in-depth knowledge and approach of problems (specialist).	Hoffses et al., 2016
		Early identification/Early assessment	14	Timely recognition of (potential) risk factors across several life domains.	Bower & Gilbody, 2005; Linton et al., 2018; Van Straten et al., 2015
		Broad assessment	36	Assessment of a broad range of problems across multiple life domains.	Bower & Gilbody, 2005; Linton et al., 2018; Van Straten et al., 2015
		Multiple, co-occurring problems	26	Interaction between multiple problems that occur simultaneously.	Henderson et al., 2017; Tausendfreund et al., 2016
Service delivery		Availability of support	78	Availability of support throughout the continuum of care.	Cooper, Evans & Phylbis, 2016; Meeuwissen, 2018
		Continuous clinical pathways/Fragmented care	48	Clear, non-fragmented routes of care through the entire continuum of care (universal services to primary care to specialized secondary care)/ Fragmentation between services or professionals.	Cooper, Evans & Phylbis, 2016; Hermens et al., 2014; Meeuwissen et al., 2018

Concept	Category	Code	Frequency of quotes per code	Description	Literature
<b>Stepped care</b>	Definition	Stepped care (definition)	4	Offering the least restrictive support as possible that is still likely to yield significant health gain and step up to more severe care if necessary.	Bower & Gilbody, 2005; Meeuwissen, 2018; Bennett-Levy et al., 2010
	Allocation of interventions	Predetermined sequence	7	Support ranked from low to high intensity in a predetermined sequence.	Firth et al., 2015; Meeuwissen, 2018; Richards, 2012
		Least restrictive	18	The least intensive support in terms of time, costs and professional's level of expertise.	Meeuwissen, 2018; Van Straten, 2015
		Intensity	14	Providing support by a predefined sequence of support options with increasing intensity.	Bower & Gilbody, 2005; Firth, 2015; Meeuwissen, 2018; van Straten, 2015
	Assessment & evaluation	Reflexive monitoring/ (ir)regular monitoring	15	Progress and outcomes are monitored by collecting data to assess if support must be altered.	Meeuwissen, 2018; Richards, 2012; Bower & Gilbody, 2005
		(standardized and systematic) Evaluation	42	Periodically and systematically evaluate progress in a care process and collaboration.	Van Straten, 2015; Meeuwissen, 2018; Firth et al., 2015; Bower & Gilbody, 2005
		Goal efficiency	14	Working efficiently towards concrete goals.	Meeuwissen, 2018



Concept	Category	Code	Frequency of quotes per code	Description	Literature
	Disadvantage stepped care	Focus on individuals/ single problems	3	Focus on individuals and single problems, omitting the complex interaction of problems.	Cross & Hickie, 2017
		Variety in steps	5	Stepped care support is heterogeneous with different numbers of steps, intensity and treatment components.	Van Straten et al., 2015; Bower & Gilbody, 2005
		Lack of predefined criteria/guidelines	41	Lack of predefined criteria and (clinical, practical or evidence-based) guidelines for monitoring and evaluation of support hinder stepped care.	Meeuwissen, 2018; Van Straten, 2015
		Undertreatment	33	Inappropriate support or inefficient allocation of resources leading to an exacerbation of family's problems.	Linton, 2018; Lovell & Richards, 2000
		Risk of drop out	10	Families refusing further support.	Seekles et al., 2011
<b>Matched care</b>	Definition	Matched care (definition)	16	Allocation of support is based (matched) on families' characteristics, preferences, risks and needs.	Van Straten et al., 2015; Linton, 2018





Concept	Category	Code	Frequency of quotes per code	Description	Literature
	Allocation of interventions	Tailored	52	Family's needs and preferences are central in the allocation of support.	Van Straten et al., 2015; Linton, 2018
	Disadvantage matched care	Lack of prognostic determinants	2	Lack of clear prognostic determinants to match families to the available support.	Bower & Gilbody, 2005; Van Straten et al., 2015
		Variety of interventions	18	Support may vary across families regarding intensity, setting and type of professional.	Linton, 2018; Van Straten et al., 2015
		Overtreatment	13	Families receiving too many support, leading to inappropriate allocation of services.	Lovell & Richards, 2000
	Decision making	Shared decision making	27	Shared decision making is based on collaboration between professionals and families, taking families' preferences into account and jointly decide the type and intensity of support.	Meeuwissen, 2018; Van Straten et al., 2015
		Intuitive decision making	27	Intuitive decision making, not based on reflexive monitoring, evaluation or predefined determinants.	Meeuwissen, 2018; Van Straten et al., 2015

Concept	Category	Code	Frequency of quotes per code	Description	Literature
<b>Quality of services</b>	Service delivery	User friendliness	10	Satisfaction with- and user friendliness of support.	World Health Organization, 2016
		Safety	26	Professionals paying attention to a family's safety.	World Health Organization, 2016
<b>Open coding</b>		Freedom of professional	28	A professional's freedom to make her/his own decisions in the care process.	
		Solution focused approach/therapy	16	Support that focuses on solutions rather than problems.	
		Familiarity	50	Familiarity with other services or professionals (often affects the feeling of availability).	
		Trust	30	Trust between professionals.	
		Early consultation	37	Early consultation function of professionals in for example schools to provide early support.	
		Care plan	18	Care plan with goals for the entire family.	



Concept	Category	Code	Frequency of quotes per code	Description	Literature
		Clinical case discussion	35	Clinical case discussions within multidisciplinary care teams to discuss and evaluate the care process.	
		Stepping up	52	Step up to more intensive support if needed.	
		Scale down	46	The opposite of stepping up, the provision of less restrictive support after intensive support.	
		Integrated care definition/in general	29	Definition of integrated care, general aspects of integrated care.	
		Warm handoff	14	The gradual transfer from one professional to another.	





## Appendix B. Overview of facilitators and barriers per theme

Theme	Facilitators	Barriers
1 Early identification and broad assessment to timely recognize potential risk factors	Early consultation Awareness of (potential) risk factors Accessibility and availability Addressing broad range of topics in broad assessment Outreaching approach Shared care plan	Risk of providing excessive support for minor problems Lack of knowledge of a broad range of problems Time consuming and burdensome for families
2 Multidisciplinary expertise: specialist professionals in a generalist team	Awareness of the reach of a professional's own expertise Multidisciplinary teams: work in pairs Keeping specialist expertise up to date	High working demands, forcing professionals to provide support on areas outside their expertise
3 Continuous pathways: flexible support throughout the entire continuum of care	Familiarity with other professionals by co-location and joint case discussion Frequent evaluation and agreements Sharing up to date information Warm handoff between professionals A care coordinator	Complexity and variability of problems Unclear tasks, roles and responsibilities Time consuming Specific organizational demands Privacy issues in sharing information Lack of availability of professionals and high turnover rates Lack of availability of support due to long waiting lists Limited availability of support for specific ethnic groups

Theme	Facilitators	Barriers
4 Current approaches in integrated care provision: a mix of stepped and matched care	<p>Providing different options for support</p> <p>Tailor care to family's needs and preferences</p> <p>Shared decision making</p> <p>Guide families through decision making process</p> <p>Future oriented (shared) care plan</p> <p>Early involvement of the informal network and schools</p> <p>Frequent evaluation of a family's progress</p>	<p>Least restrictive support inappropriate</p> <p>Time-limit for each step, not matching the pace of families and hence support is not tailored to their needs.</p> <p>Difficulties early assessment</p> <p>Lack of availability of support</p> <p>Resistance of families towards less restrictive support of scaling up</p> <p>Limited attention to scaling down</p> <p>Difficulties in objective assessment during crisis-situations</p> <p>Sense of responsibility and personal involvement</p>
5 Autonomy of professionals: tailor support and follow guidelines	<p>Autonomy to undertake a variety of tasks to tailor support</p> <p>Focus on professionals' competencies and personal development</p> <p>Discussing focus of support in multidisciplinary team</p> <p>Structure and extended expertise by following guidelines</p>	<p>Too much autonomy leads to unclear tasks, responsibilities and insecurity</p> <p>Inadmissible differences between professionals in type of support provided</p> <p>Fixed protocols limits the autonomy of professionals</p> <p>Intuitive decision making</p>
6 Evaluation of care processes: discuss progress and alter support if needed	<p>Systematic monitoring of the care process</p> <p>Concrete, usable monitoring instruments</p> <p>Weekly clinical case discussions</p> <p>Evaluation of collaboration with other professionals</p> <p>Evaluation of the care process with families</p>	<p>Lack of systematic monitoring</p> <p>Crisis-oriented focus in case discussions</p> <p>Lack of focus scaling down and preventive activities</p> <p>Lack of structure during clinical case discussions</p>







# 5

## Practical recommendations for Youth Care professionals to improve evaluation and reflection during multidisciplinary team discussions: an action research project



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*Submitted*



**ABSTRACT**

Integrated care for children and their families is often organized in multidisciplinary teams. In these teams, evaluation and reflection during Multidisciplinary Team Discussions (MTDs) are fundamental to learning, improving interprofessional collaboration, and increasing the quality of care. Since the effectiveness of MTDs varies widely, this study's objective was to identify facilitators and barriers for evaluation and reflection in MTDs, and concurrently formulate practical recommendations for professionals. This study's action research cycle consisted of a qualitative component to identify facilitators and barriers, by observations in multidisciplinary teams and interviews with professionals, parents, managers, and local policy makers. Concurrently, practical recommendations were iteratively developed in project team meetings, learning sessions, and a focus group. Based on the identified facilitators and barriers, nine practical recommendations were formulated, including: preparatory activities to ensure purpose, timing, and relevant stakeholder involvement; specific points of attention during MTDs to ensure effectiveness; and tracking follow up steps after MTDs to ensure a learning process. We conclude that the nine practical recommendations can support professionals in Youth Care to increase satisfaction and improve effectiveness of evaluation and reflection during MTDs.



## INTRODUCTION

All too often, children and their families in Child and Youth Care settings (Youth Care) experience psychosocial-, emotional-, cognitive-, or stress-related impairments impacting several life domains (e.g., at home, school, and in the community). The needs of these families exceed the expertise and possibilities of a single professional discipline or organization, due to a combination of problems including problems with parenting, learning difficulties, mental health issues, financial or housing restraints, violence or criminal activities, and substance abuse (Brooks, Bloomfield, Offredy, & Shaughnessy, 2013). Hence, multiple professionals from a wide range of services in Youth Care are involved in a family's care process, from universal and preventive services like social work and parenting support, to specialized services such as specialized mental health care (Hilverdink, Daamen, & Vink, 2015). To overcome fragmentation in support for these families, organizing integrated care is a necessity. Integrated care can be defined as coordinated, coherent and continuous support, aligned across life domains, and tailored to the needs of families (Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016; World Health Organization, 2016).

Integrated care is often organized in multidisciplinary teams to facilitate interprofessional collaboration (Cooper, Evans, & Pybis, 2016; Janssens, Peremans, & Deboutte, 2010). Multidisciplinary team composition is based on families' needs, including professionals representing community work, social work and education, specialized mental health care, parenting support, financial support, and child protection. Also, the intensity of interprofessional collaboration varies per case, from sharing brief information and consultation, to collaboratively identifying problems and developing shared care plans (Saint-Pierre, Herskovic, & Sepúlveda, 2018).

Yet, a major challenge to provide integrated care in multidisciplinary teams is that professionals frequently hold different views, adopt diverse working approaches, or lack collaboration (Cooper et al., 2016; Golding, 2010). Moreover, since the needs of families often differ across



life domains and change over time, professionals in multidisciplinary teams must be flexible in their approaches, roles, and responsibilities (Garcia et al., 2014; Golding, 2010). Hence, evaluating and reflecting on care processes in multidisciplinary teams are crucial to tailor integrated care to families' changing needs (Huxley et al., 2011; Nooteboom, van den Driesschen, Kuiper, Vermeiren, & Mulder, 2020; Raine et al., 2014; World Health Organization, 2016).

### **Background**

Evaluation is conceptualized as systematically monitoring, collecting, discussing, and interpreting information with the intention to appraise the value and effectiveness of a process, plan, or outcome (World Health Organization, 2007). Reflection on the other hand, is a structured approach to gain insight in one's own thoughts, values, experiences, and behaviors, and focusses on professional competency and professional development (Korthagen, 2017). Reflecting on prior experiences and evaluating care processes from a multidisciplinary view are both fundamental to learning and can lead to enhanced quality of care, professional development, and improved working approaches of professionals (Golding, 2010; Korthagen, 2017; Raine et al., 2015).

In multidisciplinary teams, evaluation and reflection generally take place during Multidisciplinary Team Discussions (MTDs; Nooteboom et al., 2020; Raine et al., 2014). MTDs are regularly (often weekly) held team discussions and defined as a moment of collaborative learning in which professionals evaluate and reflect on for example: (1) the care process of families, (2) interprofessional collaboration within and outside their multidisciplinary team, or (3) one's own working approach (Nooteboom et al., 2020). Evaluation and reflection in MTDs can improve shared decision making and increase insight in a care process, leading to better outcomes for people in care (Nancarrow et al., 2013; Rosell, Alexandersson, Hagberg, & Nilbert, 2018). Moreover, evaluation and reflection in MTDs can lead to improved interprofessional collaboration, by taking advantage of the broad expertise of a multidisciplinary team, developing a common vision and language between professionals, redefining roles and responsibilities if needed, and reducing fragmentation of care (Heneghan, Wright, & Watson, 2014).



Although there is an abundance of working methods available for evaluation and reflection in MTDs (Gordijn, Ernstman, Helder, & Brouwer, 2018), the implementation, effectiveness, and efficiency of these working methods vary widely across settings and teams (Raine et al., 2015; Raine et al., 2014). In that, a major barrier is the broad diversity of professional disciplines involved in MTDs, leading to misunderstanding of each other's working approach, a lack of purpose, and less effective decision making (Nooteboom et al., 2020; Raine et al., 2014; Rosell et al., 2018). Also, discussing a broad range of problems in a limited amount of time can lead to a lack of purpose and structure, a lack of in depth discussion, and inconsistent documentation of decisions during MTDs (Raine et al., 2014). Particularly in Youth Care, these barriers might hinder the effectiveness of evaluation and reflection, since there are various professional disciplines involved in the MTDs and professionals often discuss a broad range of problems that families in Youth Care encounter (Nooteboom et al., 2020). Hence, to achieve effective evaluation and reflection in MTDs, it is necessary to meet certain preconditions.

Previous research in adult mental health care led to 21 recommendations to improve the effectiveness of MTDs (Raine et al., 2015). These recommendations include the importance of a goal-oriented working approach, clear documentation of outcomes of the MTDs, and sufficient chairing of the session. Nevertheless, these recommendations were constrained to evaluations of single adult interventions and their treatment plan implementation, whereas in Youth Care, professionals often support multiple family members with a variety of problems across life domains. To our knowledge, there is a lack of practical recommendations to guide Youth Care professionals in multidisciplinary teams in improving evaluation and reflection during their MTDs. Therefore, this study's objective was to identify facilitators and barriers for evaluation and reflection in MTDs, and concurrently to formulate practical recommendations in collaboration with professionals from multidisciplinary teams, their managers, local policy makers, and families in Youth Care.



## METHOD

This study was part of a four-year research project in collaboration with local multidisciplinary teams in the Netherlands (Academic Workplace 'Gezin aan Zet' [Family's Turn]). The study approach was derived from action research, a community-based research method enabling broad understanding of complex processes in practice, while engaging all stakeholders in the research process (Abma et al., 2017; Migchelbrink, 2007). Hence, action research enhances the validity and applicability of study outcomes (Nyström, Karlton, Keller, & Andersson Gäre, 2018). The current study's action research cycle consisted of a qualitative component to identify facilitators and barriers to MTDs from multiple perspectives (i.e., by interviews and observations; Malterud, 2001), and concurrently an iterative process of formulating, discussing, implementing, evaluating, and adapting practical recommendations based on the identified facilitators and barriers (i.e., by project team meetings, learning sessions, and a focus group). Completeness and reporting quality of the practical recommendations were improved by complying with the Reporting Items for practice Guideline in Healthcare (RIGHT) statement (Chen et al., 2017).

### Setting and participants

In 2015, there has been a decentralization of the Youth Care system in the Netherlands. Ever since, municipalities are responsible for organizing and providing Youth Care on a local level, including preventive health services, youth mental health services, and specialized Youth Care (Hilverdink et al., 2015). This local organization should lead to integrated support at an earlier stage, within the family's own environment and with easy access to a variety of services in Youth Care (Hilverdink et al., 2015). To provide integrated support, almost each municipality formed local multidisciplinary teams, the so-called Youth Teams (Van Arum & Van den Enden, 2018). Youth Teams operate locally in a primary care setting as a linking pin between preventive services and specialized Youth Care (Hilverdink et al., 2015).



The current study was conducted in collaboration with six Youth Teams in the Netherlands. In general, the six teams held similar compositions and tasks: a multidisciplinary team of approximately eight to twelve professionals providing (ambulatory) support to children (aged 0-23) and their families with a broad variety of psychosocial, stress-related, and socio-economic problems. Youth Teams focus on strengthening families' capacities, involving families' social network, and coordinate support in collaboration with other (local) services. The following disciplines were represented in each participating Youth Team: social work and education, specialized mental health care, infant mental health care, support for youth with (mild) mental retardation, parenting support, and child protection. The exact composition of each team slightly changed during the research project, mostly due to turnover of staff.

Youth Team professionals were the intended primary users of the practical recommendations resulting from the current study. Approximately 60 professionals actively participated in the team observations, the semi-structured interviews, and the iterative process to developing practical recommendations. Additionally, to include relevant perspectives on facilitators and barriers, we interviewed parents of children who were supported by one of the Youth Teams, managers of the participating teams, and local policy makers. These stakeholders also participate in evaluation and reflection of Youth Team professionals, for example during clinical case discussions (families). To develop the practical recommendations, four professionals, a parent representative, two managers, and four researchers (EM, LN, CK, and JE/SvdD) closely collaborated in bimonthly project team meetings. Alongside this project team, a steering committee advised the researchers twice a year, by reviewing the recommendations and discussing the research progress. The steering committee consisted of the researchers (LN, EM, SvdD), a professor in child psychiatry (RV), six local policy makers (from The Hague and Holland Rijnland), four representatives from University (Leiden University Medical Center, The Hague University of Applied Sciences, Leiden University of Applied Sciences), a representative of TNO (independent research



organization), and one parent representative. Members of the steering committee also played an important role in the implementation of the recommendations in their own organizations.

### **Data collection**

The action research data collection cycle was divided in two interdependent processes: (1) a qualitative study to identify facilitators and barriers to evaluation and reflection by means of observations of MTDs and semi-structured interviews (Malterud, 2001), and concurrently (2) an iterative process to develop practical recommendations based on the identified facilitators and barriers (Migchelbrink, 2007). An overview of the study design can be found in Figure 1.

### ***Qualitative study: observations and interviews***

#### *Observations*

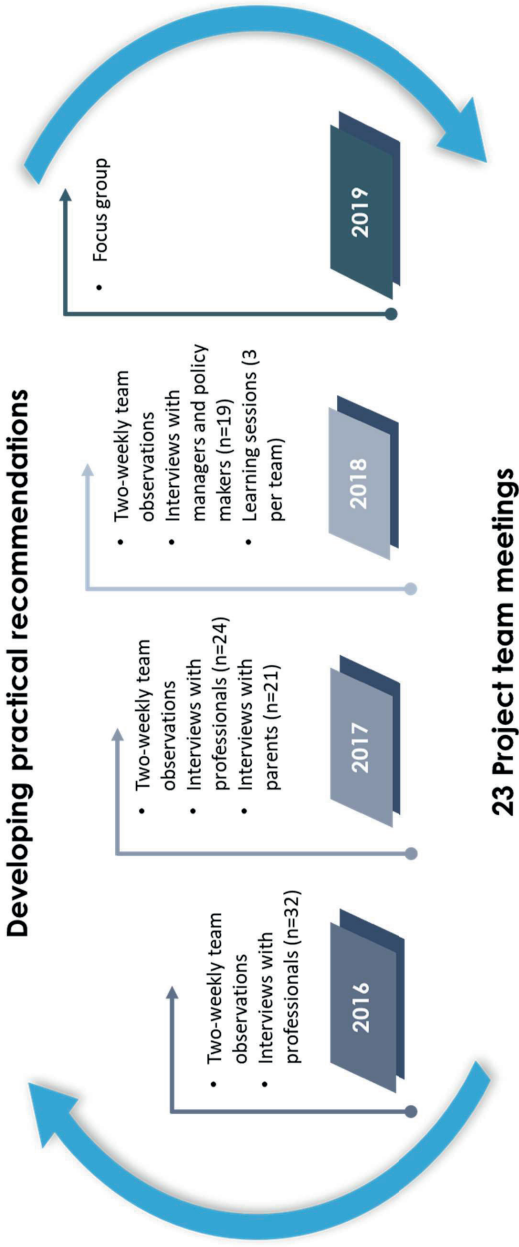
Between 2016 and 2018, two researchers (LN and JE) independently conducted bimonthly, non-participant, unstructured observations (Mulhall, 2003) of existing MTDs in the six participating Youth Teams. Each observation had a duration of approximately 2 hours. Field notes were taken, including notes on the preparation, structure, and participants of the MTDs, roles and professional behavior during the MTD, types of cases discussed, and documentation of decision making. After each observation, field notes were discussed (JE and LN) and summarized in an online logbook for further analysis.

#### *Interviews*

In 2016, 2017, and 2018, four separate rounds of semi-structured interviews were conducted: two rounds with professionals from the participating Youth Teams (2016 and 2017), one round with parents receiving support from the multidisciplinary teams (2017), and one round with managers of the teams and local policy makers (2017/2018). Participation was voluntary, and all participants were informed on the aim and procedure of the interviews by means of written informed consent. The interviews were guided by topic lists adjusted to the group



**Figure 1.** Study design





of participants (e.g., professionals, parents, managers, or local policy makers). All interviews were conducted by one of the researchers (LN or JE) together with a student of the Leiden University Medical Center. After each interview, participants were asked to fill in a demographic questionnaire. To avoid interpretation bias, all interviews were audio-recorded and transcribed verbatim afterwards (Tufford & Newman, 2010). No participant expressed interest in commenting on the transcripts.

In both interview rounds with professionals we aimed to include at least three professionals per Youth Team. Convenience sampling was applied based on availability and there were no further in- or exclusion criteria. For the 2016 interview round, the topic list included general questions regarding facilitators and barriers in their daily practice, including the MTDs. The topic list of the 2017 interviews specifically focused on facilitators and barriers of evaluation and reflection in their weekly MTDs, integrated care, and working in multidisciplinary teams. Parents were invited to participate in this study by an email from their Youth Team professional. Professionals were encouraged to approach all parents in their caseload to target a representative group of parents and prevent convenience sampling bias.

To ensure parental perspectives were based on actual experiences, we purposively included parents with at least three visits to a Youth Team professional. The topic list was formulated in collaboration with a parent representative and included questions regarding the collaboration between professionals and parents, parental involvement in shared decision making, evaluation of a care process, and interprofessional collaboration. The managers and local policy makers were recruited by the two researchers (LN and JE). There were no further in- or exclusion criteria and convenience sampling was applied based on availability. Topics for the interviews with managers and local policy makers included facilitators and barriers in evaluation, reflection, interprofessional collaboration, and integrated care.



### ***Iterative process to develop practical recommendations***

Based on the facilitators and barriers identified in the qualitative study, practical recommendations were concurrently formulated, discussed, applied, evaluated and adapted in project team meetings, learning sessions, and a focus group. These activities not only encouraged discussion to reveal multiple perspectives, but also improved the applicability and implementation of the results in practice (Femdal & Solbjør, 2018).

#### *Project team meetings*

Between 2016 and 2019, 23 project team meetings took place in which study progress and preliminary recommendations were discussed. The meetings were guided by an agenda that was formulated in advance. The project team strived to consensus by an iterative course of action and informal decision making, led by an independent and experienced action researcher (CK). After each project team meeting, field notes taken by one of the researchers (LN, JE, or Svdd) were summarized and verified by all project team members. Actions originating from these meetings (e.g., adapt recommendations, implementation activities, inform practice) were applied and evaluated in the following meeting.

#### *Structured learning sessions*

In 2018, each Youth Team participated in three structured learning sessions. The function of these learning sessions was twofold: (1) reflect on the preliminary findings and thereby stimulate in depth interpretation and a learning process in practice, and (2) a member check to validate the conceptual formulation of the recommendations by discussing the interpretation, relevance, and applicability (Thomas, 2017). A week before each learning session, professionals received a factsheet with preliminary recommendations. One of the researchers (JE or LN) was the moderator during the learning session, the other took notes for the written summary. During the learning sessions, professionals reflected on the recommendations and formulated action points to improve evaluation and reflection in their MTDs. Subsequently, professionals were encouraged to implement the formulated action points during the following MTDs. This implementation process was monitored



during the MTD observations that followed the learning session and was discussed during project team meetings.

### *Focus group*

In 2019, a focus group took place with 20 professionals from Youth Teams in Holland Rijnland and The Hague, who were unfamiliar with this study. The focus group served as a member check and as an implementation activity to improve feasibility. The focus group was led by a trained moderator (LN) and supported by an observer (SvdD) who took field notes and wrote a summary afterwards. During the focus group, preliminary recommendations were shared by means of a predefined script and a fictional case to practice with the application of the recommendations.

### **Analysis and interpretation**

All interview transcripts and observation summaries were imported into Atlas.ti (v7), a computer program for labelling and organizing text content. Thematic content analysis was applied to all imported data, to identify facilitators and barriers that might influence the effectiveness of evaluation and reflection in MTDs (Leavy, 2014). A facilitator was conceptualized as a component enabling professionals to perform evaluation and reflection in MTDs. A barrier was defined as a component limiting professionals to perform evaluation and reflection in MTDs. Each analysis followed the same structure: familiarization with the data, identifying themes, coding, charting, mapping, and interpretation (Pope, Ziebland, & Mays, 2000). Open coding was applied to transcripts of the observation summaries and the separate interview rounds by at least two of the researchers (LN, JE, SvdD). The source of the coded fragments was also labeled, to identify whether the information was based on an observation and from which team, or on an interview with one of the stakeholders (e.g., professionals, parents, managers, or policy makers). This labeling enabled us to control for potential differences between teams or stakeholders when merging the coded fragments from various sources to identify generic themes (charting). Since our aim was to find generic elements (barriers and facilitators) across participants, themes from each source were



systematically compared and eventual differences were discussed during project team meetings. The researchers looked for a consensus between the different stakeholders' perspectives to formulate generic recommendations. To limit possible adverse effects of prejudices, the data was interpreted back and forth as an iterative process and supplemented by reflective discussions of the researchers (LN, Svdd, and JE; mapping and interpretation). No interrater reliability was calculated since previous research points out that interrater reliability in coding segments seems ineffective for reliability purposes (Smith & McGannon, 2018). In general, there was agreement in coding between the researchers apart from some lingual differences.

The identified themes of facilitators and barriers formed the basis on which we formulated the practical recommendations. The researchers (LN, Svdd, EM, and CK) formulated preliminary recommendations based on the identified barriers and facilitators in the MTD observations and interviews. These preliminary recommendations were continuously discussed and refined during project team meetings, applied in learning sessions, and pilot-tested in a focus group. Written summaries of these activities were compared to the preliminary recommendations and served as an addition to the analysis to verify and refine the recommendations. Apart from some linguistic modifications, no major changes were suggested by professionals from the focus group, indicating transferability of the recommendations to other multidisciplinary teams in Youth Care.

## **RESULTS**

### **Demographics**

In 2016, 32 professionals participated in the first interview round: 5-6 professionals per Youth Team. In the second round of interviews in 2017, 24 professionals participated (e.g., 4 professionals per Youth Team), of which 10 individuals who were also interviewed during the first round. Professionals had experience in different aspects of Youth Care (e.g., social work and education, specialized mental health care, infant mental health, (mild) mental retardation, coaching, parenting



support, and child protection). In addition to the interviews with professionals, 21 parents from different families participated in a semi-structured interview. All parents had received support from a Youth Team professional. Furthermore, 19 managers and local policy makers participated in a semi-structured interview. Table 1 presents a detailed overview of participant characteristics.

## Outcomes

To identify facilitators and barriers to evaluation and reflection in MTDs, we systematically compared observational data and interview fragments from different sources. In general, professionals discussed progression of individual care processes as main part of the MTDs, followed by a shorter discussion of interprofessional collaboration, team development, and regular issues in their daily practice. Each individual team had its own working approach, structure, and culture during the MTDs, which varied during the study due to changes in team composition or new working approaches.

Table 2 presents a list of facilitators and barriers reported during the interviews and observed during MTDs. Overall, facilitators and barriers reported in the various interview rounds corresponded with the facilitators and barriers observed during the MTDs. For example, according to professionals and from the observations, it was difficult to distinguish the subject, purpose, and focus of MTDs. Moreover, most facilitators and barriers described by parents, managers, and policy makers were also reported by professionals. For example, they all described that a lack of structure and preparation of MTDs led to dissatisfaction and a lack of effectiveness. Moreover, from both the interviews and the observations, we concluded that too many professionals attending the MTD decreased the effectiveness of the MTD. Especially in case there was a broad variety of professional disciplines involved, this led to prolonged MTDs with too many topics to be discussed in a limited amount of time, an unsafe team climate, and lengthy decision-making processes.



**Table 1.** Demographic characteristics of the participants

Variable	Professionals R1 (n=32)	Professionals R2 (n=24)	Parents (n=21)	Managers and policy makers (n=19)
Interview duration min [m (range)]	49 (35-60)	56 (39-79)	53 (31-90)	48 (41-60)
Gender [n (%)]				
Male	2 (6.3%)	2 (8.3%)	4 (19.1%)	1 (5.3 %)
Female	30 (93.7%)	22 (91.7%)	17 (80.9%)	18 (94.7%)
Age in years				
Mean age in years (SD)	39.00 (9.13)	39.25 (11.04)	43.75 (8.47)	47.37 (9.38)
Age range in years	24-61	24-61	26-57	28-61
Cultural Background [n (%)]				
Western			17 (85.0%)	
Non-Western			3 (15.0%)	
Highest Educational Level [n (%)]				
Primary Education			2 (10.0%)	
Intermediate Vocational Educ.			8 (40.0%)	
Higher Vocational. Educ.	24 (75.0%)	21 (87.5%)	7 (35.0%)	9 (47.4%)
University	8 (25.0%)	3 (12.5%)	3 (15.0%)	10 (52.6%)
Study [n (%)]				
Socio-pedagogical assistance	10 (31.2%)	11 (45.8%)		
Pedagogics	8 (25.0%)	6 (25.0%)		
Psychology	3 (9.4%)	1 (4.2%)		
Social work	7 (21.9%)	5 (20.8%)		
Other	4 (12.5%)	1 (4.2%)		
Profession [n (%)]				
Manager				4 (21.1%)
Coach				4 (21.1%)
Policy maker				7 (36.8%)
Staff advisor				2 (10.5%)
Other				2 (10.5 %)
Years of work experience				
Mean years of experience (SD)	15.98 (8.78)	14.23 (9.67)		
Range years of experience	3-39	1.5-35		
Marital Status [n (%)]				
Two-parent household			10 (50.0%)	
Divorced			9 (45.0%)	
Single-parent household			1 (5.0%)	
Number of children [n (%)]				
One child			5 (25.0%)	
Two or more children			15 (75.0%)	
Missing (n)			1	

NB: R1 = interviews round 1, R2 = interviews round 2

**Table 2.** Recommendations based on facilitators and barriers to evaluation and reflection in Multidisciplinary Team Discussions (MTDs)

Recommendation	Facilitators	Barriers
1 Decide on the subject and goal of the MTD	Clear subject of the MTD (e.g. team process, content of care) Define goal and purpose beforehand	Unclear subject, purpose and focus of the MTD Interchangeably evaluate different subjects during the MTD
2 Differentiate between those involved and those attending the MTD	Decide on those involved and who should attend the MTD Inform all those involved afterwards Availability of professionals MTDs in smaller groups	Too many professionals attending the MTD Lack of sharing information afterwards A broad variety of professional disciplines involved without a clear purpose
3 Decide on the moment and duration of the MTD	Schedule MTDs in advance Sufficient time in between MTDs Estimate duration of each component of the MTD	Not prioritizing MTDs due to a high workload Too lengthy MTDs Too many topics to be discussed in limited amount of time Planning too many MTDs in a short amount of time
4 Timely prepare the MTD and gather input from stakeholders beforehand	Timely and sufficient preparation Collect relevant input from stakeholders	Lack of preparation by those involved in the MTD Lack of input from relevant stakeholders
5 Follow the general structure of MTDs and decide on the working approach	Flexible, shared working approach Time to acquire a working approach Clear format of the MTD An a priori formulated agenda Visualized structure of the MTD Reprise of a preparatory assignment	Rigid working approach that does not fit purpose of the MTD Lack of structure or agenda Variety of working approaches Lengthy decision-making processes



Recommendation	Facilitators	Barriers
6	Allocate tasks to ensure structured MTDs	No secretary Too many tasks for the chair No time guard
7	Ensure a safe team climate during the MTD	Changes in team composition Feelings of dissatisfaction (Negative) consequences after the MTD Interprofessional conflicts Unfamiliarity with those involved in the MTD Inequalities between those involved Lack of participation in the MTD
8	Ask reflective questions and provide constructive feedback during the MTD	Directly provide a solution Focus on negative feedback Focus on incidents outside the context
9	Register and monitor follow-up steps at the end of the MTD	Lack of time at the end of the MTD Undefined follow-up steps Lack of registration of follow up steps





After listing the identified facilitators and barriers, the iterative process of formulating the recommendations was conducted during project team meetings and learning sessions. This process led to nine practical recommendations to guide professionals in improving evaluation and reflection during MTDs, also listed in Table 2. In the following section, the nine recommendations are described in detail.

### ***1. Decide on the subject and goal of the MTD***

Being aware of the goal and subject prior to the MTD can lead to increased feelings of motivation, effort, and focus during MTDs. In that, professionals should be aware of goals focusing on team processes (e.g., improving interprofessional collaboration, reflect on team functioning) and goals concerning the content of care (e.g., enhance insight in care processes, reflect on client satisfaction, increase awareness of one's own working approach).

### ***2. Differentiate between those involved and those attending the MTD***

In general, MTDs are reported as more efficient in relative smaller groups. It is not always a necessity that those involved also physically attend the MTD, as long as a summary of the MTD is reported to all those involved afterwards.

### ***3. Decide on the moment and duration of the MTD***

MTDs should be scheduled in advance to ensure evaluation and reflection are regularly performed, even during busy periods. To stimulate a learning process, implement change, and ensure improvement in practice, professionals should ensure sufficient time in between MTDs. The duration of the MTD should be estimated beforehand and can vary depending on the goal, subject, and size of the group.

### ***4. Timely prepare the MTD and gather input from stakeholders beforehand***

Timely preparation of MTDs is crucial to increase the efficiency, effectiveness, and feelings of satisfaction amongst those involved in the MTD. Specifically, case discussions should be prepared by providing sufficient information to those involved in advance. Professionals can



apply various methods to collect input for an MTD from stakeholders involved, for example by means of a questionnaire, in dialogue, or by group discussions.

### ***5. Follow the general structure of MTDs and decide on the working approach***

MTDs should be guided by an agenda. In general, this agenda should include the following general structure of MTDs: (1) introduction of the goals and structure of the MTD, (2) short reprise of the preparatory assignment, (3) in depth evaluation and reflection on a topic, (4) concrete agreements or follow-up steps, and (5) a summary with the highlights of the MTD. The structure of MTDs can be improved by choosing a working approach based on a clear and short format that fits the purpose, group, and subject of the MTD (e.g., a SWOT analysis or the Signs of Safety model).

### ***6. Allocate tasks to ensure structured MTDs***

Clear allocation of tasks is needed to safeguard the structure of the MTDs and share responsibility among those involved. The four general tasks during an MTD are: (1) a process guard, responsible for planning the MTDs, inform those involved/attending, and send out the preparatory assignments, (2) a chair, guiding the team through the agenda and structure of the MTD, (3) a secretary, writing down the actions and highlights of the MTD and (4) a time guard, responsible for time monitoring during MTDs.

### ***7. Ensure a safe team climate during the MTD***

A safe team climate is essential for professionals to speak out during the MTD, to learn, and improve their practice. A safe climate can be recognized by an open atmosphere, in which professionals feel that there is room for reflection on limitations and doubts. To achieve a safe climate, all those involved should hold a basic attitude of equity, mutual respect, integrity, and trust. Also, the team climate can be improved by explicitly discussing the intention of an MTD in advance and by paying attention to eventual changes in team composition.



### ***8. Ask reflective questions and provide constructive feedback during the MTD***

Professionals should ask reflective questions with the intention to discover the underlying considerations of the other, instead of directly proposing a solution. Reflective questioning and constructive feedback does not imply that one should not be critical, as long as the feedback is objective and focused on increasing awareness on one's own actions, improvement, and learning.

### ***9. Register and monitor follow-up steps at the end of the MTD***

There should be sufficient time at the end of the MTD to repeat key lessons and register concrete follow-up steps. To ensure a learning process, keep follow-up steps simple and concrete (specific, measurable, achievable, relevant, and time-bound) and regularly monitor these steps by planning follow up evaluations.

## **DISCUSSION**

This study's action research resulted in nine practical recommendations for professionals in Youth Care to improve evaluation and reflection in MTDs. These recommendations include preparatory activities to ensure purpose, timing, and relevant stakeholders involved; specific points of attention during MTDs to ensure effectiveness (e.g., a shared working approach, clear tasks and roles, a safe team climate, and reflective questioning); and tracking follow up steps after MTDs to ensure a learning process. By closely collaborating with professionals when developing the recommendations, professionals judged the recommendations as recognizable and applicable to existing MTDs. Professionals reported that applying these recommendations guided them to improve structure, process, and effectiveness of MTDs and led to increased feelings of satisfaction among those involved. By discussing the current situation based on the recommendations, professionals developed a continuous learning process to improve evaluation and reflection in their daily practice.



Our recommendations partly corroborate with recommendations from previous research to MTDs in adult mental health care (Raine et al., 2015). However, in that research, MTDs within one organization were studied, while in Youth Care various professionals from different organizations are commonly involved in care processes. Hence, MTDs in Youth Care are not only used to discuss care processes and treatment plans, but also to evaluate interprofessional collaboration within and outside the multidisciplinary team, and to reflect on one's own working approach. As previous research points out, discussing such a broad range of topics in a limited amount of time can lead to a lack of purpose, structure, and depth in the MTD (Nooteboom et al., 2020; Raine et al., 2014). Therefore, it is crucial that professionals in Youth Care formulate the purpose of an MTD beforehand. Moreover, corroborating previous research (Raine et al., 2014; Rosell et al., 2018), our study implicates that attendance of MTDs should be limited, since too many professionals attending hinders effectiveness (e.g., lengthy decision-making progress and an unsafe team climate). Unfortunately, there is no golden standard for the number of professionals attending an MTD, since the number of professionals involved varies on families' needs and the purpose of the MTD. However, gathering relevant feedback from all those involved beforehand and provide feedback afterwards might help to limit high attendance rates during MTDs.

As suggested by professionals during project team meetings, MTDs were not the only moment of evaluation and reflection in their daily practice: professionals also reflected with families, policy makers, and collaborative partners. We believe that further application of recommendations in daily practice of Youth Care professionals is easy, since they are applicable during regular work processes, and therefore, require a minimum amount of time and no additional financial resources. However, additional implementation activities are required to improve transferability and implement the recommendations in other multidisciplinary teams in Youth Care. As we know from previous implementation studies, various factors play a role in implementation and there is no comprehensive strategy applicable to all settings (Fixsen, Blase, Metz, & Van Dyke, 2013). In our study, the members of the project team served as ambassadors, with the formal task to involve their



colleagues in the study and implement the lessons learned within their own teams. To implement the results in other settings, we recommend designating a local implementation ambassador with the responsibility to inform and support professionals in applying the recommendations.

### **Strengths and limitations**

The key strength of our study lays in its participatory approach involving over 60 professionals from six different teams in Youth Care with a variety of working experience, professional disciplines, and working approaches. Additionally, we included the perspectives of families, managers, and policy makers. This participant triangulation, together with triangulation in research methods (e.g., interviews, observations, and focus groups), enabled us to gain a rich and in-depth view of facilitators and barriers to evaluation and reflection in MTDs (Bekhet & Zauszniewski, 2012). The non-participant unstructured observations enabled the researchers to study MTDs without predetermined notion (Mulhall, 2003). Furthermore, we ensured feasibility and applicability of the recommendations in practice by collaboratively developing recommendations during project team meetings. The project team meetings and steering committee were essential components of this action research study's implementation process. Specifically, members of the steering committee held key functions within their organizations and could therefore easily spread and implement the results of this study. The focus group with professionals of other multidisciplinary teams in Youth Care enabled us to confirm the credibility, applicability, and transferability of the recommendations in teams who were unfamiliar with the research project.

This study also has its limitations. We systematically compared observational data and interview fragments of a multidisciplinary group of professionals, managers, policy makers, and families with different values and preferences. We concluded that most facilitators and barriers corresponded between sources and research methods. However, all project team members and participants in the interviews were related to Youth Teams in the Netherlands. We studied a typical Western setting, and since cultural norms might vary across countries,



we cannot conclude that the recommendations are globally applicable. Moreover, no formal consensus methods were used to formulate the recommendations, such as a Delphi method. Hence it would be interesting to focus on differences between various stakeholders and settings regarding these recommendations, to improve transferability.

Importantly, the effect of applying these recommendations on the quality of care should be evaluated through further investigation. We believe that the recommendations guide professionals to structure MTDs, however, the importance of informal interpersonal contact during MTDs should also be considered when assessing interprofessional collaboration and quality of care in future studies. Also, although triangulation of research methods was applied, the effect of each recommendation in practice is understudied and we were unable to calculate the strength of evidence for each recommendation. Based on our observations we suggest that the recommendations might be interrelated, however we did not measure the correlation between recommendations and their effect in practice or in which order the recommendations can be best applied. For example, from our study it remains unclear whether professionals should work on a safe team climate first, before discussing the structure of an MTD. Therefore, to measure their effectiveness in practice, implementation and application of the recommendations should be systematically monitored.

## **CONCLUSION**

In conclusion, the nine recommendations formulated and implemented in this study are designed to improve effectiveness of evaluation and reflection in MTDs and thereby increase satisfaction among professionals, improve interprofessional collaboration, and eventually strengthen quality of care. We believe this is of major importance in the broad field of Youth Care, where MTDs are crucial to evaluate and reflect on care processes, interprofessional collaboration, and one's own working approach.





The page features several dark red geometric shapes on a light red background. A large triangle in the upper left contains the number 6. Below it and to the left are four smaller triangles and one diamond, all pointing in various directions.

# 6

## Summary and General Discussion





## DISCUSSION

Integrated care is considered the ultimate solution to overcome fragmentation in support for families with multiple needs. By providing coherent, continuous, and coordinated support, integrated care can improve support for families with regard to access, quality, efficiency, and user satisfaction (World Health Organization, 2016). The last decade, there has been a global trend of reconstructing health care systems in order to organize integrated care. Similarly, a major decentralization of the Youth Care system took place in the Netherlands. In 2015, municipalities became responsible for organizing all support for children and their families with psychosocial needs (e.g., universal, primary, secondary, and tertiary support). By forming local, multidisciplinary Youth Teams as the core of the renewed Youth Care system, municipalities aimed to provide integrated care within families' own environment.

However, despite these organizational reforms, providing integrated care in practice remains challenging. As we know from previous research, top-down reforms tend to overlook the dynamic and complex process of providing integrated care in practice (Valentijn, Schepman, Opheij, & Bruijnzeels, 2013). Although the aim of the renewed Youth Care system was to ensure integrated support with a strong focus on family empowerment and shared decision making, it remained unclear how exactly professionals should accomplish this in practice. The variety of definitions and applications of integrated care in different contexts hampers general understanding of facilitators and barriers. As a result, professionals struggle to implement an integrated approach in their daily practice, leading to inadequate support of families. A bottom-up approach is considered vital to accomplish effective integrated care, with an emphasis on evaluation, reflection, and collaborative learning (Tsisis, Evans, Rush, & Diamond, 2013).

In this dissertation, integrated care on a professional level was studied from multiple perspectives. The main aim was to contribute to a better understanding of facilitators and barriers for professionals, which was



studied in several ways. First, we conducted a systematic review of international studies to facilitators and barriers for professionals to provide integrated care (chapter 2). Second, two qualitative studies were conducted to unravel parental perspectives (chapter 3) and professional perspectives on integrated care (chapter 4). An additional aim was to guide professionals in improving evaluation, reflection, and collaborative learning, by means of a four-year action-based research study in six Youth Teams in the Netherlands (chapter 5).

In this general discussion, main findings of the four studies are summarized. Subsequently, methodological considerations are discussed, followed by a reflection on theoretical implications. This will lead to implications for policy, practice, education, and future research.

### **Main findings**

In chapter 2, we conducted an extensive systematic literature review to identify facilitators and barriers for professionals to provide integrated care. In total, 55 studies from a variety of settings, models, and populations seen in Youth Care were included for data extraction and qualitative data synthesis. Identified facilitators and barriers were often opposing, and therefore, clustered in seven themes and 24 subthemes. Despite the diversity of studies included, the strength of evidence rating showed that the reported barriers and facilitators were generally consistent across studies and thereby applicable in a variety of settings. Most studies reported facilitators and barriers regarding interprofessional collaboration, including various forms of integrated care provision, information exchange, flexible professional roles, and shared responsibility. In addition, multiple facilitators and barriers regarding broad assessment of problems, a holistic, family centered approach, timely identification of problems, and prioritizing the needs of families were identified. The broad variety of facilitators and barriers identified in the review clearly shows that providing integrated care is a multicomponent and complex process, that requires consideration in practice, policy, education, and organizations.



To enable professionals to tailor integrated care to family's needs, we furthered our understanding of facilitators and barriers from a parental perspective in chapter 3. This qualitative study set two objectives: (1) to identify what parents considered key components of integrated care, and (2) to describe facilitators and barriers according to parents. From the 21 semi-structured interviews with parents, we concluded that parents have a strong desire for a family-centered approach and active participation in decision making over their care process. In total, we identified six key components of integrated care that were of importance according to parents: (1) a holistic, family centered approach, (2) addressing a broad range of needs in a timely manner, (3) shared decision making, (4) interprofessional collaboration, (5) referral and warm handoffs to ensure continuity, and (6) privacy. Parents described several facilitators, including transparent communication, involvement in the care process, freedom of choice, comprehensive and up to date shared care plans, and clear allocation of responsibilities. A perceived lack of access to services, long waiting lists, and difficulties in interprofessional collaboration hindered integrated care. Importantly, parents reported that an integrated approach does not mean that all needs should be addressed simultaneously, since this can lead to overburdening of families. Moreover, although parents considered active participation in decision making processes as important, they held somewhat opposing expectations concerning their own role in shared decision making. Based on the interviews, we concluded that roles in shared decision making were not fixed, and therefore, frequent evaluation of the care process, roles, and responsibilities is needed. In that, professionals should explicitly discuss mutual expectations and transparently propose different options for support.

In chapter 4, we studied facilitators and barriers professionals encounter when providing integrated care. Based on the analysis of interviews with 24 professionals from multidisciplinary teams in the Netherlands, we formed six themes covering facilitators and barriers: (1) early identification and broad assessment to timely recognize problems, (2) multidisciplinary expertise by specialist professionals in a generalist team, (3) continuous pathways to ensure flexible support



throughout the entire continuum of care, (4) stepped and matched care as current approaches in integrated care provision, (5) autonomy of professionals to tailor support and follow guidelines, and (6) evaluation of care processes to discuss progress and alter support if needed. Professionals reported that providing integrated care to families with multiple needs is complex, often due to the long-lasting, unpredictable nature of co-occurring and interacting problems of multiple family members. Professionals emphasized the need for flexible support across life domains, with varying intensity and matched to families changing needs. Facilitators reported by professionals were working in multidisciplinary teams, co-location, and being able to prioritize problems. Also, professionals described the importance of a balance between the use of guidelines and their autonomy to tailor support to families' needs. Moreover, professionals described the importance of evaluation of care processes. In fact, multidisciplinary team discussions enabled them to gain an objective approach of a care process, gain insight in potential blind spots, benefit from the broad expertise represented in their team, involve multiple perspectives in decision making, share responsibility, and learn from each other.

Previous studies (chapter 2), parents (chapter 3), and professionals (chapter 4) all acknowledge the importance of evaluation and reflection in relation to integrated care. In chapter 2, several studies described evaluation as a necessity to learn from each other's' expertise, increase feelings of self-efficacy, and improve familiarity between professionals. Moreover, according to parents (chapter 3), evaluation of the care process can improve insight in their own needs and is crucial for them to engage in shared decision making. In chapter 5, we discussed barriers and facilitators to evaluation and reflection during professionals' weekly multidisciplinary team discussions (MTDs). During MTDs, professionals discuss progression of individual care processes, interprofessional collaboration, team development, and issues in their daily practice. Based on a four-year action research with observations, semi-structured interviews, and interactive sessions, we concluded that each multidisciplinary team had its own working approach for evaluation and reflection. However, facilitators



and barriers to evaluation in MTDs were similar for all teams. Overall, barriers to effective and efficient evaluation included a lack of structure and preparation, an unclear subject and purpose of the MTD, too many professionals attending an MTD, an unsafe team climate, lengthy decision-making processes, unclear tasks during evaluation, and a lack of time to formulate follow up steps at the end of an MTD. Facilitators included allocation of tasks and sufficient preparation, a positive atmosphere with a focus on learning, and a clear purpose, structure, and working approach of the MTD. Based on the facilitators and barriers, nine practical recommendations were formulated in collaboration with professionals, parent representatives, and policy makers. These recommendations included preparatory activities to ensure purpose, timing, and relevant stakeholder involvement; reflective questioning, a safe team climate, and structure during MTDs to ensure effectiveness; and tracking follow up steps after MTDs to ensure a learning process. By applying these recommendations in practice, professionals can develop a continuous learning process to improve integrated care.

### **Methodological considerations**

This section addresses the following general methodological considerations: (1) the conceptual ambiguity of integrated care, (2) reflections on qualitative research methods, and (3) evidence-based practice. Then, three general limitations of this dissertation are discussed.

#### ***Conceptual ambiguity of integrated care***

A well-known difficulty with studying integrated care is its conceptual ambiguity and variation in applicability (Peek & The National Integration Academy Council, 2013; Valentijn et al., 2013). Integrated care is associated with a broad variety of terms, models, programs, and approaches, and is strongly related to the context in which it is applied. As a result, comparative studies to integrated care are difficult to perform. Being aware of these conceptual differences, integrated care was broadly defined throughout this dissertation as: coherent, continuous, and coordinated support, organized across services, and wrapped around families' needs (Kodner, 2009; Peek & The National



Integration Academy Council, 2013; World Health Organization, 2016). Moreover, a strength of our systematic literature review (chapter 2) was the standardized approach to control for different definitions, contexts, and applications of integrated care across studies. By using standardized extraction forms to keep track of these differences, it was possible to conduct an objective review, resulting in comparable elements across integrated care models, settings, and professional disciplines. Furthermore, with a semi-structured, qualitative approach, the heterogeneity of interpretations across participants has been recognized (chapter 3 and 4). Specifically, at the start of each interview we asked participants to define the concept of integrated care. Then, guided by a topic list, various aspects of integrated care were discussed in the interviews. This approach enabled us to gain insight in participants' associations with the concept of integrated care, and to study integrated care as a multicomponent concept.

### ***Qualitative research methods***

As shown by the large number of qualitative studies included in the systematic review, a qualitative approach to study integrated care is often preferred over quantitative research methods. Whereas quantitative research methods are valuable to quantify and classify, to test hypotheses, and to predict trends, qualitative research methods are most suitable to study the 'what, how and why' questions behind these numbers (McCusker & Gunaydin, 2015). Qualitative research provides a powerful research methodology to explore multicomponent and dynamic concepts in its context, such as integrated care (Smith & Furth, 2011). In chapter 3, 4, and 5, qualitative research methods including interviews, observations, action research, and focus groups enabled us to uncover and understand lived experiences with integrated care from various participants' perspectives. To ensure high-quality and objective qualitative research, studies in this dissertation met the following criteria: (1) a structured and systematic approach; (2) triangulation of research methods, researchers, and participants; and (3) continuous reflection on findings and interpretations.



First, various guidelines were applied to ensure a structured and systematic approach: the PRISMA guidelines (chapter 2; Liberati et al., 2009), COREQ guidelines (chapters 3 and 4; Tong, Sainsbury, & Craig, 2007), and RIGHT statement (chapter 5; Chen et al., 2017). These guidelines limited the risk of reporting bias and promoted transparent, systematic, and comprehensive interpretation and reporting of results.

Second, by means of triangulation in research methods and participants, comprehensive information was gathered (Thurmond, 2001). By combining results from interviews, observations, and focus groups, we were able to compare findings, leading to a better understanding of integrated care. Also, participant triangulation enabled us to study integrated care from multiple perspectives, including parents and professionals. To limit potential bias in interpretation of the data, researcher triangulation was applied in this dissertation (Thurmond, 2001). Thus, while coding and interpreting data, value of the findings was increased by cross-checking between researchers.

Third, to ensure confirmability and avoid interpretation bias, we continuously reflected on findings and interpretation during reflexive meetings with the research team. Reflexivity in qualitative research increases rigor and multidisciplinary insights (Barry, Britten, Barber, Bradley, & Stevenson, 1999).

### ***Evidence-based practice***

According to the principles of evidence-based practice, combining client perspectives, clinical experiences, and evidence from research is needed to organize high-quality care (Kuiper, Munten, & Verhoef, 2016). Specifically in integrated care, where multiple stakeholders are involved, this multi-perspective and participatory approach is crucial. After all, families are experts over their own care process and in combination with experiences of professionals, their insights are critical to ensure sustainable change in practice. A strength of this dissertation is its participatory character and focus on combining insights from research (chapter 2), clients (chapter 3 and 5), and clinical experiences (chapter 4 and 5). The various research methods with a strong practice-based





focus led to in depth and rich information about facilitators and barriers from multiple perspectives.

Moreover, throughout the entire research process we closely collaborated with representatives of families, practice, and policy within a project team. This project team met approximately every six weeks and played an important role in developing study methods, verifying results, and reflecting on the interpretation of findings. This approach not only encouraged discussion to reveal multiple perspectives, it also increased the credibility and applicability of our study outcomes and limited potential negative effects of interpretation bias (Abma et al., 2017; Femdal & Solbjør, 2018; Migchelbrink, 2007; Nyström, Karlton, Keller, & Andersson Gäre, 2018). In addition to the project team, a steering committee advised the researchers twice a year, by reviewing the recommendations and study progress. This committee consisted of representatives from practice, families, research, education, and policy, and played an important role in the dissemination of the study outcomes in their own organizations and network.

### ***Limitations***

Besides specific study limitations described in earlier chapters of this dissertation, there are three general limitations that should be considered. First, although the qualitative approach enabled us to gain a comprehensive overview of facilitators and barriers and thereby contributes to a better understanding of integrated care on a professional level, we did not measure the actual effects of these barriers and facilitators in practice. Specifically, we now know what facilitators and barriers are important to consider when providing integrated care, but we are still unaware how they impact practice. Hence, it is not possible to draw any conclusions to what extent our findings affect practice, or to scrutinize if and how the facilitators and barriers interact with each other. The need for high-quality studies to the effects of integrated care in practice is widely recognized (Hetrick et al., 2017; Strandberg-Larsen & Krasnik, 2009). Insights in the effects of integrated care are crucial to guide practice and policy to develop targeted interventions to improve integrated care. Furthermore, to



provide personalized support, we should further our understanding of general aspects of integrated care and individual differences based on characteristics of families and professionals ('who').

Second, this study was conducted in a restricted period and setting, within a highly changing context, with multiple organizational reforms ahead. Hence, we included a relatively small number of participants from Youth Teams with a lack of geographic spread across the country, in a typical Dutch context and within a western society. Moreover, in the qualitative part of this study we solely focused on professionals, parents, and policy makers involved in Youth Teams, and approached integrated care from that perspective. Consequently, we overlooked the interpretation of facilitators and barriers from for example the perspective of professionals in tertiary support or in universal services. Since integrated care is such a context-dependent process, results from this dissertation cannot be transferred to other contexts or integrated care initiatives without reservations. However, we suggest that the outcomes of this dissertation can be seen as generic for the broad setting of Youth Care, since the results were consistent across studies, and complementary to the results of previous research to integrated care (chapter 2).

Third, although practice-based research is crucial to improve practice, it is also time consuming and requires an open attitude of all those involved. Moreover, improvement as an outcome of practice-based research can be difficult to quantify. Since professionals were closely involved during all phases of the research, some professionals became unaware that a learning process was stimulated as a result from participating in this study. Consequently, it was difficult to keep these professionals involved: they felt that there was no need for additional support and were demotivated to participate in for example learning sessions. To keep practice involved and to avoid misunderstanding, confusion, and motivation problems across participants, it is crucial that researchers frequently discuss preliminary results with practice, adjust activities to professionals' needs, and critically reflect on their own behavior and attitudes as a researcher.



**Table 1.** Core components of integrated care on a professional level

Core components	Systematic review (chapter 2)	Parental perspectives (chapter 3)	Professional perspectives (chapter 4)
1 Family-centered focus	A holistic focus to address a broad range of needs, with both a generalist view on the entire family's welfare and a specific focus on individual needs.	Problems of one family member often influence the entire family's wellbeing. The needs of family members can vary. The importance of a holistic approach should be discussed with families.	Problems of one family member often influence the entire family's wellbeing. Family-centered support can be challenging due to chronic, interacting, and unpredictable problems.
2 Prioritize problems and needs to decide on the focus of support	Prioritize problems is crucial to decide on the focus of support and to respond to often changing needs of families. Professionals should be able to incorporate different viewpoints into a coherent plan.	Not all needs should be addressed simultaneously, too many treatment goals lead to overburdening of families. Joint assessment and shared decision making is needed, with active involvement of parents.	Professionals do not need to solve all problems, they must identify needs, prioritize problems, and timely involve other expertise. Shared decision making is crucial to tailor support to families' needs.
3 Flexible care provision across domains, responsive to the needs of families (e.g., step up and scale down)	Support should be flexible throughout the entire continuum of care, to respond to the changing needs of families.	To be involved in the care process and increase consensus on the focus of support, families need insight in the care process through up to date care plans with focus on current and future goals.	Varying intensity of support is needed to respond to the changing needs of families. Requires frequent evaluation and timely involvement of other professionals.
4 Knowledge and expertise (e.g., generalist and specialist knowledge)	There is no consensus on the knowledge and skills professionals should possess (both generalist and specialist expertise). Unrealistic that one professional can learn and apply all knowledge needed to provide a broad range of support. Need for joint learning on the job.	Multidisciplinary teams broaden the scope of expertise needed to provide a broad range of support.	Both generalist and specialist knowledge required. Multidisciplinary teams deploy a broad range of expertise to provide integrated support. Joint learning can be improved by evaluation and learning on the job.

<b>Core components</b>	<b>Systematic review (chapter 2)</b>	<b>Parental perspectives (chapter 3)</b>	<b>Professional perspectives (chapter 4)</b>
5 Self-efficacy (i.e., feeling comfortable and competent to assess a broad range of problems)	Feeling comfortable and competent to assess a broad spectrum of problems and collaborate with various professionals. Providing support outside a professionals' scope of expertise decreases feelings of self-efficacy.		High working demands force professionals to provide support outside their scope of expertise, leading to decreased feelings of self-efficacy.
6 Tools for integrated care (e.g., screening tools, shared care plans, and guidelines)	Adequate application of screening tools for broad assessment. A shared care plan should be flexible and adjustable to family's needs. Guidelines can support professionals in recognition of needs, and in interprofessional collaboration.	The aim of broad assessment, including the use of screening tools, should be explained to parents. Shared care plans can improve insight in a care process, professionals should keep these plans up to date.	Broad assessment can be burdensome for parents and is time consuming. Guidelines can assist professionals in providing integrated support, if there is sufficient room for professional autonomy to tailor support to family's needs.
7 Preconditions for integrated care (e.g., time, funding streams, and availability of support)	Integrated funding streams, time for interprofessional collaboration, and time for broad assessment. Availability of professionals is crucial; however, it is challenging to estimate the amount of time and number of professionals required. High-turnover rates hinder integrated care.	Integrated funding streams and agreements between services. A lack of access and availability are major barriers. Transparent communication on the availability of support positively influences the perceived waiting time. High-turnover rates hinder integrated care.	Sufficient time for integrated care and availability of professionals important to timely step up and refer to other services. Lack of availability forces professionals to provide support outside scope of expertise. High-turnover rates hinder integrated care.



<b>Core components</b>	<b>Systematic review (chapter 2)</b>	<b>Parental perspectives (chapter 3)</b>	<b>Professional perspectives (chapter 4)</b>
8 Forms of integrated care (e.g., multidisciplinary teams, colocation, consultation, and coordination)	Colocation, consultation, multidisciplinary case discussions, multidisciplinary teams, and care coordination are forms of integrated care that can broaden the scope of care provided, improve opportunities for learning, and stimulate interprofessional collaboration.	Colocation and care coordination can reduce fragmentation and increase coherence, collaboration, accessibility, familiarity, and early support. By working in multidisciplinary teams, diverse expertise is easily accessible, leading to increased efficiency.	Colocation and multidisciplinary teams can improve familiarity, learning from one's others expertise, and interprofessional collaboration. Multidisciplinary case discussions are crucial for collaborative learning and to make use of other professionals' expertise.
9 Collaboration between services	Schools are important collaborative partners. Warm handoffs, timely involvement of other expertise, agreements on frequency and content of sharing information facilitate collaboration. Potential confidentiality issues should be discussed with families to overcome privacy issues.	Schools and general practitioners are important collaborative partners. Warm handoffs, a contact person during transition from one care provider to another, and agreements between professionals about the content and frequency of sharing information facilitate collaboration. Privacy of separate family members should be considered during family meetings.	Schools, general practitioners, and adult care providers are important collaborative partners. Warm handoffs, timely involvement of other expertise, and share adequate information facilitate collaboration. Potential privacy issues should be discussed with families.
10 Familiarity between professionals	Familiarity with other professionals, mutual respect, and appreciation of diversity needed to make use of each other's expertise (attitudes), and to incorporate multiple perspectives into a care plan.	Familiarity between professionals, and with families, improves communication and accessibility of support.	Familiarity with other professionals is crucial to make use of each other's expertise and leads to increased trust and improved collaboration. Respectful attitude towards other professionals.

Core components	Systematic review (chapter 2)	Parental perspectives (chapter 3)	Professional perspectives (chapter 4)
11 Roles, responsibilities, and professional identity	Recognize (boundaries of) one's own expertise, roles, responsibilities, and tasks. Unclear whether roles and responsibilities should be set of flexible. Shared thinking and positive attitude towards integrated care are facilitators.	Clear tasks, roles, and responsibilities are required for coordinated support, as well as a contact person for families to ensure continuity.	Recognize (boundaries of) one's own expertise, roles, responsibilities, and tasks and timely involve other professionals if needed.
12 Evaluation and reflection	Evaluation increases familiarity, and is a necessity to recognize roles, responsibilities, and learn from each other expertise. Improves self-efficacy and shared decision making.	Multidisciplinary case discussions can increase insight in care processes and are essential for families to be involved in shared decision making. Attending these discussions can be burdensome for parents.	Evaluation and reflection improve insight in roles and responsibilities, shared decision making, and interprofessional learning, and helps to timely involve other expertise.



### **Theoretical implications**

This study has several theoretical implications. First, we reflect on core components of integrated care on a professional level based on the facilitators and barriers identified in chapter 2, 3, and 4 of this dissertation. Then, we further discuss theoretical implications regarding multidisciplinary expertise, followed by a reflection on the importance of prioritizing needs in collaboration with families.

### ***Core components of integrated care***

Our findings confirm previous statements that providing integrated care is more than forming networks and organizing interprofessional collaboration (Goodwin, 2013; Valentijn et al., 2013). In Table 1, a thematic clustering of barriers and facilitators identified in the systematic review (chapter 2), parental perspectives (chapter 3), and professional perspectives (chapter 4) is presented. As can be concluded from Table 1, integrated care on a professional level can occur in different forms, and is related to a family-centered focus, interprofessional collaboration, organizational preconditions, and tools for integrated care. Moreover, our findings demonstrate that integrated care requires specific competencies, expertise, attitudes, and behavior of professionals, with a strong focus on interprofessional learning and shared decision making. Importantly, and often overlooked when developing integrated care initiatives, core components of integrated care also include self-efficacy and feelings of familiarity with other professionals. In fact, professionals should feel comfortable and competent to provide holistic, family-centered support, they should recognize the boundaries of their expertise, and timely involve others if needed.

Moreover, as can be concluded from Table 1, most facilitators and barriers identified in the systematic literature review (chapter 2), were also described by parents (chapter 3) and professionals (chapter 4). Given this high correspondence, we are confident that the twelve core components from Table 1 should always be considered when organizing or developing integrated care initiatives in practice:



1. A family-centered focus
2. Prioritize problems and needs to decide on the focus of support
3. Flexible care provision across domains, responsive to the needs of families (e.g., step up and scale down)
4. Knowledge and expertise (e.g., generalist and specialist knowledge)
5. Self-efficacy (i.e., feeling comfortable and competent to assess a broad range of problems and engage in interprofessional collaboration)
6. Tools for integrated care (e.g., screening instruments, shared care plans, and guidelines)
7. Preconditions for integrated care (e.g., time, funding, and availability)
8. Forms of integrated care (e.g., multidisciplinary teams, colocation, consultation, coordination)
9. Collaboration between services
10. Familiarity between professionals
11. Roles, responsibilities, and professional identity
12. Evaluation and reflection

The increased understanding of integrated care on a professional level makes an important contribution to guide professionals, organizations, and policy makers in improving high-quality and sustainable integrated care initiatives in practice. This dissertation clearly demonstrates that providing integrated care is a dynamic process. Further development of current and future integrated care initiatives requires continuous evaluation of the twelve core components by all stakeholders involved: families, professionals, researchers, policy makers, and organizations. This is important, since it is to be expected that the interpretation, application, and effects of each core component slightly vary per situation. For example, although both parents (chapter 3) and professionals (chapter 4) valued clear roles and responsibilities in a care process, we also found subtle differences in their perspectives on who should take certain responsibilities. Moreover, we assume that there might be differences in perspective between professionals about their roles in individual care processes, that highly depend on family's needs. Corroborating previous research (Baxter et al., 2018; Curry &





Ham, 2010; Patel et al., 2013), there is no 'one size fits all' approach to integrated care. Therefore, contextual variations, the individual needs of families, and professionals' characteristics should always be considered when evaluating core components of integrated care to further develop integrated care initiatives.

### ***Multidisciplinary expertise***

In chapter 2, we found that various specialist knowledge and expertise are needed to address the broad range of problems families in Youth Care encounter. However, from the systematic review it remained unclear what this knowledge or expertise of professionals should look like. Moreover, it seems unrealistic that one individual professional can learn and apply all available knowledge and expertise that is needed to provide integrated care. Therefore, to ensure multidisciplinary expertise, there has been an increased focus on organizing integrated care in multidisciplinary teams (Briggs, Valentijn, Thiyagarajan, & Araujo de Carvalho, 2018; Wodchis, Dixon, Anderson, & Goodwin, 2015). Findings in this dissertation confirm the importance of multidisciplinary teams to provide integrated care. Multiple studies in chapter 2 reported that multidisciplinary teams can increase the scope of care provided. Moreover, parents in chapter 3 confirmed this finding, stating that multidisciplinary Youth Teams improved local interprofessional collaboration and increased accessibility of support. Also, professionals in chapter 4 reported that working in multidisciplinary teams enables them to learn from each other's expertise and to take different roles in a care process. These findings all provide evidence that multidisciplinary teams such as the local Youth Teams in the Netherlands, can be a step forward to provide integrated care.

However, as already stated by Goodwin (2013), integrated care requires more than establishing multidisciplinary teams. Even though multidisciplinary teams can broaden the scope of care provided, teams that solely consist of professionals with specialist expertise seem insufficient to realize integrated care in practice. Specifically, if each professional focusses on its own specialism and a restricted number of problems within a multidisciplinary team, the interrelatedness of



problems and needs can still be overlooked (Hawkins, 2009; Kodner, 2009). On the other hand, it is vital to keep specialist expertise up to date, to avoid a multidisciplinary team full of generalists (chapter 4). Hence, two issues need further consideration.

First, we suggest that all professionals in Youth Care should possess generic competencies to be able to maintain a holistic, family-centered focus during care trajectories (chapter 2, 3, and 4), to recognize the boundaries of one's own expertise (chapter 4), and to timely involve other professionals if needed (chapter 4). For example, professionals should be able to evaluate and reflect on a care process in multidisciplinary team discussions, collaborate with other professionals, and contribute to shared decision-making processes. These competencies can be expanded by for example joint learning on the job (chapter 2 and 4) and improving multidisciplinary team discussions (chapter 5).

However, it is important to critically reflect on how much we can ask from professionals in Youth Care. Providing integrated care is a time-consuming process, while professionals' availability is often limited (chapter 2, 3, and 4). As a result, it can be difficult for professionals to prioritize learning activities (chapter 2 and 4). Moreover, professionals in chapter 4 reported that combining a specialist and a generalist approach to maintain a holistic, family-centered focus, hindered them to recognize the limits of their own abilities and timely involve other professionals, and led to unclear roles and responsibilities. Also, providing integrated care often forced professionals to provide support outside their scope of expertise, leading to feelings of incompetence and uncertainty (chapter 4). Hence, it seems that providing integrated care requires more than increasing generic competencies of all professionals in Youth Care and keeping specific specialist expertise up to date.

This brings us to our second issue of consideration. The multitude of components and the complexity of tasks related to integrated care provision poses the question whether being a generalist in integrated



care should be an area of expertise in itself. For example, being able to assess and prioritize needs, ensure flexible care provision and a family-centered approach, timely involve specific expertise, incorporate multiple perspectives into a comprehensive plan, and familiarity with a broad variety of services might require specific generalist expertise.

In this light, it would be interesting to learn from recent developments within other settings, for example from the role of a hospital physician in the medical setting. Since 2014, the specialism of hospital physician is officially recognized as a response to differentiation and specialization of medical doctors. This increased specialization led to fragmentation of care within the hospital setting. There was a need for a specialist with a generalist focus, whose main task was to ensure patient-centered, holistic, coherent, continuous, and high-quality support for patients with multiple (complex) needs. Currently, medical doctors can apply for the three-year specialist training to become a hospital physician (Regts, van Offenbeek, Roemeling, Bakker, & Vos, 2019). Generalist knowledge and expertise in the field of medicine will be obtained through learning on the job at various departments within the hospital setting. We believe that a similar specialism could be applicable to the Youth Care setting to facilitate integrated care for families with multiple, complex needs. For example, this can be a generalist trained within different domains in Youth Care (e.g., universal, primary, secondary, and tertiary care), and who can facilitate an integrated approach based on the needs of families. It would be interesting to further investigate the possibilities and added value of a so-called generalist profession in Youth Care. For example, we should study what role this specialist can play in multidisciplinary teams, and what knowledge, skills, and education they need to have to deliver high-quality integrated care.

### ***Prioritizing needs in collaboration with families: shared decision making and evaluation***

Another important finding of this dissertation is that to provide integrated care, professionals should be able to prioritize needs in collaboration with families. Specifically, families with multiple needs often encounter a broad variety of interacting problems (chapter



2). These problems cannot be addressed simultaneously, since this can lead to overburdening of families (chapter 3). As we know from previous research to families with multiple needs, broad assessment is needed to gain insight in problems, needs, and strengths across life domains (Tausendfreund, Knot-Dickscheit, Schulze, & Knorth, 2015; Van der Steege & Zoon, 2015). However, professionals in our study reported that it was difficult to prioritize needs based on this broad assessment (chapter 4). Furthermore, although professionals did not feel that they had to solve all problems, it was difficult for them to decide on the most appropriate focus of support (chapter 4). For example, difficulties in prioritizing occurred when needs of individual members seemed incompatible (chapter 2), or when professionals held different views on the most appropriate support (chapter 2, 3, 4). Moreover, the interaction of problems families in Youth Care encounter is still poorly understood, leading to difficulties in deciding the order in which needs should be addressed to achieve the best outcomes for families. This is a major knowledge gap that requires further research to improve integrated support for families with multiple needs.

In addition, to guide professionals in prioritizing needs, two aspects of prioritizing in integrated care should be further considered: (1) shared decision making and (2) evaluation and reflection.

First, shared decision making, defined as the process in which professionals and families jointly assess needs and decide on the focus of support (Bunn et al., 2017; Smits & Jukema, 2016). Previous studies reported shared decision making as a facilitator to decide on the type and intensity of support (Axelsson & Axelsson, 2009; Cohen et al., 2015). Moreover, parents (chapter 3) and professionals (chapter 4) in our study confirm the importance of shared decision making in integrated care. They underlined the need to provide different options for support, explicitly discuss mutual expectations, and taking all perspectives into account when deciding on the focus of support. According to parents, shared decision making can increase families' feelings of empowerment, and thereby positively influence a care process. However, both parents and professionals reported difficulties



in shared decision making. Specifically, it became increasingly clear that shared decision making was not something fixed, but a context-dependent process, in which parental and professional roles differ per family and change over time.

In our study, both parents and professionals reported the need for guidance in shared decision making. Currently, there are already multiple guidelines available to support professionals in shared decision making, for example the Dutch guideline 'Richtlijn samen met ouders en jeugdige beslissen over passende hulp' (Bartelink, Meuwissen, & Eijgenraam, 2015) and the NHS 'Shared Decision-making Guide' (2019). However, based on the interviews in chapter 4, we suggest that these guidelines might not be implemented sufficiently in professionals' daily practice. It is possible that professionals are unaware of the existence of these guidelines, or that there is some controversy about the applicability. On the one hand, professionals indicated that the use of guidelines can support them in their daily practice. On the other hand, they also reported that strict guidelines hinder the application in practice, since it leads to a lack of professional autonomy to tailor support to family's needs. Hence, there should be a focus on appropriate implementation of existing guidelines in current practice, training, and education. In that, there should be a balance between the use of guidelines, and professionals' autonomy to tailor support to family's needs.

The second aspect to guide professionals in prioritizing needs is to consider the importance of evaluation. Based on this dissertation, we conclude that evaluation of care and care processes is crucial to prioritize families changing needs, to make use of the broad range of expertise in multidisciplinary teams, and to improve interprofessional collaboration (chapter 3, 4, and 5). Moreover, the needs of families often change over time and therefore, require continuous monitoring and evaluation to ensure tailored support (Firth, Barkham, & Kellet, 2015). Although professionals and organizations are often aware of the need to monitor and evaluate care processes, in practice this is often hampered by a perceived lack of time for evaluation, crisis-oriented focus of evaluations, and lack of structure during evaluations (chapter



4 and 5). The practical guidelines in this dissertation (chapter 5) are an important contribution to improve evaluation in practice, and thereby facilitate the process of prioritizing needs.

### **Implications**

In this section, we further discuss implications for policy and organizations, practice, education, and future research.

#### ***Implications for policy and organizations***

Policy makers and organizations in Youth Care play an important role in organizing integrated care, and thereby substantially influence integrated care provision in practice (Valentijn et al., 2013). A first evaluation of the decentralized Youth Care system in the Netherlands shows that despite organizational reforms, integrated support for families with multiple, complex needs is still lacking (Friele et al., 2018). Although there are positive developments as a result of the local organization of Youth Care, including shorter lines between local services, there is still a lack of coordination between care providers, a lack of availability of support, and limited coherence in the care process of families. Policy makers admit that we are not there yet (De Jonge & Dekker, 2020). Currently, families with multiple needs all too often do not receive the support they need and professionals still encounter difficulties in providing integrated support. As a solution, policy makers and organizations again focus on interventions at the organizational level, intended to support existing structures or forming new networks. Examples of this organizational focus are the development of local integrated teams for specialist support that operate alongside the existing Youth Teams, and the organization of supra-regional expertise centers that should improve care for the most vulnerable families in the country.

However, these are again solutions sought in structure and organization of integrated support. Although it is important that there is a certain structure at the organizational level to organize integrated care, this is only a starting point. This dissertation clearly shows that integrated care is not something you merely organize, but a process that requires



continuous development in practice. Corroborating previous research (Wodchis et al., 2015), initiatives to improve integrated care should be bottom up to ensure sustainability, with top-down (organizational) support. Therefore, to stimulate substantial improvement of integrated care in practice, we strongly recommend policy makers and organizations to focus on integrated care on a professional level, in addition to ensuring organizational preconditions. In that, the twelve core components that emerged from this dissertation should be the basis to further evaluate and develop integrated care initiatives in collaboration with practice.

### ***Implications for practice***

This dissertation has a strong practice-based focus. Therefore, multiple implications for practice are addressed in the separate chapters. A critical issue that professionals should be aware of is that providing integrated care is not 'something that you do or organize'. As Miller and Stein stated (2018): 'Integrated care is a highly complex intervention and adopting its principles can take time, flexibility, and understanding'. Therefore, professionals should consider integrated care as a profession that requires both collaborative working and collaborative learning.

First, professionals should pay attention to collaborative working as a facilitator to provide integrated care. To address a broad range of needs, it is crucial that professionals can collaborate with a variety of partners in the field of Youth Care, including general practitioners and schools. To ensure interprofessional collaboration, professionals must be aware of the boundaries of one's own expertise, acknowledge when additional expertise is needed, and timely involve other professionals. In addition, to provide integrated support to families with complex needs, professionals should appreciate other professionals' expertise and working approach, there should be mutual trust, transparency, continuous communication, and feedback (Bevington, Fuggle, Cracknell, & Fonagy, 2017). Furthermore, professionals should be aware that collaboration in integrated care does not only apply to interprofessional collaboration. In fact, collaboration with families is just as important. To be able to provide integrated care tailored to



family's needs, involving family's perspectives is a necessity. In that, professionals should always discuss the importance of an integrated approach to families, ensure an up to date care plan, and guide families in shared decision making.

Second, professionals should pay attention to collaborative learning as a facilitator to provide integrated care. Integrated care is a dynamic and complex process, that requires multidisciplinary expertise and continuous evaluation of the care process to respond to the changing needs of families. To make use of the multidisciplinary expertise in for example a Youth Team and facilitate interprofessional collaboration, it is important to frequently discuss both clinical cases and team functioning during Multidisciplinary Team Discussions (MTDs). To ensure collaborative learning during these meetings, professionals should consider the practical recommendations for evaluation from chapter 5. Specifically, professionals should pay attention to preparatory activities, a safe team climate, and monitoring progress to ensure learning. During these MTDs, the twelve core components of integrated care described in this dissertation can be discussed to further develop integrated care initiatives. Importantly, organizations should stimulate collaborative learning activities by incorporating these activities in their policies and in their own working approach.

### ***Implications for education***

This dissertation has a primary focus on professionals that are currently employed in Youth Care. However, we strongly recommend to also invest in future professionals. In line with Stein (2016), we suggest that it is not only needed to introduce the concept of integrated care into curricula of a broad range of mental health-oriented studies (e.g., Psychiatry, Psychology, Social Work), but also to make interprofessional education and training the norm. Corroborating Miller and Stein (2018), we suggest that there should be a shift from uniprofessional education to interprofessional education. Of course, specialist training is needed to prepare future professionals and ensure the required specialisms in the broad field of Youth Care. However, it would be valuable to also invest in interprofessional courses, to improve feelings of familiarity





with other professions. For example, students from various faculties (e.g., Medicine, Psychology, Social Work) can collaboratively learn from clinical case discussions. In that, a strong focus should be on increasing generic competencies to provide integrated care, such as holding a holistic view on family functioning, being able to collaborate with other professionals, and shared decision making.

### ***Implications for future research***

This dissertation has thrown up various new research questions discussed in the separate chapters. In addition, the following two topics need further consideration: (1) in depth research to the 'how' and 'who' of integrated care, and (2) studying and learning from various integrated care initiatives in practice.

First, there is a need for in depth research to the 'how' and 'who' of integrated care. Although this dissertation contributes to increased understanding of 'what' barriers and facilitators should be considered when providing integrated care, we are still unaware of how these core components affect practice and for who, how they interact with each other, and how they can be applied by various professionals. For example, it remains unclear how, under what conditions, and for who shared decision making and evaluation positively affect the process of prioritizing. To further our understanding of integrated care on a professional level, we suggest future studies to work from a realist evaluation approach. This approach can guide researchers in unraveling what works, how and why, and under what circumstances when providing integrated care (Marchal, van Belle, Olmen, Hoerée, & Kegels, 2012; Pawson & Tilley, 1997). Realist evaluation not only focusses on the implementation and effectiveness of interventions and processes, but also on contextual factors and casual mechanisms that underlie change (Marchal et al., 2012). Based on the findings of this dissertation, theories can be formulated, discussed, and tested in practice, by both quantitative and qualitative research methods.

Second, future research should focus on studying and learning from various integrated care initiatives in practice. Since integrated care is a



context-dependent process, there is a substantial variety of integrated care initiatives. To prevent fragmentation in knowledge and to learn across domains, it is crucial that these small-scale initiatives are further studied and compared from multiple perspectives. If not, these initiatives will only have a limited impact on a small scale, and each new initiative has to reinvent the wheel. Learning from various integrated care initiatives can be stimulated in so-called communities of practice (Wenger, 2011), such as the Academic Workplaces in the Netherlands. In these communities, representatives from practice, families, organizations, policy, and research share knowledge and experiences, and reflect on current practice to stimulate collaborative learning. We suggest that to study and further develop integrated care initiatives, it is crucial to collaborate across domains, and learn from for example the medical sector, public administration, and adult care initiatives. Additionally, integrated care initiatives should be systematically monitored and compared to study generic elements, applicable to all integrated care initiatives, and elements that can only be applied under certain circumstances. In that, Qualitative Comparative Analysis can be a helpful research method (QCA; Thomann & Maggetti, 2017). With QCA, patterns can be systematically discovered in small groups and complex situations, enabling comparison between integrated care initiatives in different contexts.

## CONCLUSION

Providing integrated care is crucial to support families with multiple needs and should be considered as a profession on its own. There is no one size fits all approach, and solely organizing integrated care on an organizational level is insufficient to facilitate professionals in providing integrated care. This dissertation aimed to increase our understanding of integrated care on a professional level from various perspectives. The twelve core components described in this dissertation should be the basis to further develop integrated care initiatives, for both policy and practice. However, the core components should not be considered as a checklist, but as guidance for collaboratively discussing and developing integrated care initiatives. This requires continuous evaluation and



reflection in a learning environment, including professionals and their organizations, families, policy makers, and researchers, with a focus on improving integrated care for families with multiple needs.







The left side of the slide features four abstract geometric shapes in two shades of red. At the top is a large, dark red triangle pointing downwards. Below it is a smaller, dark red triangle pointing upwards. Further down is a medium-sized, light red triangle pointing downwards. At the bottom is a small, light red diamond shape.

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The background is a solid light pink color. On the left side, there are several abstract geometric shapes. At the top left, a large white triangle points downwards. Below it, a smaller white triangle points upwards. Further down, there are several pink shapes: a small triangle pointing right, a diamond shape, and a larger triangle pointing right. These shapes are scattered along the left edge, creating a modern, minimalist design.

# Nederlandse samenvatting





## NEDERLANDSE SAMENVATTING

Gezinnen met problemen op verschillende levensgebieden krijgen vaak te maken met een veelheid aan professionals en organisaties. Te vaak is deze hulpverlening gefragmenteerd, bijvoorbeeld doordat elke professional vanuit zijn eigen specialisme werkt, er te weinig wordt samengewerkt, of door organisatorische beperkingen. Integrale hulp wordt wereldwijd gezien als de oplossing om deze versnippering in hulpverlening tegen te gaan. Integrale hulp gaat om het bieden van samenhangende en passende zorg, met als doel het verbeteren van toegang, kwaliteit, efficiëntie van zorg en toenemende cliënttevredenheid. Om integrale hulp te realiseren vonden in de afgelopen jaren wereldwijd diverse stelselhervormingen plaats. Zo ook in Nederland. In 2015 kenden we een landelijke decentralisatie, waarmee gemeenten verantwoordelijk werden voor jeugdhulp en ondersteuning. Met multidisciplinaire teams (jeugdteams) als kern en transformatiedoelen als streven (zoals meer preventie, eigen regie, samenhang en samenwerking) trachtten gemeenten integrale hulp op maat in de eigen leefomgeving van gezinnen te organiseren.

Ondanks deze hervormingen blijft het bieden van integrale hulp in de praktijk, het integraal werken, een grote uitdaging. Uit een eerste evaluatie van de Jeugdwet blijkt dat er positieve ontwikkelingen zijn sinds de decentralisatie, zoals kortere lijnen tussen professionals in de wijk (Friele et al., 2018). Tegelijk bestaan er nog te veel knelpunten, vooral voor de meest behoeftige gezinnen; die met meervoudige en complexe problematiek. Onder andere door beperkte beschikbaarheid van zorg, en te weinig samenhang in het hulpverleningsproces krijgen deze gezinnen niet de hulp die zij nodig hebben.

Hoewel de transformatiedoelen bedoeld waren om richting te geven aan de uitvoering van een integrale aanpak in het vernieuwde jeugdhulpstelsel, was het onduidelijk hoe professionals en organisaties dit precies moesten doen. Deze problemen waren te verwachten. Uit eerdere onderzoeken weten we namelijk dat bij top-down hervormingen zoals een decentralisatie het dynamische en complexe

proces van integraal werken in de praktijk steevast over het hoofd wordt gezien. Daarnaast maakt de verscheidenheid aan definities en toepassingen van het concept integraal werken dat we nog weinig inzicht hebben in wat werkt in een integrale aanpak. Daardoor hebben professionals moeite om een integrale aanpak in hun dagelijks werk te implementeren, wat weer weerslag heeft op kwaliteit van zorg voor gezinnen.

In dit proefschrift staat daarom de volgende vraagstelling centraal: wat zijn werkzame en belemmerende elementen van integraal werken voor professionals in de jeugdhulp? Deze vraag onderzochten we vanuit verschillende perspectieven: een systematisch literatuuronderzoek (hoofdstuk 2), kwalitatief onderzoek met ouders (hoofdstuk 3) en kwalitatief onderzoek met professionals uit jeugdteams (hoofdstuk 4). Een bijkomend doel was om professionals uit jeugdteams te begeleiden bij het verbeteren van evaluatie, reflectie en gezamenlijk leren in de praktijk om zo integraal werken te stimuleren (hoofdstuk 5). De studies beschreven in het proefschrift zijn allemaal onderdeel van het vierjarige project Gezin aan Zet van de Academische Werkplaats SAMEN. In deze samenvatting worden de resultaten van de afzonderlijke studies gepresenteerd, en de daaruit voorkomende implicaties en aanbevelingen voor beleid, praktijk, onderwijs en onderzoek besproken.

## **Resultaten**

*Hoofdstuk 2* beschrijft een systematisch literatuuronderzoek naar werkzame en belemmerende elementen van integraal werken. In totaal werden 55 internationale onderzoeken naar integraal werken in de jeugdhulp met diverse methodologieën, populaties en soorten integrale hulp systematisch beoordeeld. De meeste onderzoeken rapporteerden werkzame en belemmerende elementen op het gebied van interprofessionele samenwerking, waaronder het belang van goede communicatie, duidelijke en flexibele rollen van professionals en gedeelde verantwoordelijkheid. Daarnaast werden er in vele studies werkzame en belemmerende elementen gevonden met betrekking tot een gezinsgerichte aanpak, een brede beoordeling van

problematiek, tijdige herkenning van problemen en het prioriteren van de hulpvragen van gezinnen. De grote verscheidenheid aan werkzame en belemmerende elementen die uit de literatuurstudie naar voren komt, toont duidelijk aan dat integraal werken in de praktijk uit vele componenten bestaat en een complex proces is.

In *hoofdstuk 3* wordt het perspectief van ouders op integraal werken belicht. Uit een thematische analyse van interviews met 21 ouders uit verschillende gezinnen kwamen zes kerncomponenten van integraal werken naar voren: (1) een holistische, gezinsgerichte benadering, (2) tijdig inspelen op een breed scala aan problematiek, (3) gedeelde besluitvorming, (4) interprofessionele samenwerking, (5) doorverwijzing en warme overdracht om continuïteit van zorg te waarborgen en (6) privacy van het gezin. Ouders beschreven verschillende werkzame elementen, waaronder transparante communicatie, betrokkenheid bij het hulpverleningsproces, keuzevrijheid, en duidelijke rollen en verantwoordelijkheden. Belemmerende elementen waren onder andere een gebrek aan toegang tot zorg, lange wachttijsten en moeilijkheden in interprofessionele samenwerking. Een belangrijk aandachtspunt uit dit onderzoek is dat volgens ouders integraal werken niet betekent dat alle hulpvragen tegelijkertijd opgepakt moeten worden, aangezien dit kan leiden tot overbelasting van gezinnen. Daarnaast, hoewel ouders actieve deelname aan besluitvormingsprocessen belangrijk vinden, kunnen de rollen in gedeelde besluitvorming gedurende een hulpverleningstraject veranderen. Daarom is regelmatige evaluatie van het proces, de rollen en verantwoordelijkheden nodig. Ook dienen professionals expliciet verwachtingen over het hulpverleningsproces met ouders te bespreken.

In *hoofdstuk 4* beschrijven we werkzame en belemmerende elementen van integraal werken volgens 24 professionals uit zes lokale jeugdteams. Uit de theoriegestuurde analyse van de interviews blijkt dat professionals integraal werken met gezinnen met meervoudige complexe problematiek uitdagend vinden, vooral omdat de problemen elkaar beïnvloeden, onvoorspelbaar zijn en vaak langdurig spelen. Professionals benadrukten het belang van flexibele ondersteuning

op alle levensdomeinen, met wisselende intensiteit en afgestemd op de veranderende behoeften van gezinnen. Werkzame elementen waren onder andere het werken in multidisciplinaire teams, werken op dezelfde locatie en het in staat zijn om gezamenlijk prioriteiten te stellen in het hulpverleningstraject. Ook gaven professionals aan dat het belangrijk is om een balans te vinden tussen het volgen van richtlijnen, en hiervan afwijken op basis van eigen inzicht om zo hulp op maat te bieden. Tevens werd het belang van evalueren en reflecteren genoemd, bijvoorbeeld tijdens multidisciplinaire casuïstiekbesprekingen. Belemmerende elementen waren onder andere problemen met het in kaart brengen van de verschillende en vaak wisselende hulpvragen van gezinnen, het stellen van prioriteiten, de samenwerking met andere professionals en een tekort aan beschikbare hulp, onder meer door lange wachtlijsten.

Het belang van evalueren in relatie tot integraal werken komt in alle hoofdstukken van dit proefschrift terug. In hoofdstuk 2 beschrijven verschillende onderzoeken evaluatie als een noodzaak om van elkaars expertise te leren, gevoelens van zelfredzaamheid te vergroten en het vertrouwen tussen professionals te verbeteren. In hoofdstukken 3 en 4 geven zowel ouders als professionals aan dat evaluatie van het hulpverleningsproces zorgt voor inzicht in behoeften van een gezin en betere gedeelde besluitvorming. Ook helpt regelmatige evaluatie om meerdere perspectieven te integreren en van elkaar te leren. Het vierjarig actieonderzoek Gezin aan Zet was gericht op het ondersteunen van professionals bij het vormgeven van evaluaties in hun dagelijks werk, en dan vooral in de wekelijkse multidisciplinaire teamoverleggen (casuïstiekbesprekingen en teamvergaderingen).

In *hoofdstuk 5* beschrijven we verschillende werkzame en belemmerende elementen voor efficiënte en effectieve evaluatie in het dagelijks werk van professionals die uit dit actieonderzoek naar voren zijn gekomen. Op basis van deze elementen zijn in samenwerking met professionals, gezinnen en beleidsmakers negen praktische aanbevelingen geformuleerd. Deze aanbevelingen omvatten het belang van voorbereidende activiteiten om het doel, structuur en

betrokkenheid van relevante stakeholders vast te stellen; het stellen van reflectieve vragen en een veilig klimaat tijdens evaluaties; en het vaststellen van vervolgstappen na evaluaties om een leerproces te garanderen. Met deze aanbevelingen kunnen professionals in jeugdteams een continu leerproces in gang zetten om integrale hulp voor gezinnen te verbeteren.

### **Discussie en aanbevelingen**

Er komen in dit proefschrift een aantal belangrijke implicaties naar voren. Allereerst dat integraal werken meer is dan het vormen van netwerken of het organiseren van multidisciplinaire teams. Hoewel de jeugdteams in Nederland een stap in de goede richting lijken, omdat er een breed scala aan kennis en expertise beschikbaar is, vraagt integraal werken om specifieke competenties, expertise, houding, en gedrag van professionals met een sterke focus op interprofessioneel leren en gedeelde besluitvorming. Professionals moeten zich bekwaam voelen om samenhangende, gezinsgerichte ondersteuning te bieden, ze moeten de grenzen van hun eigen expertise herkennen en tijdig de ander inschakelen wanneer nodig. Het is belangrijk om te erkennen dat integraal werken een complex en dynamisch proces is, zeker als het gaat om het ondersteunen van gezinnen met meervoudige, ernstige, en langdurige problematiek.

Op basis van de bevindingen in dit proefschrift zijn twaalf kerncomponenten van integraal werken geformuleerd (Tabel 1), die inzichtelijk maken wat er nodig is om tot integraal werken op het niveau van professionals te komen. Deze kerncomponenten laten zien dat we integraal werken moeten benaderen als expertisegeraad op zichzelf, een vak apart waar (toekomstig) professionals gericht in opgeleid dienen te worden. In andere sectoren zijn hier al stappen in gezet. Bijvoorbeeld in de medische setting, door het oprichten van de functie van ziekenhuisarts. Dit is een arts die gespecialiseerd is in generalistische ziekenhuiszorg, kennis heeft van verschillende vakgebieden, en zorgt voor continuïteit van zorg tussen verschillende afdelingen. Het is zaak dat we goed in kaart brengen in hoeverre een soortgelijk specialisme in de jeugdhulp van toegevoegde waarde kan zijn.

**Tabel 1.** Kernelementen van integraal werken op het niveau van professionals

Kernelement	Definiëring
<b>Brede blik op gezinsfunctioneren</b>	Met een brede benadering van het gezinsfunctioneren worden problemen van verschillende gezinsleden in kaart gebracht. Er is zowel aandacht voor het individu, als voor de invloed die problemen op andere gezinsleden hebben.
<b>Gezamenlijk prioriteren en beslissen over passende hulp</b>	Problemen worden tijdig herkend, prioriteiten worden gezamenlijk gesteld en er is sprake van gedeelde besluitvorming om te komen tot een samenhangend plan.
<b>Flexibele inzet van hulp over domeinen heen (op- en afschalen)</b>	Er kan flexibel op- en afgeschaald worden door de hele keten van zorg heen. Zo wordt ingespeeld op de wisselende behoeften van gezinnen met meervoudige en langdurige problematiek.
<b>Kennis en expertise</b>	Er is zowel generalistische als specialistische kennis en expertise nodig om integraal te werken. Omdat het niet haalbaar is dat één professional over deze kennis en expertise beschikt, is interprofessionele samenwerking nodig.
<b>Gevoel van bekwaamheid</b>	Professionals voelen zich bekwaam om een breed scala aan problemen te beoordelen en samen te werken met verschillende disciplines. Ook onder hoge werkdruk of buiten het eigen expertisegebied.
<b>Hulpmiddelen en richtlijnen</b>	Professionals maken op passende wijze gebruik van bestaande screeninginstrumenten en richtlijnen, waarbij er voldoende ruimte is om hulp op maat te bieden.
<b>Randvoorwaarden</b>	Er is voldoende tijd om het gezinsfunctioneren goed in kaart te brengen en een gezamenlijk plan op te stellen. Hulp is beschikbaar en er is duidelijkheid over de financiering van zorg en ondersteuning.
<b>Vormen van interprofessioneel samenwerken</b>	Multidisciplinaire teams, het werken op dezelfde locatie en het bieden van consultatie en zorgcoördinatie kunnen leiden tot een breder ondersteuningsaanbod, versterkte samenwerking, en vermindering van fragmentatie van zorg.
<b>Samenwerking tussen domeinen en organisaties</b>	Scholen en huisartsen zijn belangrijke partners in de jeugdhulp. Samenwerking wordt versterkt door warme overdracht, helderheid over privacy en afspraken over de frequentie, inhoud en wijze van informatie delen.
<b>Bekendheid met andere professionals en organisaties</b>	Elkaar kennen is cruciaal voor het tijdig invoeren van expertise, leidt tot meer vertrouwen onderling, verbeterde toegang tot zorg en verbeterde samenwerking. Belangrijk zijn wederzijds respect en het waarderen van diversiteit.



Kernelement	Definiëring
<b>Rollen, verantwoordelijkheden en professionele identiteit</b>	Herkennen van de (grenzen van) de eigen expertise, rollen, verantwoordelijkheden en taken is nodig om tijdig andere expertise in te roepen en als professional te weten 'waar je van bent'.
<b>Evalueren en reflecteren</b>	Evalueren en reflecteren vergroot inzicht in rollen en verantwoordelijkheden en kan leiden tot verbeterde gedeelde besluitvorming, gezamenlijk leren, en het tijdig inschakelen van passende expertise.

Een andere belangrijke implicatie uit dit proefschrift is de noodzaak van prioriteiten stellen en gedeelde besluitvorming binnen een integrale werkwijze. Wanneer er sprake is van meerdere problemen in een gezin, dienen niet al deze problemen tegelijk aangepakt te worden, benadrukken zowel ouders als professionals. Het is dus zaak dat professionals in staat zijn om samen met het gezin prioriteiten te stellen. Gedeelde besluitvorming gaat over het gezamenlijk in kaart brengen van behoeften van een gezin en samen beslissen over passende hulp op maat. Hierbij dienen professionals zich ervan bewust te zijn dat de rollen van gezinnen in een besluitvormingsproces niet vaststaan, maar kunnen veranderen over tijd. Het is voor ouders belangrijk dat er verschillende keuzemogelijkheden voor hulp worden geboden, verwachtingen over en weer worden besproken en verschillende perspectieven worden geïntegreerd in een eenduidig plan.

Dit is echter geen gemakkelijke opgave, bijvoorbeeld door verschillende behoeftes van individuele gezinsleden, de interactie tussen problemen en visieverschillen tussen professionals of gezinsleden. Professionals geven aan dat ze behoefte hebben aan ondersteuning bij het stellen van prioriteiten en het uitvoeren van gedeelde besluitvorming met gezinnen. Er bestaan diverse richtlijnen die professionals hierbij kunnen helpen, waaronder de richtlijn 'Samen met ouders en jeugdige beslissen over passende hulp'. Het lijkt er echter op dat deze richtlijnen door professionals onvoldoende eigen zijn gemaakt om toegepast te





worden in de dagelijkse praktijk. Een belemmering zit hem in de juiste toepassing van een richtlijn, aldus professionals. Enerzijds dienen richtlijnen houvast te bieden en te zorgen voor een bepaalde structuur, anderzijds dienen professionals in staat te zijn om met behulp van een richtlijn hulp op maat te bieden, passend bij de hulpvragen van een gezin.

Om tot goede prioritering en gedeelde besluitvorming te komen is het daarnaast belangrijk om hulpverleningsprocessen regelmatig te evalueren in samenwerking met gezinnen en betrokken professionals. Door hulpverleningstrajecten te monitoren en de uitkomsten gestructureerd te evalueren lukt het professionals beter om in te spelen op de veranderende hulpvragen van gezinnen en continuïteit te waarborgen. Gezinnen krijgen op deze manier ook meer inzicht in hun eigen hulpverleningstraject.

### **Aanbevelingen voor beleid**

*Integraal werken is niet iets dat je simpelweg organiseert; het is een vak apart dat vraagt om focus op de professional en continue evaluatie en ontwikkeling in de praktijk.*

Beleidsmakers en organisaties spelen een grote rol in het creëren van randvoorwaarden en organiseren van integrale jeugdhulp, en hebben daardoor ook een grote invloed op de uitvoering in de praktijk. De primaire focus op het organiseren van structuren en diensten, zoals het vormen van multidisciplinaire teams of netwerken leidt echter niet tot een integrale aanpak in de praktijk. Ondanks de organisatorische veranderingen van de afgelopen jaren, waaronder de decentralisatie van de jeugdhulp en het vormen van lokale jeugdteams, zijn er nog te veel gezinnen met meervoudige problematiek die niet de zorg krijgen die zij nodig hebben. Als reactie op deze geluiden wordt opnieuw de oplossing in organisaties en structuren gezocht, zoals het opzetten van regionale expertisecentra en het vormen van integrale specialistische teams naast bestaande jeugdteams. Zoals in dit proefschrift wordt benadrukt, is het noodzakelijk dat beleid en organisaties hun focus verschuiven

van het organisatieniveau naar het niveau van professionals. Integraal werken is namelijk niet iets dat je organiseert. Het is een proces dat vraagt om continue evaluatie en ontwikkeling in samenwerking met de praktijk. Om integraal werken te bewerkstelligen dient er meer aandacht te gaan naar het in staat stellen van professionals om gezamenlijk te prioriteren en te beslissen over passende hulp. Daarnaast moet aandacht zijn voor het flexibel vormgeven van een domeinoverstijgend hulpaanbod, het gevoel van bekwaamheid van professionals om integraal te werken, en passende inzet van bestaande hulpmiddelen en richtlijnen. Het structureel evalueren van de twaalf kerncomponenten uit Tabel 1 in samenwerking met praktijkprofessionals en gezinnen, helpt beleidsmakers en organisaties om integrale hulp beter vorm te geven.

### **Aanbevelingen voor de praktijk**

*Integraal werken vraagt om zowel gezamenlijk werken als om gezamenlijk leren.*

Om tot gezamenlijk werken te komen is het belangrijk dat professionals in staat zijn om met diverse partners samen te werken, waaronder scholen en huisartsen. Professionals moeten zich bewust zijn van de grenzen van hun eigen expertise, kunnen (h)erkennen wanneer andere expertise nodig is, deze expertise er tijdig bijhalen en kunnen vertrouwen op de expertise van de ander. Gezamenlijk werken gaat niet alleen om het samenwerken met andere professionals, maar ook om het samenwerken met gezinnen. Om gezamenlijk werken in de praktijk beter vorm te geven dient aandacht te zijn voor transparante communicatie, waardering voor andermans visie, regelmatige evaluatie en investering in gedeelde besluitvorming met professionals en gezinnen.

Daarnaast is het belangrijk dat professionals voldoende investeren in gezamenlijk leren, om zo gebruik te maken van de brede expertise van bijvoorbeeld een multidisciplinair team. Gezamenlijk leren kan vorm krijgen tijdens multidisciplinaire teamoverleggen, waarin het

evalueren van casuïstiek of de onderlinge samenwerking centraal staat. Hoewel professionals zich vaak wel bewust zijn van het belang van het evalueren tijdens hun werk, schiet het goed evalueren van hulpverleningsprocessen en samenwerkingen er vaak nog bij in. Veelvoorkomende redenen zijn een gebrek aan tijd voor evaluatie en reflectie, een gebrek aan focus of structuur tijdens evaluaties, of een gebrek aan systematische monitoring van voortgang en resultaat. De praktische aanbevelingen uit hoofdstuk 5 van dit proefschrift dragen bij aan het gestructureerd vormgeven van deze evaluaties, zodat professionals een integrale aanpak al lerende kunnen ontwikkelen.

### **Aanbevelingen voor onderwijs**

*Maak interprofessioneel opleiden tot de norm.*

Naast het versterken van huidige professionals, is nodig om te investeren in toekomstige professionals. Hierbij is het cruciaal dat er niet alleen aandacht is voor het concept integraal werken in verschillende vakken, maar dat interprofessioneel opleiden de norm wordt. Door toekomstig professionals uit verschillende vakgebieden (zoals psychologie, geneeskunde en sociaal werk) samen te laten leren gedurende hun opleiding, worden zij meer bekend met de visie en werkwijze van andere disciplines, en wordt integraal werken een onderdeel van hun professionele DNA.

### **Aanbevelingen toekomstig onderzoek**

*Onderzoek hoe werkzame en belemmerende elementen de praktijk beïnvloeden.*

Dit proefschrift biedt inzicht in werkzame en belemmerende elementen van integraal werken. Nu is het tijd om de volgende stap te zetten, door te onderzoeken hoe deze werkzame en belemmerende elementen de praktijk precies beïnvloeden. Het blijft bijvoorbeeld nog onduidelijk onder welke condities gedeelde besluitvorming een positief effect heeft op het stellen van prioriteiten, en hoe daarmee integraal

werken in de praktijk verbetert. Toekomstig onderzoek moet zich daarom richten op het doorgronden van verschillende initiatieven in de praktijk. Omdat een integrale aanpak vaak verschilt per context, is het daarnaast belangrijk om zicht te krijgen op de verscheidene lokale initiatieven en generieke lessen met elkaar te verbinden. Zo voorkomen we kennisversnippering en leren we domeinoverstijgend. Als we dit niet doen, hebben lokale initiatieven slechts een beperkte impact op kleine schaal, en moet iedereen opnieuw het wiel uitvinden. Het onderzoeken en leren van lokale initiatieven kan onder andere gestimuleerd worden in Academische Werkplaatsen, waar vertegenwoordigers vanuit praktijk, gezinnen, beleid, onderzoek en onderwijs kennis en ervaringen uitwisselen. Door gezamenlijk te onderzoeken, ontwikkelen en leren, versterken we de integrale aanpak, en werken we samen aan duurzame verbetering van de zorg voor jeugd en gezin.





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Dankwoord

## Dankwoord

Het zit erop. Wat een feest om met zo velen samen te werken aan dit project. Vooral de 'JGT-ers', bedankt voor jullie tijd en inzet. Jullie hielden mij met beide benen in de praktijk.

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# CV Laura Anne Nooteboom



Laura Anne Nooteboom was born on July 10th, 1992 in Utrecht, the Netherlands. She completed her secondary education (VWO) at College de Heemlanden in Houten. In 2010, she started studying Psychology at Leiden University. During her studies (2010-2015), she worked for Inzowijs providing ambulatory support to children and families with (complex) mental health problems. In between her bachelor and master, she worked as a clinical intern at Karakter, Child and Adolescent Psychiatry in Oosterbeek. During her master Clinical Neuropsychology at Leiden University, she worked as a research intern at the University Medical Center Utrecht (department Psychiatry, neuro-imaging study) and as a clinical intern at Curium-LUMC (Department of Child and Adolescent Psychiatry, Leiden University Medical Centre). After obtaining her Master's degree cum laude in 2015, she started as a psychologist in a local Youth Team in Noordwijk. In 2016, Laura became a research assistant and psychologist at Curium-LUMC. Soon after, she started her PhD trajectory. During her PhD, Laura continued her work as a psychologist at the Consultative and Liaison department of Curium-LUMC. In 2020, Laura started working as a senior researcher at Curium-LUMC.





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# Publications

## **PUBLICATIONS**

### **In this dissertation**

Nootboom, L.A., Mulder, E.A., Kuiper, C.H.Z., Colins, O.F., & Vermeiren, R.R.J.M. (2020). Towards Integrated Youth Care: a systematic review of facilitators and barriers for professionals. *Administration and Policy in Mental Health and Mental Health Services Research*. <https://doi.org/10.1007/s10488-020-01049-8>

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### **Other publications**

Nootboom, L.A., Eilander J., Voet, J. van der, Kuipers, B.S., Steijn, A.J., Vermeiren, R.R.J.M., & Mulder, E.A. (2020). Verschillend organiseren, verschillend functioneren? De invloed van de organisatie van Jeugd- (en Gezins)teams op het teamfunctioneren. *Beleid en Maatschappij* (47), 1, 3-20.

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## **Reports**

Nooteboom, L., Mulder, E. Kuiper, C., van den Driesschen, S., Eilander, J., Vermeiren, R. (2019). Bouwstenen van evalueren voor jeugdhulpprofessionals. Link online: <https://www.awsamen.nl/wp-content/uploads/2019/12/Bouwstenen-van-Evalueren-voor-Jeugdhulpprofessionals-Gezin-aan-Zet.pdf>

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Eilander, J., Nooteboom, L. A., Mulder, E. A., Kuiper, C. H. Z. & Vermeiren, R. R. J. M. (2017). Werkzame en belemmerende factoren van het werken in een Jeugd- (en Gezins) team: Visie van de professional. Link online via: <https://www.awsamen.nl/wp-content/uploads/2018/07/Rapport-Gezin-aan-Zet.pdf>



