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.