



Faculty of Medicine and Health Sciences
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**JOINING PERSPECTIVES ON COLLABORATIVE CARE BETWEEN CHILD
AND ADOLESCENT PSYCHIATRY AND CHILD WELFARE TO ADDRESS
MULTIPLE AND COMPLEX NEEDS IN ADOLESCENT GIRLS: A
PARTICIPATORY ACTION RESEARCH**

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ABBREVIATIONS

CAP: child and adolescent psychiatry
CW: child welfare
fte: full-time equivalent
MCN: multiple and complex needs
PAR: participatory action research
SW: social worker

INTRODUCTION

Background

A., who just turned 16, is a bright and kind girl who enjoys singing and playing volleyball, and who wants to become a kindergarten teacher. However, her leisure time activities and plans for the future are complicated by numerous severe difficulties, spanning (mental) health and social domains. These affect her development and functioning.

A. suffers from post-traumatic stress disorder related to sexual traumatization. She has had three episodes of major depression and she has suffered from eating disorders throughout her adolescence. She has an average IQ, but a disharmonious intelligence profile with better performance on verbal tasks in comparison to performance tasks. There are concerns regarding her attachment and personality development. Frequent and aggressive suicide attempts and self-harming behavior as well as verbally and physically aggressive and oppositional behavior further complicate her situation. Poor emotion regulation and difficulty engaging in stable relationships add to her difficulties. A. is underweight, has cardiac arrhythmias and asthma, and suffers from musculo-skeletal pains and headaches, which have been labeled as functional. A. has age-appropriate daily living skills (organizing her schedule, ...), but she needs support for self-care (hygiene, healthy eating).

A. comes from a broken home. She has regular contact with her mother, but no contact with her biological father. The familial context cannot provide a consistently safe and nurturing environment. There was sexually transgressive behavior and intra-familial violence by both A.'s stepfather and a stepbrother. At times, her mother was emotionally unavailable due to physical and mental illness.

There is a restraining order against her mother's ex-partner and against one of A.'s ex-boyfriends. Her three step-siblings are placed in different facilities. Her family is described as socially isolated. They have a low socio-economic status and are challenged by employment and housing difficulties.

A.'s school career has been very fragmented due to several placement changes, suspensions, and school refusal. She has had several long periods (more than 6 months) without schooling. A. frequently absconds to unsafe environments where there is a suspicion of teen prostitution.

In the past, A. has been in contact with many professionals. She has had child and adolescent psychiatry (CAP) residential stays (crisis unit, internalizing disorders unit, forensic unit), as well as a stay in a juvenile judicial institution. She has been a client of ambulatory services for mental health, school counseling, child welfare (CW) and child abuse. She has had a total of 11 residential stays across sectors, lasting between 3 weeks and 29 months, and countless short crisis placements, cumulating in near-continuous residential treatment from the age of 5.

A. enrolled in the Van Celst collaboration project after residing in a juvenile justice institution for five months, and was referred by the juvenile judge. This project seemed the most adequate service provision, because A. was in need of a long-term safe and stable living environment, with adequate psychiatric monitoring, while avoiding chronic "psychiatrization". The treatment goals for A. are to improve psychiatric symptomatology, specifically to decrease her self-harm behavior and suicide attempts, to enhance her emotion regulation, and to engage her in stable and trusting relationships in a safe living environment. An equally important goal is to strengthen her self-care and independent living skills and to assist her to get back to attending school, to facilitate her social insertion.

A. is part of a growing group of adolescents with profound and intertwined difficulties in different life domains that threaten their development and well-being, complicate their integration into society, and pose great challenges to their relatives and the variety of professionals and institutions with which they come into contact. The fragmented care delivery she has experienced could not meet the extent of her needs.

Although an agreed-upon definition and epidemiological data are lacking (Burnside, 2012), for matters of readability, the term multiple and complex needs (MCN), used in practice and in some literature accounts (Rosengard, Laing, Ridley, & Hunter, 2007), will be used in this thesis when referring to intense and intertwined needs such as those illustrated in the case of A.

* This illustrative case is based upon a combination of case stories of adolescents enrolled at Van Celst in order to ensure anonymity.

The Van Celst project is a unique collaboration between a tertiary child and adolescent psychiatry center (Universitaire Kinder- en Jeugdpsychiatrie Antwerpen; University Child and Adolescent Psychiatry Antwerp) and a residential child welfare facility (Van Celst, Jeugdzorg Emmaüs Antwerpen; Van Celst, Youth Care Emmaüs Antwerp), established to optimize services for adolescent girls with MCN in Flanders (the model is described in detail in chapter 5).

All disciplines working in both organizations engage in a structural collaboration for all cases and for the entire care delivery trajectories. At the case level, this starts with a joint intake, and responsibility is shared until the transition from care. At the organization level, the engagement is reflected in joint meetings, permanency, intervision, debriefings and training. The intensively collaborating 'core' of Child and adolescent psychiatry (CAP) and Child Welfare (CW) is embedded in a larger cross-sector network of external partners (such as general practitioners, education, juvenile justice).

To the best of our knowledge, there is no precedent of a collaboration of this intensity between CAP and CW, adding to the practice and research challenges this projects presents. Indeed, the needs and experiences of girls enrolled at Van Celst, their relatives and professionals involved provide the opportunity for a critical appraisal of current care delivery and research concerning vulnerable young persons.

Practice Challenges

The scarce accounts in the current literature confirm the anecdotal experiences of increasing case complexity in health and social sectors (Bass, Shields, & Behrman, 2004; Hood, 2015; Webb et al., 2014). People experience MCN as a reflection of severe difficulties in different domains, including intertwined physical and mental health problems, social exclusion, educational issues, unemployment, or involvement in judicial procedures (Rosengard et al., 2007; Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016). Such difficulties have an impact on the quality of life of these individuals and their relatives. The (over)consumption of health and social care services, along with the higher unemployment rates and the risk of criminal involvement that are associated with some of their problems, result in high societal costs (Davidson, Bunting, & Webb, 2012; Stalker et al., 2003; Webb et al., 2014).

One dimension that is specific to the growing population of adolescents with complex needs is the developmental impact of these problems on young people, which puts their personal well-being, identity development, and integration into society at stake (Burnside, 2012; Stalker et al., 2003). It is known that adolescents and young adults have the highest incidence and prevalence of mental health problems, and the

poorest access to care (Henderson, Cheung, & Cleverley, 2017; McGorry, Bates, & Birchwood, 2013). Regarding gender, girls with multiple problems are known to be an even more vulnerable population, in terms of their psychosocial and physical health, and their access to care, than their male counterparts (Handwerk et al., 2006; Hussey & Guo, 2002; Nelson et al., 2011). Such problems increase the risk for future poor physical and mental health, substance abuse and addiction, antisocial personality disorder, and criminal behavior (Burnside, 2012; Leve & Chamberlain, 2004; Webb et al., 2014). The combination of child psychiatric problems, poor physical health, and social issues, can lead to considerable costs for society (Chamberlain & Moore, 2008; Pajer, 1998). As such, adolescent girls with MCN are an especially vulnerable population whose needs are expected to increase in the near future (Bor, Dean, Najman, & Hayatbakhsh, 2014).

Persons with MCN need simultaneous expertise and support from professionals from several sectors (Robertson, 2011; Tausendfreund et al., 2016) and typically come into contact with different social welfare and health care agencies (Keene, 2001; Walker, 2003). Their needs currently tax youth (health) care services beyond their ability to cope (Carter, Cummings, & Cooper, 2007; Rankin & Regan, 2004). Difficulties to engage with services, fragmentation and discontinuity caused by repeated referrals and sequential or parallel interventions by different service providers, and a lack of coordination between sectors, are complicating care delivery (Katz & Spooner, 2006; Tausendfreund et al., 2016; Malvaso & Delfabbro, 2018). These shortcomings in services can worsen the personal prognosis of these adolescents, and negatively impact society (Chamberlain & Moore, 2008; Davidson et al., 2012; Stalker et al., 2003). Moreover, the overwhelming and unmet demands undermine the confidence and aptitude of health social care professionals (Robertson, 2011; Worrall-Davies, Kiernan, Anderton, & Cottrell, 2004).

No single agency or sector has all the resources, skills, mandate, or reach to deal with the wide range of personal needs of these vulnerable adolescents and their families, and to simultaneously address the social and economic factors that aggravate the complexity of these needs (Hornberger, Martin, & Collins, 2006; Webb et al., 2014). The intensity and multiplicity of challenges faced by adolescents with MCN calls for the development of rigorous collaborative care delivery approaches that exceed the boundaries of any one of the partner organizations (Katz & Spooner, 2006; Macias Balda, 2016; Mitchell, 2012).

While cross-sector collaboration has been recommended in order to meet the needs of cases at the extreme end of the case complexity spectrum (Bryson, Crosby, & Stone, 2015; Hornberger et al., 2006; Winters, Magalhaes, Kinsella, & Kothari, 2016), it is also known that collaboration is not easy to implement, and that

many collaboration projects do not achieve their objectives due to a variety of personal, structural and organizational reasons (Cooper, Evans, & Pybis, 2016; Horwath & Morrison, 2007). Differences in use of language, organizational cultures and procedures make collaboration of agencies with different backgrounds especially challenging (Huxham & Vaugen, 2000). Yet, in an increasingly collaborative professional field, uniting the skills and expertise of professionals from different backgrounds is amongst the most important actual challenges for CAP (Falissard, 2018; Fritsch, Schlesinger, Habeger, Sarvet, & Harrison, 2016).

Cross-sector collaboration can therefore be seen as doubly bound up with complexity, in that it constitutes a response to complex problems but is also a complex area of practice in itself (Bryson, Crosby, & Stone, 2006; Hood, 2015). Unfortunately, there is very little guidance for the development and implementation of these collaborations in the context of agencies that serve children and adolescents (Cooper et al., 2016; Mitchell, 2012; Winters et al., 2016).

Research Challenges

Existing research does not offer a uniform language to define MCN nor provides theoretical guidance for the collaborative care delivery needed to meet these needs.

Different sectors that come into contact with individuals with MCN use a variety of terms interchangeably, and the term MCN is often used to define very heterogeneous populations (Keene, 2001; Robertson, 2011). This lack of conceptual clarity hampers research (prevalence studies, prognosis estimates) and the design, delivery, and evaluation of care delivery for those with MCN. Indeed, to the best of our knowledge, there is no epidemiological data available pertaining to adolescent girls with MCN. Several authors indicate the need for a concretized and agreed-upon definition of MCN (Burnside, 2012; Miller & Ahmad, 2000; Stalker et al., 2003) as well as a comprehensive evaluation of service needs (Katz & Spooner, 2006; Wong & Sumsion, 2013).

Regarding the cross-sector collaboration that seems promising to meet complex needs, research accounts are scarce. Although collaborative projects in health and social care have been launched for several decades at the policy level, there are few comprehensive descriptions of such collaborations (Winters et al., 2016). In particular, the lack of attention for “people factors” in the process of collaboration is pointed out as an important lacuna (Horwath & Morrison, 2007). Comprehensive reports on the development of collaborative services, the pitfalls that impede their success, and the factors that positively impact it, could assist in tailoring new approaches to specific subgroups of individuals with MCN (Cooper et al., 2016; Mitchell, 2011).

An overarching gap identified in health, social and public management literature on both MCN and collaborative care delivery in health and social care, is the client perspective (Banfield et al., 2018; Katsikitis, Lane, Ozols, & Statham, 2017). Children, adolescents, and parents possess unique experiences and expertise regarding the difficulties they encounter and the services they use. Their perspectives are very valuable for deepening our understanding of their complex needs. Thus, including their point of view is important in order to develop and evaluate services (Calheiros, Patrício, & Graça, 2013; Head, 2011). Especially lacking are clients' and professionals' perspectives on the earliest stages of development of new programs (Katsikitis et al., 2017). Research that integrates patients' and parents' perspective is of great actual importance for CAP research (Falissard, 2018).

Recent reviews from both the public management and health and welfare perspective recommend research combining quantitative and qualitative methods, with a focus on process and people factors and addressing the lack of the client perspective in the current literature (Bryson et al., 2015; Winters et al., 2016).

Opportunities

Adolescent girls with MCN are a poorly defined, yet extremely vulnerable population whose needs have a large impact on themselves, their relatives, professionals, and society as a whole. This calls for reflection on developing new approaches for care delivery.

Exploring the characteristics and needs of adolescents with MCN, and trying to optimize services, provides important opportunities for reflecting on the needs of and services for the most vulnerable populations and can address particularly important issues for research and practice.

Objectives and Research Approach

The research project described in this thesis was prompted by the practical needs in the Van Celst collaboration between CAP and CW. It was also guided by considerations from the professional field and at the societal level regarding support and inclusion of the most vulnerable members of society. The target population of this collaboration project had to be described with regard to characteristics and service needs. There was also the aim to describe this innovative collaboration model and to identify its main components and its perception by all different stakeholders. Intrinsically connected to these questions, and further

stimulated by the findings concerning the Van Celst collaboration project, is the need to explore and define the concept of MCN using an approach that integrates research and practice and that combines perspectives from service users, professionals, and researchers.

On this basis, three research objectives were formulated:

- Objective 1: to describe characteristics and needs of the target population at Van Celst.
- Objective 2: to explore the collaboration model in the Van Celst collaboration project.
- Objective 3: to systematically build a consensus definition of MCN in Flanders and assess the

international perspective on this definition.

The setting and objectives at the outset of this research project pointed at participatory action research (PAR), with a combination of quantitative and qualitative methods, as the most appropriate research approach. Amongst other arguments for its use, the PAR approach allowed the professionals at Van Celst and UKJA and the researchers to obtain rich research data and positive practice outcomes without undermining the changes their practice is intended to achieve.

In PAR, the researcher and participants in the researched setting engage in a research process prompted by a “real life” interrogation that is meaningful for them (Reason & Bradbury, 2008). PAR takes the form of a cyclical research process with repeated steps of reflection and action (Kemmis & McTaggart, 2005). Starting with practice needs, researchers and stakeholders collaborate in the decision-making process, from the beginning of the research project through its conclusions and any subsequent actions that arise from the project (Migchelbrink, 2016). Thus, PAR is characterized by shared ownership of the research, and it is oriented towards inciting social change and reflection (Kemmis & McTaggart, 2005). This approach can enrich knowledge in clinical practice and academic research, generate favorable social change, and empower all stakeholders.

A Delphi approach was chosen for objective 3. Consensus methods, such as the Delphi method, can be part of PAR approaches and they are recommended as a way to help enhance effective decision-making in the fields of health care and social care services (Hasson, Keeney, & McKenna, 2000; Vernon, Salsberg, Erikson, & Kirch, 2009), especially when stakeholders with different visions and approaches are involved (Kemp & Avella, 2016; Landeta, 2006). Experts are invited to participate anonymously in several consecutive survey rounds, and the results are fed back after each round, with the aim of clarifying the subject or reaching consensus (Shelton, Haynes, & Creghan, 2017). The current study used this method to build a definition of MCN with experts

representing all sectors of mental health care, youth care, juvenile justice, and education in Flanders in a three-round online Delphi study. An additional survey with international experts sought to assess their level of agreement with the Flemish definition of MCN.

All three objectives and the chosen methods are in line with the need for participative and consensus-based research, moving away from the exclusive use of biological and statistical studies and taking into account the complexity of mental health and the sociopolitical and socioeconomic reality in the field of mental health care (Falissard, 2018).

Organization of the Thesis

This thesis is divided into two parts. Part 1 describes the PAR approach used in this research project. It aims to conduct an in-depth analysis of the Van Celst collaboration by evaluating the target population's characteristics and needs and the collaboration model. It involves the adolescent girls enrolled in the Van Celst project and their (step)parents, as well as the professionals. This covers the objectives 1 and 2. Part 2 builds on the questions that arose in part 1 and reports on a Delphi study and an international survey regarding the definition of the concept of MCN. This concerns objective 3.

Part 1 is divided into seven chapters that sequentially cover the topics of the PAR approach, the target population, and the collaboration model. Part 2 is concerned with how MCN can be defined in a way that is meaningful to the diverse professionals working with individuals with these needs (data collection sources per chapter are detailed in table 1).

- Chapter 1 provides an overview of the main characteristics of PAR and the arguments for its use in youth mental health. It also provides details about its implementation in the Van Celst collaboration project.
- Chapter 2 highlights the main characteristics of the adolescent girls who are enrolled in the Van Celst collaboration project, based on in-depth file analysis and questionnaires.
- Chapter 3 presents an account of the service needs of adolescent girls with MCN from their own perspectives, and that of their (step)parents and the professionals involved. Data was obtained via focus groups and in-depth interviews.

- Chapter 4 reports on the service needs of the (step)parents of the adolescent girls with MCN, based on the findings obtained from in-depth interviews.
- Chapter 5 addresses the characteristics and principles of the collaboration model used in the Van Celst project, drawing on data from the professionals' focus groups.
- Chapter 6 presents the reported benefits and pitfalls of the collaboration project from the perspectives of the adolescents, their (step)parents and professionals.
- Chapter 7 analyses the development process of the collaboration and relates this to the Life Cycle Model.
- Chapter 8 presents the Delphi study that aims to build a consensus definition of MCN. It also presents the results of an additional survey that explored the international perspectives based on the Flemish definition of MCN.
- The general discussion draws upon the entire thesis (Part 1 and Part 2). It includes a reflection on and a discussion of the implications of the findings to practice, and presents suggestions for future research in this area.

Table 1. Data sources per chapter

Chapter 1

- literature on PAR general principles; literature on PAR use in mental health
 - also global information from the PAR data: files, questionnaires, interviews with adolescents and (step)parents, focus groups
-

Chapter 2

- literature on MCN; literature on adolescent girls in residential care; information regarding questionnaires and earlier research using the selected questionnaires.
 - parameters based on literature regarding MCN, and regarding vulnerabilities of adolescents in residential care; working groups with all stakeholders
 - files from CW and from CAP:
 - intake report from the facility, including information on family context, school, administrative information.
 - reports from earlier stays in facilities or psychiatric hospitalizations
 - daily observations from the CW team
 - medical data, medication scheme
 - agenda with appointments
 - questionnaires (detailed in Chapter 2)
-

Chapter 3

- literature on MCN; literature on service user participation; literature on needs-led (youth) care
 - interviews with 9 adolescents
 - interviews with 12 (step) parents; 4 of the interviews with couples
 - focus groups with 30 professionals from CW and from CAP: all but 2 professionals who are active in the planning and practice of the project on a daily basis
 - focus groups with 14 external professionals: all external sectors/agencies/fields mentioned by the professionals from CW and CAP were included, with the exception of the school system
-

Chapter 4

- literature on the effects of parental involvement for children in care; literature on the position and experiences of parents of children in care (in CW and mental health)
- interviews with 12 (step) parents; 4 of the interviews with couples

Chapter 5

- literature on cross-sector collaboration; literature on service-user involvement in design of care delivery
- focus groups with 30 professionals from CW and from CAP: all but 2 professionals who are active in the planning and practice of the project on a daily basis
- focus groups with 14 external professionals: all external sectors/agencies/fields mentioned by the professionals from CW and CAP were included, with the exception of the school system

Chapter 6

- literature on barriers and facilitators to cross- sector collaboration; literature on collaboration projects in child serving agencies; literature on service user participation in services design and evaluation.
- *same as chapter 3 regarding the interviews and focus groups*

Chapter 7

- literature on the development process of collaborations; publications on the life cycle model; literature on (causes for) failure of collaboration projects
- focus groups with 30 professionals from CW and from CAP: all but 2 professionals who are active in the planning and practice of the project on a daily basis

Chapter 8

- literature on Delphi approach; literature on MCN
 - in defining the objective, in preparing the open question and in our own reference frame, all data from the aforementioned chapters was used
 - data for the Delphi study came from the answers of 47 participating experts in Flanders
 - data for the subsequent international perspective came from the 25 participating international experts
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General
discussion

- all data sources mentioned above, as well as further literature sources on participation, cross- sector collaboration, and the study of complexity
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PART 1

PART 1

The first part of this thesis reports on a participatory action research (PAR) relating to an innovative collaboration project between child and adolescent psychiatry (CAP) and child welfare (CW) that aims to address the needs of its target population of adolescent girls with multiple and complex needs (MCN).

In an approach that aims to enhance knowledge and facilitate social change, the following research objectives were addressed:

- Objective 1: to describe the target population's characteristics and needs, reported in chapters 2, 3 and 4.
- Objective 2: to explore the collaboration model in the Van Celst collaboration project, reported in chapters 5, 6 and 7.

CHAPTER 1

The Value of Participatory Action Research for Clients, Professionals, and Researchers in Mental Health Care*

*Accepted for publication in *Tijdschrift voor Psychiatrie*:

Participatief actieonderzoek: toepassing in (kinder- en jeugd)psychiatrisch onderzoek en illustratie aan de hand van een participatieve studie omtrent een cross-sectoraal samenwerkingsverband.

Abstract

In Participatory Action Research (PAR), researchers, professionals and the (professional) community engage in a research process together. This research approach has the potential to assist in bridging the research–practice gap by starting from practice needs and using joint expertise and experiences to enrich scientific knowledge and to optimize clinical practice. Moreover, it has the potential to empower stakeholders from different backgrounds.

This paper discusses the potential benefits of PAR for clients, professionals and researchers in the field of mental health care (MHC). Starting from the literature on PAR, fundamental characteristics and benefits of this research approach in the field of MHC are described. A practice example regarding the collaboration project Van Celst is used to illustrate some aspects of PAR.

PAR in the field of MHC can enrich propositional and practical knowledge, facilitate positive social change in care delivery, empower all stakeholders, and ultimately contribute significantly to integration of research and practice.

PAR is valuable for clients, professionals and researchers in a variety of projects in MHC.

The Value of Participatory Action Research for Clients, Professionals, and Researchers in Mental Health Care

There is a growing need for research approaches that can bridge the gap between science and practice in health care, especially in the field of mental health care (MHC) (Chambers, Pringle, & Juliano-Bult, 2012). The main stimulus is the realization that research findings do not (yet) sufficiently influence clinical practice (Hicks & Hennessy, 1997; Kazdin, 2016). Balas and Boren (2000) found that it takes an average of 17 years before published research findings in health care are used by practitioners, and that only 14% of the data from research is employed in a way that benefits service users. Several authors suggest that the research–practice gap results not merely from a problem with translating research findings into practice, but is also caused by a shortcoming in data collection methods as they do not sufficiently consider the stakeholders who ultimately should benefit from the research (Baum, MacDougall, & Smith, 2006; Van de Ven & Johnson, 2006).

Participatory action research (PAR), where researchers and practitioners or persons in the community go through an iterative research process together, is gaining in popularity because of its potential to integrate science and practice. Indeed, this type of research allows relevant challenges in clinical practice to be identified and addressed (Hart & Bond, 1995; Meyer, 2000; Baum et al., 2006). In health care and more specifically in MHC, PAR is increasingly put forward as a way to give clients a voice and to increase their input in planning and evaluation of their treatment (Baum et al., 2006; Weaver & Nicholls, 2001; Chambers et al., 2012; Banfield et al., 2018).

In this chapter the essential features of PAR are described, and illustrated with a recent PAR concerning the collaboration project Van Celst. Potential benefits of this research approach for clients, professionals and researchers, as well as common pitfalls, are discussed. A literature search in PUBMED, ERIC and WOS with search terms (((participatory) action research) AND (mental health care)) was used to inform the argumentation regarding PAR in MHC.

Basic Principles of Participatory Action Research

According to Kurt Lewin, one of the first proponents of PAR, “Research that produces nothing but books will not suffice” (Lewin, 1946, p. 35). With this statement, Lewin addresses one of the fundamental characteristics of this research approach: the aim to bring about (social) change through research. In this research approach, researchers work closely with people in the surveyed setting to enrich knowledge and bring about positive social change, empowering stakeholders in response to a real-life issue (Waterman et al., 2001). PAR combines experiential, practical, and research knowledge to achieve positive outcomes for science and

practice (Reason and Bradbury, 2008). In this integration of practice and research, the surveyed setting itself plays an active role in research planning, data collection, and interpretation (Brydon-Miller, Greenwood, & Maguire, 2003). It uses the acquired knowledge not only to understand reality, but also to make positive changes to it (Migchelbrink, 2016).

The aims of PAR are (Boog et al., 1996; Waterman et al., 2001):

1. theoretical advances, acquiring propositional and practical knowledge
2. changing daily practice, adjusting action in response to research findings
3. increasing the possibilities of those involved, aiming for empowerment of all stakeholders.

The participatory character of PAR is reflected in the fact that it is not research “about” or merely “for” the surveyed setting, but research with the people involved (Reason & Bradbury, 2008). Service users and professionals play an active role as they develop the research questions and design, and execute the research together with a researcher (McTaggart, 1994; Waterman et al., 2001; Wright et al., 2013). Rather than participants being disinterested observers, PAR is as much as possible set up as a joint learning process for researchers and the “researched”. Starting from the idea that research can never be value-free (because all perception is influenced by theory), together they determine which goals and values the research must yield, and try to achieve this by active exchange between stakeholders.

An important assumption of PAR is, that when people are encouraged to reflect upon and adjust their own actions, they can bring about favorable social changes (Whitehead & McNiff, 2006). Indeed, PAR is described as a self-reflective enquiry. This transformative power is central to PAR (Baum et al., 2006). That way, in addition to developing knowledge and creating social change in a participatory process, PAR is also empowering, since it acknowledges and strengthens the various groups of stakeholders. By breaking the traditional separation between “subject” (researcher) and “object” (researched) and the hierarchical power relationship of this division, PAR creates the opportunity for all those involved to arrive at new, useful knowledge, insights, and skills by reflecting on their own actions and raising awareness of their own positions (Reason & Bradbury, 2008).

The PAR Process

In PAR, the process is just as important as the research findings (Migchelbrink, 2016). A practical need serves as the impetus for starting a PAR. The research questions and design are guided by the practical challenges and questions encountered by the group of people involved and their desire to increase knowledge

and create beneficial social change. PAR is based on a cyclic, iterative process (see Figure 1, from McTaggart, 1994), in which successive steps of action and reflection are repeatedly taken by the researcher together with all other stakeholders in the surveyed setting. These phases can be described as: planning (designing the next action), action (performing the planned action), observation (monitoring the impact) and reflection (evaluating the results of the action) (Reason & Bradbury, 2008; Migchelbrink, 2016). In the reflection phase, results are critically examined. The insights gained can give rise to a renewed cycle of planning, action, and evaluation. In this way, the research will gradually take shape, and in each cycle scientific and practical knowledge will be deepened, awareness will grow, and action will be adjusted.

PAR is a flexible research approach, and can be used in very diverse projects. To collect data, PAR makes use of various social-science research methods (Martí, 2016; Migchelbrink, 2016). Rather than committing itself to a predetermined method, the research team re-evaluates at each step how the research questions can be further refined and addressed, and all those involved are consulted about interpreting the (provisional) findings (Schneider, 2012).

Theoretical Background

The philosophical underpinning of PAR is in line with the postmodern tradition emphasizing that multiple or shared realities exist. This acknowledges the relevance of different kinds of knowledge and different ways to generate this knowledge (Melrose, 2001; Kelly, 2005). PAR is inspired by theories from different backgrounds (experiential learning, critical education, reflection, reflexivity, and soft systems methodology), conferring the general ideas of being “critical, evaluative, systematic, strategic, participatory, collegial, collaborative, self-reflective about practice, empowering, emancipatory, and having theory inform practice and practice inform theory” (Melrose, 2001, p. 161). PAR is considered an alternative approach to traditional research, as it moves social inquiry from a linear cause and effect perspective, to a participatory framework that considers the contexts of people’s lives (Kelly, 2005). It thus completes positivist social science research as a valid source of knowledge in its mandate to remain a collective, self-reflective inquiry for the purpose of improving a situation (Koch, Selim, & Kralik, 2002). The strong interconnection of action and reflection in PAR can be seen as in line with Paulo Freire’s epistemology, embracing the idea that critical reflection is already action (Baum et al., 2006), and that action and reflection are indissolubly united as reflection and action can act on the world in order to transform it (Freire, 1972, pp. 1-28). As Freire put it (p. 58): Through praxis, critical consciousness develops, leading to further action through which people cease to

see their situation as a “dense, enveloping reality or a blind alley” and instead as “an historical reality susceptible of transformation”. With PAR as a research paradigm, researchers can engage in several methodologies, each drawing on a number of methods for data collection and interpretation (Dick, 2015).

PAR in Health Care

PAR is increasingly used in health care (Meyer, 2000). Wright et al. (2013) discussed Participatory Health Research (PHR), participatory research that focuses specifically on the health care context. For PHR, the primary underlying assumption is that participation on the part of those whose lives or work is the subject of the study, fundamentally affects all aspects of the research. The engagement of patients, caregivers and health care professionals in the study is an end in itself and is the hallmark of PHR, recognizing the value of each person’s contribution to the co-creation of knowledge in a process that is not only practical, but also collaborative and empowering (Onwuegbuzie et al., 2009; Wright et al., 2013).

The goal of PAR in healthcare is therefore to contribute to the acquisition of knowledge about health and disease, and at the same time to change the processes of care delivery so as to enrich the user, practitioner, and researcher (Migchelbrink, 2016). Shared ownership of the research questions and the research process results in accessible, understandable, and relevant outcomes that encourage awareness of all stakeholders and contribute to amelioration of health care delivery (Reason & Bradbury, 2008; Salimi et al., 2012).

Figure 1. The spiral of participatory action research (Kemmis & McTaggart, 1994)

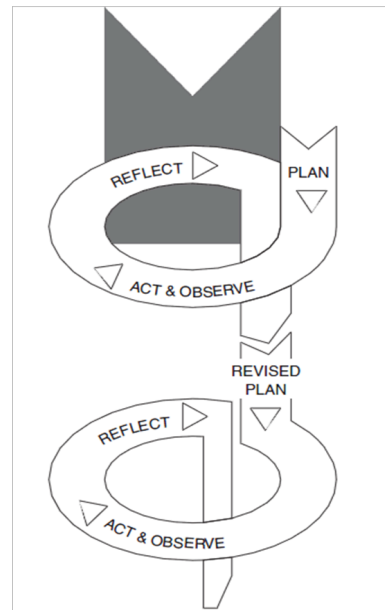


Illustration of PAR Implementation: Research Project Van Celst

Data collection

The impetus for the Van Celst research project was an innovative collaboration between the University center for Child and Adolescent Psychiatry (CAP) Antwerp, UKJA, and a residential youth care (child welfare, CW) facility, Van Celst. This collaboration was established to provide assistance to adolescent girls with multiple and complex needs (MCN). Within this partnership, CAP and CW take joint responsibility for the complete care trajectory of these girls. The academic partner in this PAR was CAPRI – Youth (Collaborative Antwerp Psychiatric Research Institute), at the University of Antwerp. Detailed information regarding the objective, method and findings of the research project is described in the research report (Van den Steene et al., 2018a). Methods used in this PAR were questionnaires, file analysis, focusgroups and individual interviews (for file parameters and interview topics, see table 1; for an overview of data sources see table 1 chapter 1; for questionnaires, see table 1 chapter 2).

In planning the focus groups and in choosing focus groups over individual interviews, we took expected focus group dynamics into account. Indeed, we hoped to achieve more depth by stimulating discussion between the professionals. We chose to make interdisciplinary mixed focus groups, in order to engage discussion between persons involved on the work floor, and those who have more of a policy function.

We did separate focus groups with the CW vs the CAP setting for practical reasons, and because we wanted to avoid groups that were too heterogeneous regarding the extent to which participants knew each other.

Moreover, conducting 44 individual interviews would not have been possible due to time constraints, and we wanted to give everyone the opportunity to participate in data collection (as all of them were also included in the discussion of each phase of research findings).

During the focus groups, we paid attention to the focus group dynamics and other factors that influenced the data collection / was part of the data but would be lost by just using the transcript of verbal information. The observer had an observer document on which several aspects related to this and to the context of the focus group were listed (if everyone was on time, interruptions or distractions, atmosphere, tone of voices, interrupting each other, nonverbal explicitation of perspectives, reactions of the group to quotes of participants, findings that were or were not verbally or nonverbally reinforced by others, impression of security/insecurity in the group, and if there were especially dominant or passive participants; and regarding the process: impression of 'starting up phase' and repetition), and where she wrote down examples. These were always discussed between researchers in the debriefings.

An additional observation after performing the focus groups was the impression that the fact that team members engaged in this conversation together strengthened their bond and motivation.

Table 1. File parameters and interview topics

Data collection source	Location	Parameters/topics + how they were decided on	(Examples of) main parameters/guide per topics (<i>questions</i>)
Files	Van Celst (CW), CAP	Working groups with all stakeholders / literature	<p>Biological: physical illness, ailments, medication use, doctor appointments, ...</p> <p>Psychological: trauma experiences, IQ, suicidality, self-harm</p> <p>Social: family composition, mental health issues in family members, school type, school problems, leisure activities, ...</p> <p>Care delivery: previous placements, previous ambulatory care delivery, time-outs, incidents in the facility, absconding, ...</p>
Interviews with adolescents	Van Celst	Working groups with all stakeholders / literature	<p>Needs of adolescents</p> <p>Needs (from services) to enhance wellbeing and functioning</p> <p>Preferences in care delivery</p> <p><i>"What is most important for services to be able to support you?"</i></p> <p>Evaluation of the collaboration project</p> <p>Effects</p> <p><i>"Do you see effects of this collaboration project?"</i></p> <p>Benefits</p> <p>Pitfalls/warnings/negative experiences</p>
Interviews with (step)	Van Celst/	Working groups with all stakeholders /	<p>Needs of adolescents</p> <p>Needs (from services) to enhance wellbeing and functioning</p>

parents	their home	literature	<p><i>“What is determining the extent to which the needs of your daughter are met?”</i></p> <p>Needs as a parent</p> <p>Needs (from services) to enhance wellbeing and functioning Preferences in care delivery <i>“What is important for professionals to know, concerning the needs of parents who are in your situation (having a child in residential care)?”</i></p> <p>Evaluation of the collaboration project</p> <p>Effects <i>“What is your perception of the main effect of this collaboration project on the level of the organization?”</i></p> <p>Benefits Pitfalls/warnings/negative experiences</p>
Focus groups with professionals from CW and CAP	Van Celst	Working groups with all stakeholders / literature	<p>Needs of adolescents</p> <p><i>“What are their needs (from services) to enhance wellbeing and functioning?”</i></p> <p>Guiding principles of the collaboration</p> <p>Description <i>“How would you describe the collaboration to someone who doesn’t know it?”</i></p> <p>Distinguishing features <i>“What is characteristic for the Van Celst collaboration?”</i></p> <p>Evaluation of the collaboration project</p> <p>Effects <i>“What is the main effect of this collaboration?”</i></p> <p>Benefits Pitfalls/warnings/negative experiences</p> <p>Development process of the collaboration project</p> <p>Development course <i>“How did it go, to start this collaboration?”</i></p> <p>Comparison to the beginning <i>“What has changed most, comparing to the start?”</i></p>
Focus groups with professionals external to the project	Van Celst	Focus groups with CW - CAP professionals	<p>Needs of adolescents</p> <p>Needs (from services) to enhance wellbeing and functioning <i>“What are specific requirements to address the needs of these adolescents?”</i></p> <p>Guiding principles of the collaboration</p> <p>Description <i>“How would you describe the collaboration to someone who doesn’t know it?”</i></p> <p>Distinguishing features <i>“What is characteristic for the Van Celst collaboration?”</i></p> <p>Evaluation of the collaboration project</p> <p>Effect <i>“What is the main effect of this collaboration?”</i></p> <p>Benefits Pitfalls/warnings/negative experiences</p>

Data analysis

In this section we detail how we followed the 4 consecutive steps of systematic text condensation in each of the Chapters 3 to 8 included.

We started with transcription of the entire content of each interview and focus group, including the notes that were made on nonverbal information and dynamics. The processes of data collection and data analysis

overlapped each other. Interim analyses enabled us to make small adaptations to the interview guide and to estimate when we had included enough persons to achieve a 'thick description'.

For each group of transcripts (the adolescent interviews, the (step)parent interviews, the focus groups with CAP and CW professionals, the focus groups with external professionals), we used systematic text condensation (Malterud, 2012) for data analysis. This is a descriptive analysis approach presenting the experiences of the participants as described by them, without the ambition of interpreting or exploring the underlying meaning. Specific for systematic text condensation is the procedure presented for condensation (step three), with text from all meaning units within a subgroup incorporated in the condensate which safeguards a systematic review of sorted meaning units and prevents the researcher to favor meaning (Malterud, 2012). We followed all four sequential steps of this approach to data analysis for each set of transcripts.

Findings were presented to and discussed with all stakeholders in the PAR, but also with the external expert commission composed of experts in the field (CW, youth care policy, child and adult psychiatry, juvenile justice, ...), who are not directly involved in the Van Celst project but represent an important external sounding board. After translation from Dutch to English, we presented analytical texts, i.e. the (re-contextualized) abstracted condensates with illustrating quotes in the corresponding 'results/findings' sections of the chapters 3 to 8 included.

Systematic text condensation (Malterud, 2012) is composed of 4 sequential steps.

Step	What?	Who?
1. Finding themes	read and re-read the transcripts in order to identify preliminary themes	All researchers identify preliminary themes independently; then discuss to agree on final themes
2. From themes to codes	a. Identify and sort relevant text units, the meaning units by reviewing the text line by line; remove parts of the transcript that are not relevant to the research question b. The relevant quotations are coded (attributing numerous labels) and sorted into code groups within each theme.	All researchers first independently identify code groups and then discuss to agree on them.
3. From code to meaning through abstraction	a. Decontextualize the code groups into a condensate (an imagined narrative based on the meaning units within the code group) in order to tell a story in the first person. b. Write an abstraction by describing the essence of the narrative (without searching for underlying meaning)	First author
4. Synthetization and recontextualization	a. Reconceptualize the data (check if content of code group matches transcript content and if theme appears in most) b. Create an analytic text. c. Add relevant quotations	Independent reconceptualization by all researchers

In short, we used the same approach to data analysis in each of the chapters: 4 steps of Malterud and consecutive feedback of results to participants from all stakeholder groups, but also to the steering committee of the research project (every 2-3 months), and an external expert commission (every 6 months) composed of experts in the field of youth care/child welfare, juvenile justice, child and adolescent and adult psychiatry, ...

In every chapter of this thesis that reports qualitative findings, in the results/findings section we present the synthesized condensates, illustrated by quotes.

In chapter 8, that uses Delphi approach to systematically construct a definition of MCN in children and adolescents, we used systematic text condensation in line with the method of data analysis in the previous chapters. In the Delphi study, we had decided on this strategy for analysis before data collection, based on the familiarity of the researchers with STC. We could not exactly estimate how extensive the data would be. Another, simpler approach to text analysis would have been suitable for analyzing the answers to the first round open question of this Delphi. An alternative would have been content analysis such as described by Graneheim and Lundman (2004).

Process

Because the Van Celst collaboration project was innovative in all areas, practical questions arose, regarding its conceptualization and implementation. These practice interrogations were the starting point of the PAR. In terms of questions and approaches, as well as in interpreting the data, ideas from practice guided the research. Conversely, research results and knowledge from the scientific literature were directly used in practice. Figure 2 illustrates the course of this PAR process in a schematic way. It is somewhat artificial to represent a PAR as subsequent steps or cycles, as successive cycles were in reality often parallel. There were cycles within cycles within cycles, and larger cycles spanned whole phases of the research program. Researchers were fine-tuning their actions moment by moment as their understanding of the situation grew.

For the purpose of illustrating some main goals and steps in the Van Celst research project, an overview in two large actions is given. Each of the cycles occurred in dialogue with all participants: clients via low-threshold meetings or telephone; professionals in team meetings. A steering group (every 2-3 months), and an external expert group (every 6 months) supervised the project.

Action 1: Target group description. The research parameters were determined by all stakeholders together, based on the literature and working groups with adolescents, parents and professionals (planning phase). The aim was to obtain a target group description (action and observation phase) that could both yield scientifically relevant information regarding the concept of MCN in adolescent girls, and that made sense for practitioners and could be used to guide the practical development of the collaboration project.

In the target group profile, an unexpected and striking finding was the frequency and extent of traumatic events and of post-traumatic stress disorder (reflection phase). These findings led to adjustments towards a more trauma-sensitive approach in training of staff and daily routines in the residential center (new action phase). At the individual level, the findings from the questionnaires on psychological well-being, quality of life, attachment, and personality development were also considered by the psychologists in the individual sessions with adolescents and in team meetings (also a new action phase).

Action 2: Collaboration. To gain insight into the collaboration process, as a first step, focus groups with professionals involved in CAP or CW were organized (planning phase). During the focus groups (action and observation phase), valuable information was gathered about the needs of the target population; the origin, characteristics, and evolution of the current collaboration; and the perceived added value and pitfalls of this collaboration model (action and observation phase). In evaluating the findings of this research phase,

practitioners suggested to survey professionals who play an important role in the care delivery to the target population, but do not participate on a daily basis in the collaboration project (e.g. juvenile court, general practitioner). Based on this reflection phase, two additional focus groups were organized (new action and observation phase), collecting the perspectives of those identified by the practitioners as external partners. When discussing these results (new reflection phase), two findings led to additional meetings being planned. It occurred that “school counseling/education” was a partner that unfortunately could not be present in the focus groups, but with whom collaboration was believed to be very important. Discussions between CAP and CW, and juvenile judges, also revealed differences in expectations concerning collaboration. In order to further optimize these aspects of care delivery, a meeting was planned with people in charge of school counseling and with juvenile judges, aiming to improve cooperation and coordination with schools, centers for school counseling and juvenile court (new planning and action phase).

After joint consultation on content and approach (planning phase), in-depth interviews were also conducted with adolescents and (separately) with their relatives (action and observation phase). Different aspects of the collaboration project were discussed. In the interviews with adolescents, for example, it became clear that they experienced the fact that therapy could take place in the facility, rather than in the CAP center, as significantly lowering the threshold towards CAP. On one hand, care providers were satisfied with this finding, because the accessibility of MHC was promoted. On the other hand, they were concerned that therapy provided in the facility conflicted with the “normalizing” aspect of a stay in youth care, and might not adequately stimulate the adolescents’ sense of responsibility. The steering group and the professionals decided (reflective phase) to share these reservations with the adolescents and to organize individual discussions to plan each individual trajectory (new action and observation phase).

Interviews also showed that professionals and adolescents do not always assign the same meaning to certain concepts. For example, they put a different emphasis on “continuity in care”. While the adolescents referred to maintaining relationships of trust with known caregivers, the professionals related it to placement stability. Such insights were regarded as very valuable for the adjustment of care delivery. Professionals had the intention to have a continuous dialogue with the adolescents in order to gain more insight into their needs and interpretations (new action phase).

Figure 2. PAR process in Van Celst project

<p>Action 1: Profile of the target population</p> <p>Planning: Definition and selection of (preliminary) goals, research parameters, research methods based on the combined input of all stakeholders (adolescents, parents, professionals, researchers) using workgroups and literature search.</p> <ul style="list-style-type: none"> . e.g. the adolescents completed the research parameters, adding several of their strengths, to be checked as research parameters in the file studies . e.g. the parents asked to also examine their needs . e.g. professionals refined the goals regarding the care delivery history . e.g. choosing the questionnaires used to study the target population based on the scientific value and relevance for practice. <p>Action and observation: Action by all stakeholders</p> <ul style="list-style-type: none"> . e.g. questionnaires filled out by adolescents, parents and professionals, file analysis and scoring of questionnaires by the researcher, interviews and focus groups with adolescents, parents and professionals, ... <p>Reflection: Joint reflection regarding the research goals, and concerning all preliminary findings</p> <ul style="list-style-type: none"> . e.g. comparing the profile of the target population in interviews and focus groups vs. in questionnaires and files . e.g. discussion of the practical implications of (preliminary) findings, such as the finding that traumatic events in the past play a greater role than initially thought . e.g. discussion of the experience of those involved in these findings; this was how the empowering effect of research came up. <p>New planning: Reflection, feedback and changes in practice; Goals, working method and practical approach were adjusted</p> <ul style="list-style-type: none"> . e.g. detailed mapping of care prior to stay at Van Celst, medication use or school career were new objectives . e.g. in practice, training sessions were more attuned to trauma. 	<p>Action 2: Studying and supervising the collaboration</p> <p>Planning: Work objectives, research parameters and research method were determined on the basis of the input from adolescents and parents, care providers and researchers</p> <ul style="list-style-type: none"> . e.g. care providers formulated an additional objective with regard to the mapping of conditions for this cooperation model . e.g. researchers introduced additional themes for the focus groups on the basis of the literature (e.g. added value and obstacles for cooperation models) . e.g. researchers and adolescents preferred interviews instead of focus groups for adolescents and parents. <p>Action and observation: Implementation by all parties involved</p> <ul style="list-style-type: none"> . e.g. questionnaires filled in by care providers, interviews with adolescents, focus groups with care providers ... <p>Reflection: Joint reflection with regard to the objectives and working method on the aforementioned consultative structures</p> <ul style="list-style-type: none"> . e.g. coordination with regard to all who had to be consulted about the cooperation model. . e.g. comparing cooperation model with literature . e.g. reflection on effective factors in this cooperation model. <p>New planning: Goals, working method and practical approach were adjusted</p> <ul style="list-style-type: none"> . e.g. professionals formulated a new objective with regard to the impact on the broader care delivery landscape, for which two additional focus groups were planned . e.g. consultations planned with the educational sector as a result of the finding that coordination with this external partner could be optimized . e.g. the insights regarding the development phases in this cooperation model were published (Van den Steene et al., 2018b) and presented at study days with research and practical input. In response to the recommendations, a policy-based panel discussion took place, in which the broader relevance of certain concepts from the Van Celst project was discussed.
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Experiences

Mutual benefit. In this PAR research, questions, approach and data interpretation were continuously influenced by suggestions from practice. For the research parameters in files and daily observations, the ideas of adolescents, parents and professionals completed the information from the literature. Not only in refining “what” should be explored, but also in deciding “how” it could best be done, the exchange with service users and professionals proved very valuable for the researchers e.g. in estimating preferred ways of data collection, and taking into account factors such as group dynamics. Indeed, all preliminary research findings were fed back at the group level, but data collection for adolescents and parents was done on an individual basis (interviews

rather than focus groups); as preferred by these stakeholder groups and judged favorable for individual wellbeing and for richness of individually provided data by the professionals. Also for data interpretation, participants gave new insights that guided further literature searches and added to the knowledge generated in the research project. Furthermore, the intensive exchange provided rich information for the contextualization of the focus group data, such as the organizational culture. Also, the feedback received when discussing data was very motivating to further invest in the research project.

The other way around, the intensive exchanges also benefited practice in different ways. Seeing the data regarding the target population was described as very rewarding by the professionals, because it legitimated their impression of complexity in the cases at the facility. The information that researchers could gather from the literature also increased the (theoretical) knowledge, for example regarding the impact of multiple placements, or the different interpretations of continuity of care. Practical knowledge also grew, thanks to exchanges, for example concerning the use of questionnaires for case evaluation.

Feedback and reflection were not limited to the adolescents, parents and professionals involved, but also reached much further. Indeed, the results were also discussed between researchers, presented at congresses and written down in papers. Moreover, other practice workers and policy makers were fed back preliminary and final results of the project in seminars. In these interactive contacts, ideas from other professionals in other settings were considered, and strengthened the reflection of the Van Celst project. During the meetings professionals clearly described an experience of empowerment and awareness, which benefited their confidence and action in practice.

Discussion

Potential of PAR in MHC

The gap between research and practice leads healthcare workers in their daily work to fall back on intuition and experience when scientific knowledge concerning service delivery for their clients is not readily available or not integrated in practice. The Institute of Health and other international health organizations have highly prioritized closure of the research-to-practice gap in MHC (Committee on Developing Evidence-Based Standards for Psychosocial Interventions for Mental disorders, 2015). PAR is promising in this respect, because it involves relevant and directly applicable research based on practical needs and experiences (Meyer,

2000). The added value of PAR for science and practice has led to this research approach receiving more and more attention in research directives and in the practice of health care (Meyer, 2000; Brydon-Miller et al., 2003; Migchelbrink, 2016).

PAR can be used in MHC for various purposes (Chambers et al., 2012), for instance to gather additional knowledge about psychiatric problems, to develop and improve participative practice, or to promote the inclusion of persons with psychiatric problems (Chambers et al., 2012; Schneider, 2012; Banfield et al., 2018). Its utility applies to both adult psychiatry (Schneider, 2012; Delman, 2007) and to projects involving adolescents (Ochocka, Janzen, & Nelson, 2002; Chambers et al., 2012). As personal experiences form the core of psychiatric issues, it is particularly valuable to unite various perspectives (client, relatives, professionals) when conducting research about psychiatric problems. Moreover, different but interconnected systems are involved in mental health services, increasing the potential of a partnership between stakeholders and researchers (Chambers et al., 2012). Professionals and clients are given a special position in PAR, because their experience, opinions and views are given as much value as those of researchers and make an important contribution to the results. Reducing stigmatization can improve the position of clients in MHC.

For care providers, PAR can be supportive and enriching when working with emotionally and interpersonally complex problems. As MHC goes through organizational changes, collaboration between clients and care providers allows the practical impact of programs to be evaluated and adjusted from different perspectives and starting from practical needs, and can result in useful and applicable guidelines.

Expand propositional and practical knowledge. PAR has the potential to enrich theoretical and practical knowledge within MHC, particularly with regard to complex concepts such as psychiatric disorders or symptoms. The knowledge thus acquired gains in depth, credibility, and applicability, thanks to a greater involvement of the participants and the cyclical re-evaluation of findings (Altrichter, Kemmis, McTaggart, & Zuber-Skerritt, 2002; Migchelbrink, 2016). An advantage of the cyclic process is the possibility to deepen the analyses in each round, based on exchanges between all parties involved. This results in a deeper understanding of the problem under investigation (Altrichter et al., 2002).

An example of a recent PAR in MHC, with an explicit focus on knowledge enhancement, is the publication by Nieweglowski and colleagues (2017), about the concept of stigma towards substance abuse disorders from the perspectives of users and ex-users of MHC, their relatives and professionals. Kidd, Kenny and McKinstry (2015) also contributed to practical and theoretical knowledge regarding the concept of

“recovery”, drawing on the combined perspectives of MHC users, their relatives and professionals. When considering the value of PAR for adding to the knowledge base in MHC, the review by Wright and colleagues (2014), describing the role of participatory approaches in the reconceptualization of autism, is also very interesting. In the work of Vincent et al. (2017) for example, students who themselves have an autism diagnosis, collected and analyzed the information in order to enlarge the theoretical knowledge on autism spectrum disorders.

In the Van Celst project, the close collaboration with care providers and clients led to a complete and in-depth answer to the research questions. From a scientific point of view, the detailed description of the target group and the collaboration concept addressed gaps in the literature, while in terms of practice, applicable and multifaceted knowledge was collected.

Bring about social change. In the health literature, PAR is seen as a transformative and empowering process whereby researchers and participants co-create knowledge while developing a sense of community, educating each other by negotiating meanings and raising consciousness (Fals Borda, 2001; Kemmis & McTaggart, 2003). Waterman, Tillen, Dickson and De Koning (2001) describe the process of “executing a change intervention aimed at improvement and involvement” as a cornerstone of PAR. They argue that PAR is a group activity, which relies on the critique of existing social situations, partnership and collaboration between action researchers and participants, to generate change and new knowledge. It aims to facilitate favorable social change, ameliorating clinical practice based on the input of those involved (Dewar & Sharp, 2006). Bradbury and Reason (2003) argument how action research can be used to both implement and influence the creation policies in social work and the work of social workers. Involving professionals in research can lead to more effective implementation strategies, thanks to increased awareness and by taking account of contextual factors (Denning & Verschelden, 1993). PAR is especially suitable to evaluate innovative processes, because it is responsive to changes in daily practice in the field (Meyer, 2000), and to translate research findings into practical implementations (Ungar et al., 2015).

An interesting extension of the PAR methodology, particularly useful in the setting of care delivery planning and evaluation, are “participatory evaluation methodologies” that emerged from the extension of PAR to evaluation (Garaway, 1995) and the growing interest in evaluation as an action learning and capacity building process. Collaborative or participatory forms of evaluation have several assets that make them valuable for the development and evaluation of care delivery: they are useful in assessing the impacts of

“complex system changes and comprehensive community initiatives” and enable community members and other stakeholders to collaboratively plan and conduct evaluations that assist in developing more effective and sustainable solutions to local problems and issues, to continually learn about what’s working and what’s not working so well, and thus to improve programs and to mobilize communities for regional action, empower local agents and enhance learning capacity (Lennie, 2002). However, participatory evaluations require significant amounts of time and resources, particularly in the early stages where some participants or stakeholders may be unfamiliar with participatory methods or may see evaluation as a judgmental process that could affect their program funding or jobs.

As an example of PAR used in reorganization of services, Roose and De Bie (2003) asked the perspective of users of child welfare to find out how a reformation of child welfare could be useful for them. Connolly, MacGabhann and McKeown (2015) describe how the input of care providers and clients led to the reformation of a service for assistance to persons with a double diagnosis. In Ochocka’s (2002) research, together with users of MHC, practical changes were carried out, which they then also evaluated together. PAR can contribute to concrete favorable changes in practice, based on the combined knowledge, input and experience of scientists, care providers and users of MHC.

In the Van Celst project, thanks to participatory research, the way of working could be adjusted to the needs of the target population on the basis of experiences and suggestions from clients and professionals. The flexibility offered by PAR, and the possibility it provided to study a changing context, were an important additional benefit that allowed the Van Celst research project to start right away, and that guided the development process of the partnership.

Empower. PAR has the potential to empower all those involved in a number of ways: by giving them respect and recognition, through information and education, by making use of everyone's strength and unique perspective, and by stimulating awareness and reflection (Meyer, 2000; Banfield et al., 2018). In the research project by Schneider et al. (2012), people with schizophrenia were co-researchers, and one of the objectives was to increase their scope for action through reflection on their own situation and experience and needs for recovery. Also in the PAR by Hitchen, Williamson, & Watkins (2015), users of MHC were involved, with one of the central objectives being to give a meaningful, strong and effective voice to this group of people and increasing their influence on MHC.

More specifically for persons with mental health concerns, empowerment by participatory research approaches is very valuable, as it gives a voice to people whose views may otherwise be marginalized and is thus very powerful when the intention is to offer them better services (Hitchen et al., 2015). Koch and Kralik (2006) suggest that commitment in PAR increases as people identify therapeutic benefits from their involvement, and that telling their personal stories can be empowering, described as giving “voice to the voiceless” (Koch & Kralik, 2006, p. 19), increasing their self-awareness and providing an impetus for change. In the study of Hutchinson and Lovell (2013) the transformative effect of PAR over three years is described, involving six co-researchers with mental health problems, who gained greater control over their lives. They describe greater self-belief as central to underpinning collaboration.

In the Van Celst project, the participatory approach contributed to a self-aware and reflective attitude that in turn was empowering for care providers. Seeing the favorable effects brought about by the changes that were made in clinical practice, further contributed to this empowerment. Discussing the findings from the focus groups also emphasized the common motivation in working with this target group. For the adolescents and parents, the fact that their input was valued and respected was also empowering, and this was also their main motivation to participate in the research.

Contribute to bridging the gap between research and practice. PAR is a collaborative approach to undertaking research and is recognized as one means of minimizing the gap between research and practice (Meyer, 2000; Baum et al., 2006). It carries the promise that academics, together with the community, can make a difference, which is an appealing prospect. Combining PAR with other qualitative approaches has the potential to address health inequities, promote community participation, and foster individual empowerment (Bailey, Convery, Mort, & Baxter, 2006).

PAR in the context of health research has the potential to meet the growing demand for bridging the gap between clinical practice and science (Wells, 2000). Starting from joint questioning and the use of common expertise and experience, it aims for favorable changes in clinic and an increase in scientific knowledge (Froggatt & Hockley, 2011). In fact, inherent in the design and working method of PAR is bringing together research and practice and strengthening both. Within PAR, the view is that theory cannot only inform practice, but must also be generated through practice, and that theory can only be meaningful to the extent that it benefits practice (Brydon-Miller et al., 2003). In the Van Celst project, research and practice were inextricably linked through the PAR process, and they were mutually reinforcing. In practice, direct use was

made of the information that emerged from the research, and the research, for its part, experienced the advantage of different practical perspectives.

Challenges

In order to optimally utilize the potential of PAR, all parties involved must have the possibility and willingness to invest time, energy and resources, and the openness must exist to come to (self-) reflection (Migchelbrink, 2016; Williamson & Prosser, 2002). PAR requires a lot of time for joint consultation and reflection, resources to generate change and also the flexibility of both researchers and practitioners (Baum et al., 2006; Tapp, White, Steuerwald, & Dulin, 2013). Community members may struggle to maintain their commitment to the research project over time (Macdonald, 2012). PAR requires time, knowledge of the community, and sensitivity on the part of the researcher to participants' agendas (Macdonald, 2012; Young, 2006). Moreover, there may be a divergence of perspectives, values, and abilities among community members. Consensus for determining what social issues require attention and the time frame anticipated for the change might thus be difficult (Macdonald, 2012). Researchers face additional challenges: the loss of independence and control as a result of the greater participation from the community, overcoming mistrust that can exist in stakeholders, and the additional ethical considerations that the participation entails (Israel, Schulz, Parker, & Becker, 2001; Tee & Lathlean, 2004; Horowitz, Robinson, & Seifer, 2009). Furthermore, the relative unpredictability and required time investment of PAR complicates both the acquisition of funds and publications (Baum et al., 2006). The PAR by Roose and De Bie (2003), which concerned the reorganization of child welfare, illustrates how the tension between reorganization from an expert perspective and the realization of participatory care delivery from a client's perspective, made working together in a PAR more difficult. They emphasize the importance of a common inquiry and goal (Boog, 2002). They also illustrate how delicate the balance in the living social network of a PAR is, as replacing one researcher involved as an insider had adverse effect on involvement and dynamics throughout the project (Boog, 2002; Roose & De Bie, 2003). In the Van Celst project, the main challenge was that all parties involved had to invest a great deal of time and resources for a continuous coordination of data collection and interpretation, and the adjustment of actions. A self-critical attitude and the willingness to review their own perspectives were also important points of attention for researchers and participants.

Trade-offs when choosing PAR. As with any methodological choice, there are trade-offs involved when using PAR instead of other methodologies. An important justification for (qualitative) PAR in the context of the Van Celst project was the need for responsiveness. As the intention was a stepwise change and amelioration of the clinical practice in the collaboration project, the chosen research approach had to allow these changes in practice and to use the gathered information in each step to gradually improve practice. PAR values responsiveness over replicability, although optimizing both should be the aim (Dick, 1999). The PAR approach allowed to study the change process of the collaboration project, and to achieve “action” as a part of the research process. Inherently, this approach complicates potential replication of findings. Yet, establishing exact findings that are confirmed by independent experiments is not the goal of a PAR, which is primarily concerned with the questions that arise in its specific context, while also inciting reflection in other contexts.

Somewhat related is the fact that PAR sacrifices global relevance for maximization of local relevance. Indeed, a criticism can be that generalizability is greatly reduced because of the context-specificity of findings in PAR (Baum et al., 2006). An important strength of qualitative PAR is its greater “ecological validity”. However, the fact that in-depth explanations and solutions for local issues in the Van Celst project were sought, decreases the likeliness that these findings would apply to or suit a different situation. Again, the use to other settings would be in terms of stimulating reflection and flexible use rather than direct transfer of findings. As the findings from the PAR process take into account a very broad range of local variables, they are locally applicable and cannot be treated as inflexible universal principles (Dick, 1999).

Yet another trade-off consists in the academic communication. Findings in a PAR are typically shared and discussed by stakeholders and others who are directly concerned, but may be more difficult to publish in international peer reviewed literature. Dilemmas arise for academics in the use of PAR, because it can be more time-consuming and unpredictable than conventional research, making it less likely to attract competitive research funding or a high production of articles in refereed journals (Baum et al., 2006; Kavannah, Daly, & Jolley, 2002; Brydon-Miller et al., 2003). Broader acceptance of PAR may require academic instances to value engagement and bringing about change in communities in the evaluation of research performance (Baum et al., 2006).

Ethical issues. Some ethical challenges arise when conducting a PAR. These are rarely discussed in the health literature (Coghlan & Brannick, 2001). In PAR, it may be more difficult than with other research methodologies (both quantitative and qualitative) to offer certain ethical guarantees concerning confidentiality

and anonymity, informed consent, and protection from harm (Williamson & Prosser, 2002). The close relationship between researcher and participants, and the explicit aim of changing practice, make anonymity more complicated. For participating professionals and/or researchers who are part of the research context, PAR could have potential consequences for their careers. Data analysis can be made confidential and anonymous, but completely disguising data in finished reports can be difficult. Others in the organization will know who participated, making it difficult to guarantee confidentiality and anonymity. The “action” characteristic in PAR also complicates anonymity (Hitchen et al., 2015). For example, in Van Celst, all interviews and questionnaires are kept anonymous, but the changes resulting from them, such as inviting school counselors to discuss certain aspects or implementing trauma oriented care, are visible to everyone in the facility.

Besides anonymity, informed consent can also be difficult in PAR. As a big contrast with a RCT, a PAR is a journey (Williamson & Prosser, 2002), evolving through participation, reflection and purposeful action. It is unlikely that “informed consent” is as meaningful as in other research approaches: researcher and participants don’t know in advance where the journey will take them, and cannot fully be aware of what they are consenting to. In the Van Celst project, informed consent was obtained of all participants, and the information sheet and verbal information highlighted the ongoing process where it was impossible to predict exactly what further data collection would take place, or what changes would be made in practice. Meyer (1993) goes as far as to state that the traditional concept of informed consent is inadequate in PAR, as consent involves participants’ willingness to take part in the project and support the initial ideas for change. For Meyer, a PAR is to some degree forced, for example because of observational data being collected in the organization, contradicting the concept of willing collaboration. This might have been less of a problem in the Van Celst project than in some other research projects, as no “observation” as data collection method per se was included (from which participants could not easily have chosen to be excluded). Some argue that the principle of informed consent should be viewed in combination with other ethical principles, not as the overriding principle. Indeed, in the continuous spiral of debate and reflection of a PAR, the informed consent should receive attention and be a topic of discussion and reflection (Bryden, 2003).

A general interesting approach to ethics in health and social PAR, is that it might be the most appropriate for researchers and co-researchers to refer to their individual and professional morality, rather than to a specific set of ethical research principles. As Freshwater (2001, p. 790) states: “Research that is

focused on practice and has its emphasis on engagement has a political and ethical agenda, which the practitioners can begin to articulate through a critical and reflexive dialogue with their own individual and professional morality”.

Enhancing trustworthiness of the research project. PAR methodologies emphasize knowledge constructed through lived experience rather than solely through social science (Vanderplaat, 1995). Therefore, a holistic approach that openly acknowledges and takes into account the diverse perspectives, values and interpretations of participants, is privileged, rather than solely the scientific ideal of objectivity. However, and very importantly, evaluation rigor may not be lost in this approach (Baum et al., 2006).

Four criteria, traditionally used to establish the trustworthiness (Lincoln & Guba, 1985) of qualitative research are mostly used in PAR: credibility, dependability, conformability and transferability (Korstjens & Moser, 2018 ; Mckay & Marshall, 2000). However, other authors have described specific quality criteria for PAR (Herr & Anderson, 2014; Melrose, 2001).

Credibility. Credibility reflects the confidence that can be placed in the truth of the research findings (Mckay & Marshall, 2000 ; Michgelbrink, 2016). It establishes whether the research findings represent plausible information drawn from the participants’ original data and is a correct interpretation of the participants’ original views (Creswell, 2017). The better the match between the representations constructed by participants and those attributed to the participants by the researcher, the more credible the research. Credibility requires that the parameters of the research (setting, participants, method, ...) are adequately stated. Strategies to ensure credibility are prolonged engagement, triangulation and member check and other strategies that enable the reader to know the parameters of the research. Several strategies increased the credibility of the PAR project at Van Celst. First, researchers invested in prolonged engagement and persistent observation. A researcher took the time to familiarize herself with the organizational culture through frequent presence in the facility and with formal and informal contacts (working in an open work space at the facility, participating in seminars and festivities ...). There was also the explicit choice to engage in long-term data collection with close collaboration of all stakeholders, aiming at maximizing their trust and engagement and thus enhancing credibility. Second, different forms of triangulation (methods, sources, analysts) further enhanced credibility. For example, the profile of the target population was made on the basis of extensive file analysis, checking of the daily observations and questionnaires. Interviews from stakeholders with different perspectives were

compared. Moreover, different researchers were involved during data collection and analysis. Debriefing after the focus groups permitted to reflect on initial ideas, and doing the data coding with three researchers led to extensive reflection on possible data analysis and interpretation. Member checking is a third strategy we used to enhance credibility. It refers to the fact that the participants had the opportunity to discuss, correct and comment in different phases of data collection and analysis (summarizing after the focus groups, reading and commenting the transcripts, discussing the data interpretation). In order to provide the reader with enough information permitting to judge credibility, we included information on the quantitative research parameters as well as the interview/focus group topics and questions and further details concerning this data collection (e.g. location of the interviews and focus groups).

Dependability. Dependability includes the aspect of consistency and can be seen as related to reliability (Lincoln & Guba, 1985). Dependability relies on a transparent process, one that is in line with accepted standards and well documented (Mckay & Marshall, 2000; Reason & Bradbury, 2001). Important to PAR, dependability is not threatened if changing conditions require a change in process. The researcher is responsible for describing the changes that occur in the setting and how these changes affected the way the research approached the study. Dependability depends on the auditability of the research process, or the ability of another researcher to follow the “decision trail” of the original researcher (Korstjens & Moser, 2018). We noted all decisions made concerning data collection and interpretation, and motivated these choices. We described all phases in the PAR. We tried to document the setting and changes to the setting in detail.

In order to further increase dependability, it is important that the interpretation of findings is not overly dominated by the reference frames and preconceptions of the researcher. The researcher being the main instrument in data gathering and data analysis, it is important that he/she is aware and explicit of his own subjectivity. We tried to include enough information in these factors of author reflectivity (background, experience, hypothesis, ...) to ensure maximum transparency. Moreover, discussions among others with the supervisors of the project and the steering group enabled discussion, disagreement and challenging of the interpretations of the researcher. Moreover, attention was paid to negative case analysis. We looked specifically for parts of the data that contradicted the main findings.

Confirmability. Confirmability refers to the degree to which the results could be confirmed or corroborated by others. In a sense, confirmability is the partner of dependability. Whereas dependability relies

on transparency of process, confirmability requires that research data can be traced back to their source, and judgements and assertion made about that data are logical and coherent, and are able to be confirmed by an expert other than the researcher (Mckay & Marshall, 2000). Different strategies were used in order to enhance confirmability (Mckay & Marshall, 2000). Broader context descriptions and clarification of methods and framework for data analysis: in the publications and in the chapters of this thesis, background information is given on the context in which data collection took place and the way it was performed. Self-reflection is another strategy to enhance confirmability: as part of the PAR each stakeholder, including the researcher, was called upon to self-reflect on the different aspects of the project. The research findings were also checked and rechecked and discussed at various moments in the PAR cycles.

Transferability. Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts or settings. Action research does not aim to produce outcomes which can be immediately generalized to an entire population or another setting. Researchers have the responsibility to provide the reader with thick description of participants, research process and outcomes to enable the reader to assess whether our findings are transferable to their own setting (Mckay & Marshall, 2000). In this project we aimed to provide enough information and theoretical base to make this transferability possible. We tried to describe the research context and the assumptions made in enough detail to facilitate reflection on possible transfer of ideas to other contexts.

Author Reflexivity

When performing a PAR, it is very important to examine and consciously acknowledge the assumptions and preconceptions you bring into the research, as this shapes the PAR process and outcome. Throughout the research project, we tried to be attentive to our background and position as a researcher and to how these factors influenced the research project. We consciously made time for reflection and discussion on these matters, between researchers in the project, and with other researchers who knew the setting but were not involved in the project. Informally, these aspects also came up in different conversations with stakeholders from practice. Several characteristics of the research team were topics of (meta)reflection as they were presumed to have an influence on the researchers' account on the PAR.

In our research approach frequent discussion and iteration in the research process with the associated reflection process made us aware of how our own reference frame and position as a researcher influenced the research project.

Dialogue between all researchers and with participants, before and after data collection and when analyzing the data, increased the awareness of one's own preconceptions and ensured all data was looked at from different angles. Moreover, as all methods and findings were discussed together, this ensured that all perspectives and backgrounds were given credit in the PAR process. Different aspects of data collection were thoroughly discussed, e.g. by debriefing after the focus groups. The data analysis strategy, involving systematic text condensation, also implied frequent exchange between the researchers.

Discussing with the participants also helped us to be aware of preconceptions, such as having more of a care provider perspective when considering the organizational aspects of the collaboration, rather than a policy perspective. Findings were summarized by the participants, for every interview and focus group participants could give feedback on the transcripts, and after analysis the findings were also discussed. This helped to look at the data from different angles and to thoroughly consider all information collected.

Different specializations were represented in the research team and added richness to the data interpretation: CAP, clinical psychology, anthropology. This diversity in background was perceived as a strength that was maximally exploited by in-depth discussions between the researchers. Within the steering committee further expertise was present, for example from social work and management. This yielded interesting discussions concerning data interpretation or further research topics.

The research team had more experience in CAP than in CW. This was a point of attention, because of a potential bias in data collection and interpretation. The researchers (especially the first author) spent a lot of time in the CW setting, gaining insight into the organizational culture and practices. A very concrete example of a moment very early on in the research project when we realized our own medical reference frame rather than the welfare frame in Van Celst was when we inadvertently used the word 'patients' when talking about the girls enrolled in the project. We also paid special attention to topics such as medication, which may not have been the case with researchers coming from another background. However the impact of our reference frame on research questions and parameters was limited by the fact that input came from the practice stakeholders.

Besides the diversity in expertise and more relevant to avoiding confirmation bias (tendency to favor information that affirms one's prior hypotheses) - or social desirability bias (to answer in a way that is expected to be viewed positively by others), the degree of involvement in daily practice in the Van Celst project differed between the researchers. While the first author was more immersed in the setting of the collaboration project (gaining insight into the organizational culture and the daily work in the facility; engaging in informal

communication with adolescents and professionals), other members of the research team could offer a meta-perspective and challenge ideas and views that may be biased by having less distance from the research setting. What was additionally helpful in this regard was the fact that besides time spent in the CW facility and to a lesser extent the collaboration CAP hospital, the first researcher spent a large fraction of the research time in the university setting, what was perceived as helpful to take a step back and perform data analysis or critically reflect on earlier findings.

Besides the reference frame and potential biases, we were also aware of the fact that this project was one of the first experiences the first author had with qualitative methods. Literature, training courses and the help of experienced co-researchers guided the first author along this path of getting to know the theory and practice of qualitative research methods. We are well aware that this learning process, along with the fact that most of the research team stems from a more positivistic, quantitative research culture has influenced some aspects of the data collection, interpretation and presentation. As this thesis text was built around the publications associated with the research project rather than being constructed as a new text summarizing all findings, insights that came in the late phases of the research project may not be fed through all manuscripts. Also, at the beginning of the project, for the first author, it took some time to get used to the position as a researcher, rather than as a member of a team, treating patients (as was the case in prior experience as a child psychiatry trainee). As, following the PAR principles, the stakeholders initiated the research and were all together engaged in the collaboration process, this common lived experience may influence results. The expert commission that discussed and evaluated the project every 4 months provided more of an 'outsider' perspective that assisted the reflection process on bias sources.

The CW facility engaged in the Van Celst project already had a culture of dialogue and participation to a certain extent, before the PAR. This may have contributed to the observations that professionals of the facility (regardless of their hierarchical position), didn't engage in harsh discussions of differing opinions during the focus groups.

It was very motivating to experience how the confidence of the professional participants and the service users grew during the project. As the project progressed, and with frequent contact and dialogue, the enthusiasm of participants grew, and they were even more engaged in the research project. They came with new ideas to investigate, suggested interpretations of findings, and ways to communicate findings to a wider

audience. With the service users too, it was the repeated contact and open dialogue that facilitated the participation. No material incentives were given to participants. This was a conscious choice because of the concern that this may not motivate a true engagement in the project. It was also very rewarding to see the positive changes that occurred in practice, following the research findings. For example, the data regarding the target population led to very clear changes towards a more trauma-oriented training for staff.

Globally, it was enriching as a researcher to learn about all these different perspectives. It was also rewarding that, thanks to a PAR approach, an integration of research and practice took place at this small scale, giving the feeling that research can make a difference. A participatory inquiry with co-researchers with mental health problems, undertaken by Tee and Lathlean (2007), found similar benefits to those in this study and included insight into service-user perspectives, enhanced confidence in decision-making and appreciating power issues.

Some of the challenges commonly described in PAR, were also faced in the Van Celst project, especially the fact that the flexibility that brings much of PAR's benefits, also entails unpredictability and requires large time investments from researchers and participants alike. In the setting of a doctoral thesis and of applying for funding, this can be challenging, because it is not possible to give a detailed protocol or timetable for the research project. Also, especially regarding the target population and care delivery characteristics, the local validity of findings was ensured, but the amount of detail and the specificity to the local context made considerable parts of the data not automatically of use in other contexts.

Recommendations

An interesting recommendation for future research would be to illustrate the experiences of stakeholders during a complete PAR process. Asking them which steps or approaches were useful, what difficulties they encountered and what personal and broader (organization/community) effects the PAR had.

Conclusion

The benefit of PAR lies in the equivalent position of researchers and practitioners, and the fact that practical needs guide the research. The aim is to increase both scientific and practical knowledge, to obtain favorable changes in practice, and to empower the people involved. As such, PAR can contribute to bridging the gap between practice and research. This research approach can be very valuable in the field of mental health care.

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CHAPTER 2

Target Population: Personal and Care Delivery Characteristics*

*Based on publication

Van den Steene, H., Glazemakers, I., & Van West, D. (2016). Adolescent girls in residential care: biopsychosocial characteristics. *JSM health education & primary health care*, 1(2), 1-13

Abstract

A growing number of clients in social and health sectors have needs that are “multiple” and “complex” (referred to as MCN) and overwhelm current care delivery systems. A variety of terms are used to designate these heterogeneous populations. Specification of characteristics of adolescents with “MCN” is lacking. Enhancing the knowledge base concerning definition and specification of MCN in different populations could profit clinical practice and inform research in the field.

The aim of this facet of the participatory action research was to make a description of the population of adolescent girls with MCN at Van Celst. This contributes to the clarification of their service needs. A profile of target population characteristics was described, based on findings from file analysis (past and current reports, daily observations) and questionnaires. A selection of the extensive quantitative data, collected at the Van Celst facility, is presented in this chapter, in order to describe the characteristics of this target population in a comprehensive yet concise manner.

Intertwined difficulties exist in biological, psychological and social domains, and regarding the use of services. Their difficulties in multiple life domains are extensive, both in intensity (“depth”) and in multiplicity (“breadth”). Although caution is warranted when comparing with other populations, the needs of this population are extensive, with several aspects surpassing the needs described for adolescents in other child welfare (CW) and juvenile justice settings. In practice, the specific profile of vulnerabilities guided the project towards a more trauma-sensitive approach. The findings were also perceived as an acknowledgement of the complexity especially by professionals. The research questionnaires were used to guide the individual care delivery planning. In a broader perspective, in-depth target population knowledge can contribute to optimizing care delivery programs and can be valuable for research in the field.

Target Population: Personal and Care Delivery Characteristics

Social and health care sectors are increasingly challenged by the needs of clients with very complex difficulties (Keene, 2001). The heterogeneous population at the extreme end of a spectrum of case complexity is designated with the term “multiple and complex needs” (MCN) (Keene, 2001; Rosengard, Laing, Ridley, & Hunter, 2007). These persons come into contact with different professionals across sectors, because of profound and intertwined needs in different life domains. Their difficulties span from (mental) health issues, to a fragile social network and societal integration, academic and work challenges, contacts with justice and socio-economic fragility (Keene, 2001; Rankin & Regan, 2004).

Children and adolescents with MCN are especially vulnerable, due to the developmental impact of their problems (Burnside, 2012; Tausendfreund, Knot-Dickscheit, Schulze, Knorth, & Grietens, 2016). Their constellation of needs is very challenging for care delivery. These clients need specialist expertise from different sectors at the same time, and have fluctuating difficulties, where the priorities may change over time (Burnside, 2012; Mitchell, 2011). Often, they suffer cumulative harm due to discontinuity in care delivery (Katz & Spooner, 2006; Malvaso & Delfabbro, 2018).

A Need for Concretization of “MCN” in Different Populations

A fundamental step in optimizing care delivery for children and adolescents with MCN is to better understand these needs and to characterize how they affect specific subgroups and their families. Currently, a variety of terms are used for those whose needs are “multiple” and “complex” (Rosengard et al., 2007). Very heterogeneous populations are defined by these terms, most often without specification of their characteristics or needs. This is hampering clinical advances (e.g. planning adjusted collaborative programs) and research (e.g. evaluating needs, or outcomes). Knowing the specific strengths, problems, needs and wishes of target populations helps professionals to adjust the content and delivery of services (Katz & Spooner, 2006). It also facilitates the communication between the different sectors involved in care for complex cases. Multimodal descriptions of subgroups with MCN also add to the conceptual definition and knowledge base regarding collaborative care delivery.

Purpose

The aim of this chapter is to describe the characteristics of the adolescents enrolled in the Van Celst collaboration between child and adolescent psychiatry (CAP) and child welfare (CW). This is done as a part of a

participatory action research (PAR) with input from the adolescents, their relatives and a variety of professionals involved.

Method

This chapter describes characteristics of the adolescents enrolled in the collaboration project Van Celst, that seemed relevant to them, their relatives, professionals and the researchers. That collaboration aims to optimize care delivery for adolescents with MCN, starting from intensive collaboration between CAP and CW.

The goal of the current chapter in this thesis is to provide a global illustration of the population at Van Celst. The lack of a definition or set diagnosis to include adolescents makes a comprehensive description of characteristics of the target population useful for practice. Many sets of data were presented and discussed in much more detail in the feedback sessions with stakeholders, as they had specific practical relevance. Especially the data extracted from detailed analysis of all observations written down (CAP and CW) provided detailed insights and prompted discussions. This general description, however, is mostly based on data from previous and actual files and questionnaires.

Based on the PAR principles, exchange and involvement with adolescents, their relatives, and the professionals was central to the research approach.

A literature search (PubMed, the Web of Science, ERIC and PsycInfo) and working groups with the adolescents enrolled in the program, their relatives and professionals involved, assisted in choosing the parameters of the file analysis and the questionnaires. The final selection of questionnaires was made in agreement with the professionals at Van Celst. Besides their scientific relevance, the questionnaires had to be practical to use in the facility, as they were implemented as a part of daily practice for all adolescents enrolled in the collaboration project.

The CW and CAP files from all participating adolescents were screened in detail for several biological, psychological and social characteristics, as well as information regarding care delivery trajectories. All available documentation in the CW and CAP files was used. This includes reports from earlier stays, medication registers, and documents from schools or juvenile court. Additionally, for a selection of cases, all daily observations and notes registered in the CW facility where the girls reside (made mostly by social workers and psychologists), were screened for relevant parameters. Selection criteria were: start of enrolment during the research period, and at least 6 months before the end of the research period (March 1st 2015 and February 1st 2017).

The questionnaires were selected with the aim to deepen the target population description and to complement the clinical practice. They were not only used for the adolescents who participate in the research project, but for everyone starting at Van Celst. Most questionnaires were completed in three to four separate sessions in the first six months after enrollment in Van Celst. While the girls were filling out the questionnaires, their therapist or personal social worker was nearby in case they were distressed or needed help. Others were (re)used on indication (e.g. IZIKA to evaluate intensity of care needs when changing programs within Van Celst). The questionnaires evaluate different aspects of the target population (for the full list of questionnaires, see Table 1):

- mental health needs
- trauma (history and PTSD)
- personality development
- attachment
- quality of life.

A total of 30 adolescent girls participated in the research project. For 29 of them, the data from files and questionnaires were included, one of them provided the questionnaires but did not agree with an inclusion of the rest of her files in the research project. The 30 cases represent a global inclusion rate of 71.4%.

Table 1. Questionnaires used for the target population description

Questionnaire	Reference	Goal	Informant
Strengths and Difficulties Questionnaire	SDQ; Goodman, 1997	Emotional and behavioral screening questionnaire for children and adolescents	Adolescent, relatives, personal social worker
Massachusetts Youth Screening Instrument	MAYSI-2; Grisso & Barnum, 2000	The MAYSI-2 is a brief behavioral health screening tool designed especially for juvenile justice programs and facilities.	Adolescent
Childhood Trauma	CTQ; Bernstein & Fink,	Early traumatic experiences	Adolescent

Questionnaire	1998	(death, divorce, violence, sexual abuse, illness or other), and assesses individual's understanding of their childhood trauma.	
Children's Revised Impact of Event Scale	CRIES-13; Children and War Foundation, 2005	Screening post traumatic stress disorder	Adolescent
Kidscreen-52	The Kidscreen Group Europe, 2006	Quality of life in 10 domains	Adolescent
Severity Indices of Personality Problems-118	SIPP-118; Verheul et al., 2008	Personality functioning and problems	Adolescent
Inventory of Parent and Peer Attachment	IPPA; Armsden & Greenberg, 1987	Attachment relationships	Adolescent
Child and Adolescent Service Intensity Instrument	IZIKA; Deboutte, 2013, original instrument CASII, AACAP, 2005	Service Intensity Instrument	Professional

All questionnaires were scored by the researchers. The individual psychologist of each adolescent received the individual data of his/her clients (anonymized) in order to use them in clinical practice. After anonymization, all file data was analyzed with Excel 2011 (version 14.7.2) and presented using descriptive statistics. On team meetings and when discussing with other professionals, adolescents or parents, only group-level data was presented.

This research project was approved by the ethics committee UZA/University of Antwerp. Prior to participation, all potential participants (adolescents, relatives, professionals) were extensively informed concerning the research project. Researchers presented themselves and the research project in the facility (adolescents), on team meetings and via emails (professionals), and via telephone/letters (relatives). All potential participants received written information regarding the goal, benefits, risks, and practical aspects of

the project as well as data handling and participants' rights. They had the opportunity to fully discuss their potential involvement in the project with a member of the research team and signed a consent form before participation. In order for an adolescent to participate (in file and/or interviews), consent from themselves and both (step)parents or other persons with custody was warranted. As a part of the PAR approach, all (preliminary) findings were discussed with the different stakeholders.

Findings

In this section, a profile of characteristics of the target population of Van Celst is described against the background of international literature findings.

Demographic data and registration

Age, length of stay and transition. As shown in Table 2 on average, the adolescents who participated in the research project were almost 16 years old when enrolling in the collaboration project Van Celst. For those who ended their trajectory at Van Celst during our data collection period (i.e. from March 1st 2015 to August 31st 2017), this was on average a few months after their 17th birthday. There were 11 adolescents (36.6%) during the study period who were (still) enrolled in the Van Celst project after the age of 18. Twelve of the girls finished their stay at van Celst during the research period. The median age at departure was 17, four of the girls (33%) departed after their 18th birthday. Indeed, in certain cases adolescents chose to remain in the facility after their 18th birthday, even though most of them are at that time no longer under the jurisdiction of the juvenile judge.

For those who completed their trajectory during the study period, the average length of stay was three months short of two years. For the girls who were still residing at Van Celst at the end of the study, the average length of stay was already more than one and a half years at that moment.

Table 2. Demographic data and length of stay of the participants present between March 1st 2015 and August 31st 2017, who participated in the file study of the research project Van Celst (n=29)

Age	Average
Enrolment	15.8 years
For trajectories completed during the research period, age at completion	17.3 years
When completing questionnaires	16.4 years
Length of stay	
For trajectories completed during	1 year and 9.2 months
For trajectories that are still ongoing	1 year and 7.2 months

Nationality. The majority of the adolescents at Van Celst during the research period have the Belgian nationality. Forty-five percent of these adolescents have a migration background on their father's and/or mother's side in 1st, 2nd or 3rd generation. This is shown in Table 3.

Table 3. Nationality and migration background of the adolescents present between March 1st 2015 and August 31st 2017 who participated in the research project Van Celst (n=29)

Nationality (n=29)	
Only Belgian nationality	89.7%
Non-Belgian or dual nationality	10.3%
Detailed Immigration background (n= 13)	
First generation	10.3%
One or both parents 2nd generation	17.2%
One or both parents 3rd generation or further	17.2%

Referrer and previous stay. Referrals by juvenile court are the most frequent. All adolescents who started in the last year of the research period were referred by the juvenile judge. Other referrers are child psychiatric hospitals and CW facilities.

The most frequent previous stay before an adolescent enrolls at Van Celst is the juvenile justice institution, followed by CW facilities. This data can be found in Table 4.

Table 4. Referrals of the adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29)

Referrer

Juvenile court	86.2%
Child welfare	6.9%
Child and adolescent psychiatry	6.9%

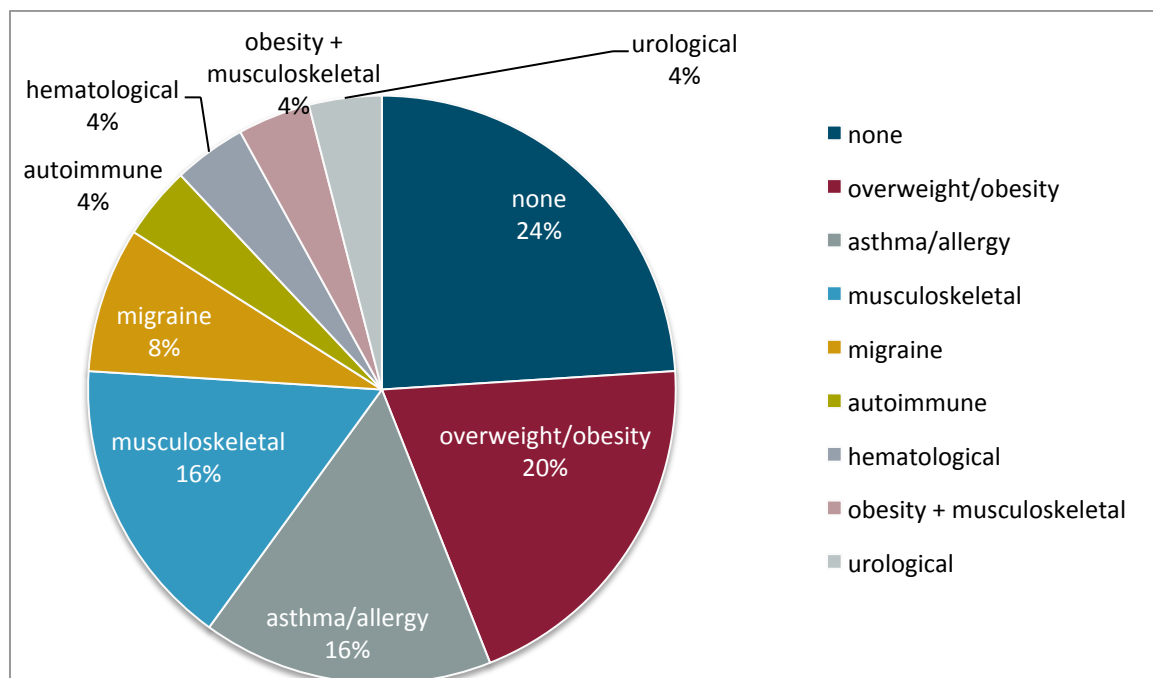
Previous stay / support

Juvenile justice institution	55.2%
Child welfare	20.7%
Child and adolescent psychiatry	13.8%
Relatives with professional support	10.3%

Biological

Chronic physical disorders. In the group of girls enrolled at Van Celst, physical complaints and disorders are frequent. The most frequent issues are overweight and obesity (present in 20% of the girls), asthma and allergies (present in 16% of them) and musculoskeletal problems (present in 16% of them) (see Figure 1).

Figure 1. Chronic physical disorders among adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29)



The frequent occurrence of certain physical disorders (particularly related to overweight and/or asthma and allergy) is in line with the vulnerabilities described in the international scientific literature for adolescent girls in residential care (Nelson et al., 2011). In previous research among adolescents at the start of their stay in residential centers in the United States (Nelson et al., 2011), at least one ICD-10 recognized medical condition was diagnosed in 33.7% of the adolescents against 12% for the general population. Because we only described file data, and no medical investigations were done, care must be taken when comparing our findings with these data. Nevertheless, physical disorders seem to occur to an increased extent in the group of adolescents at Van Celst.

In research by the same authors (Nelson et al., 2012) it was found that the increased prevalence of psychopathology (particularly internalizing) is associated with a higher risk of physical health problems and

medication use. Conversely, psychopathology (in particular various comorbid problems) was associated with physical health problems. These authors point out the need for an integrated approach to the psychological and physical needs of vulnerable adolescents in care.

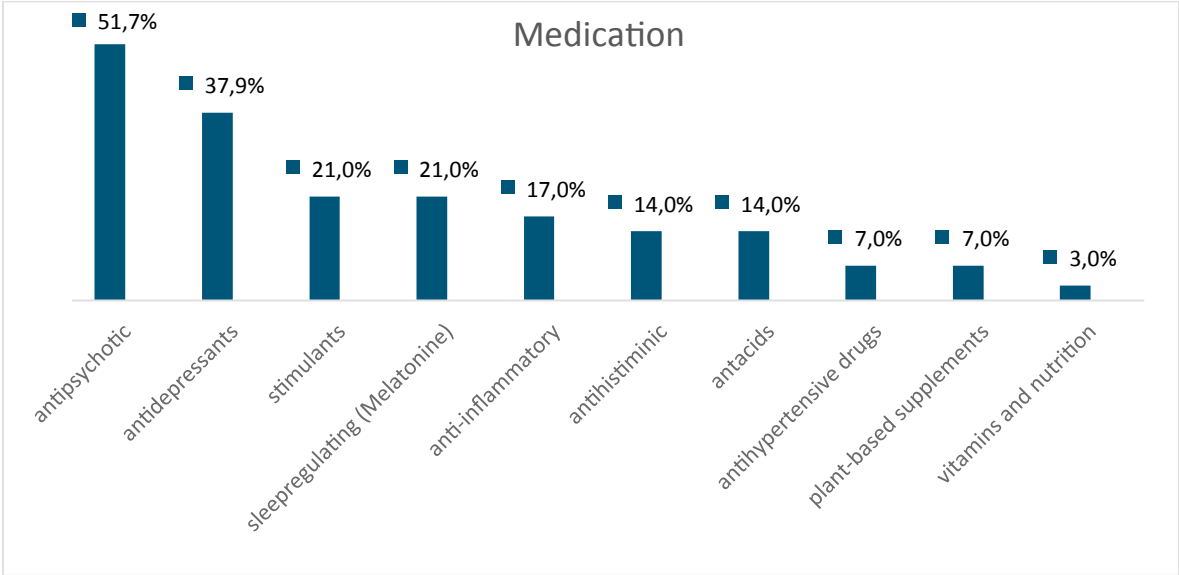
Medication use. Seventy percent of the participants had at least one medication prescribed for more than one month of the study period (Figure 2). When considering their entire trajectory, over half of the adolescents at Van Celst used antipsychotics and nearly 40% used antidepressants. As non-psychopharmacological medication, antacids are also frequently prescribed (20%).

In 46% of the participants, two or more products are prescribed simultaneously, and a quarter of the adolescents took two psychopharmacological products in combination with a non-psychopharmacological drug.

Literature research describes that adolescents in residential care take more medication than adolescents in the general population. Research in an American residential facility for adolescents with behavioral and emotional problems (1010 adolescents) found that 49% of the adolescents took psychotropic medication during their stay (Handwerk, Smith, Thompson, Spellman, & Daly, 2008). At Van Celst, however, that is the case in 69% percent of the adolescents.

As these medication prescriptions could not be linked to current or past diagnosis or illness, no statements about adequacy or efficacy can be made. However, the finding of frequent medical conditions and use of medication does support the assumption that expertise and coordination from a medical perspective is important in comprehensive care delivery for these adolescents.

Figure 2. Medication prescribed for the adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the Van Celst research project (n=29). Percentage of the 29 adolescents taking a certain class of medication.



Physical ailments. During the working groups that prepared the data collection, adolescents as well as professionals repeatedly mentioned the impression that physical ailments were very frequent in this group and impacted their wellbeing. The literature also clearly mentions the frequency of physical problems, ailments and medication use in vulnerable populations such as adolescents in residential care.

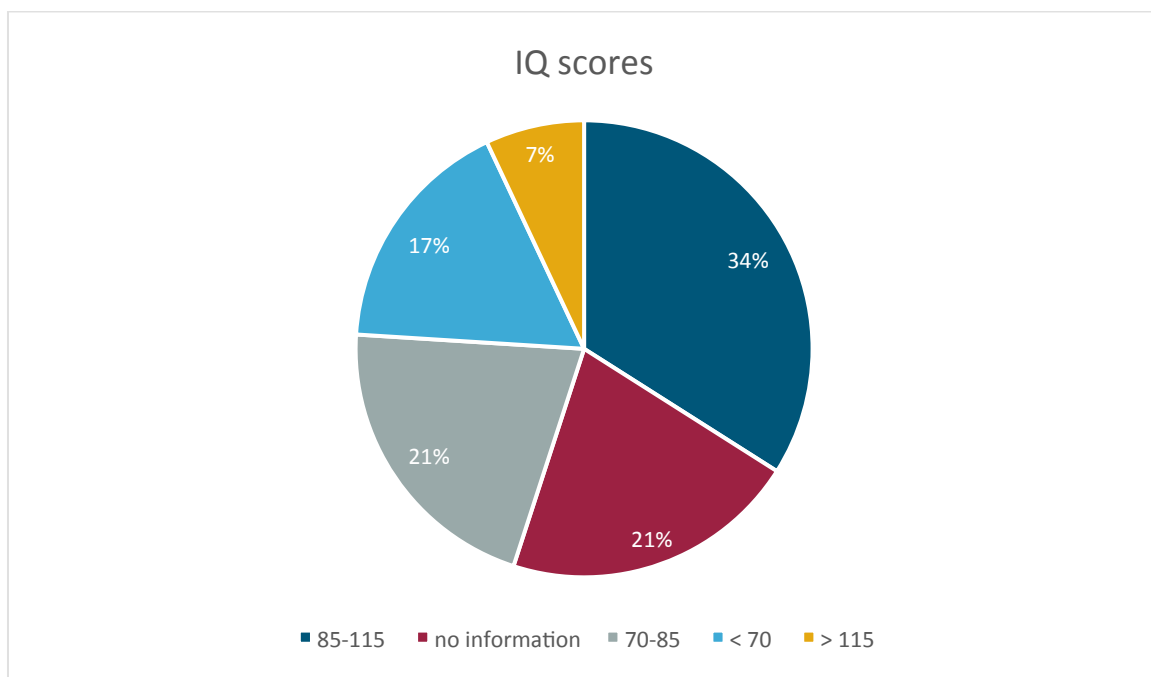
Information retrieved from the 10 files where daily observations were analyzed indicates how frequently the social workers report that the adolescents complain of physical ailments. These daily observations give an idea of frequent types of ailments: headaches and muscular pains are the most frequent complaints, followed by gastro-intestinal pain. The average number of times physical complaints are noted per month is four (range 1 to 7) per participant. These complaints are reported throughout the trajectory.

Psychological

Variable IQ. In the file data, for approximately 80% of the adolescents, an IQ score was found. However, these IQ scores come from very different sources (including school counseling, CAP screening) and are not always recent (Figure 3).

For more than a fifth of the participants, no IQ data were available. For those who had IQ scores in their files, the largest group had an average IQ (85-115). Seventeen percent of adolescents have an IQ below 70, while seven percent have a score higher than 115.

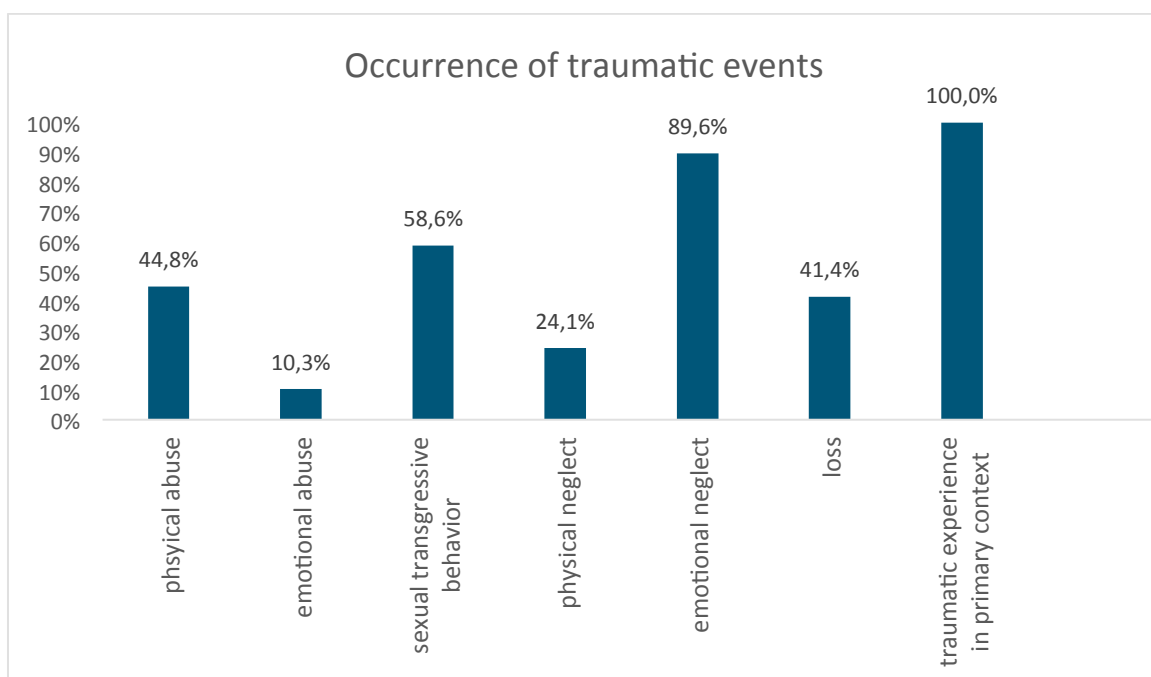
Figure 3. IQ scores of the adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the Van Celst research project (n=29). Percentage of the adolescents with an IQ score in one of the following categories: >70; 70-85; 85- 115; > 115.



Trauma. The file data of participating girls clearly points out an extensive history of various forms of trauma. As shown in Figure 4, the occurrence of different types of (potentially) traumatic experiences in this group of adolescents is very high. In particular, there is a very frequent (almost 90% of the population) report of emotional neglect. Victimization of sexually transgressive behavior is also mentioned in more than half of the files. In addition to experiences of abuse and neglect, more than 40% of the adolescents also experienced

significant losses (for example, death of a relative). All participants report at least one major event involving the primary context. Moreover, only a small proportion of the participants (14%) had a single traumatic event, while most of them have experienced various potentially traumatic events. For example, 35% of them experienced 3 types of trauma, and in 7% the files mention 6 types of traumatic experience.

Figure 4. Occurrence of traumatic events in the files of adolescents enrolled at Van Celst between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29). Percentage of files of the participating adolescents reporting a certain type of traumatic event.



Based on these file data and confirmed by the findings from questionnaires, a trauma-focused approach within this target group is extremely valuable. In practice, investments were made in trauma education and in the use of a trauma-oriented framework (based on the program “Sleeping dogs? Wake them up!” (Struik, 2010).

Self-injurious behavior and suicide attempts. Files and daily observations also mention suicidal thoughts, and suicide attempts as well as self-injurious behavior. The percentage of adolescents who, on the basis of file data, showed self-injurious behavior or a suicide attempt prior to their stay at Van Celst is both 24% (cumulative). During the stay at Van Celst, that percentage is 13.8% for a self-harm and 4.4% for suicide attempts.

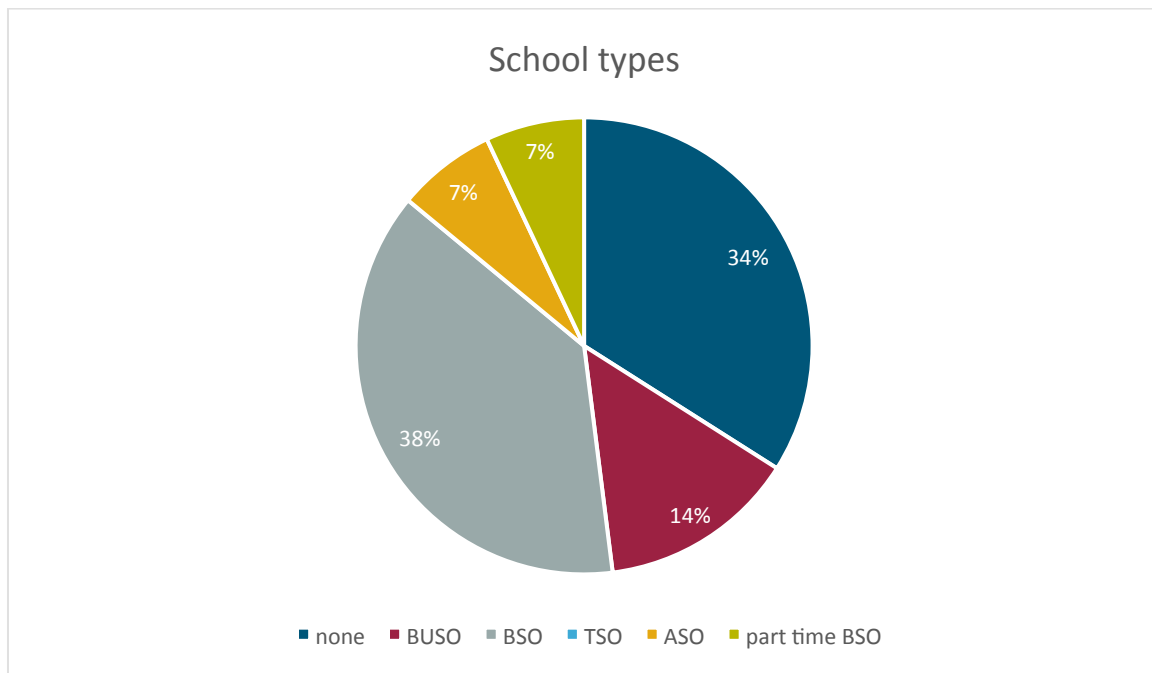
In previous research in the United States and the United Kingdom self-injurious behavior is found to be much more frequent in girls in residential care (up to 33%) than in adolescents in the general population. A history of suicidal thoughts and/or attempts is twice as frequent among adolescents in facilities than in the general population (Duppung Hurley, Wheaton, Mason, Schnoes, & Epstein, 2014).

The daily observations in our study also gave information about self-harm, suicidal behavior, and attempted suicide. Suicidal thoughts and self-injurious behavior are noted throughout the trajectory but show a tendency to lessen over time. This frequent occurrence of suicidal thoughts or self-injurious behavior emphasizes the importance of cooperation with CAP and illustrates the high demands placed on employees.

Social

School problems. In the field of social integration, the school career of adolescents in care is of great importance. Figure 5 gives an overview of the school types.

Figure 5. School types in the files of adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the Van Celst research project (n=29). Percentage of the participating adolescents with following categories of schooling: BUSO = Special secondary education, BSO = Vocational secondary education, TSO = Technical secondary education, ASO = General secondary education)



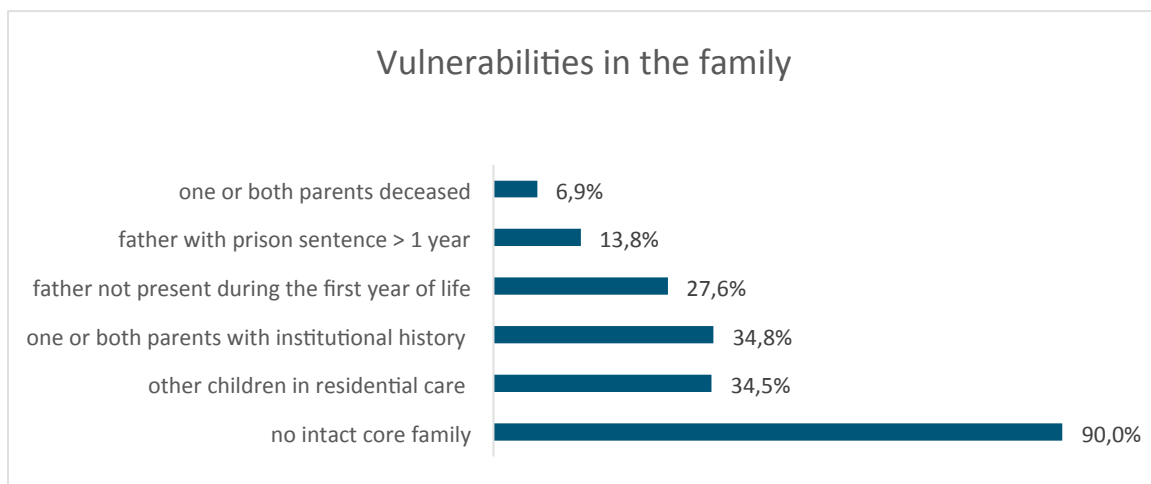
It is striking that more than a third of the adolescents do not report a (permanent) school when they arrive at Van Celst. Of those who are enrolled at school, this is for the most part in the vocational secondary education (BSO) (38% full-time and 7% part-time BSO). Almost one in six girls were enrolled in special needs education at the start of the trajectory at Van Celst. The school career of these adolescents is often very fragmented. The majority of the adolescents (86%) changed school at least three times since the transition to secondary school, and 79% interrupted school for more than two consecutive months (with exclusion of summer holidays).

Difficult schooling during the stay at Van Celst. The daily observations also record whether the adolescents get to school. These registrations show that the vast majority of them does not go to school, or

only gets there sporadically. For most of the time, nearly half of the girls (48%) do not go to school. In the first month for example, 80% of the girls does not attend school at all.

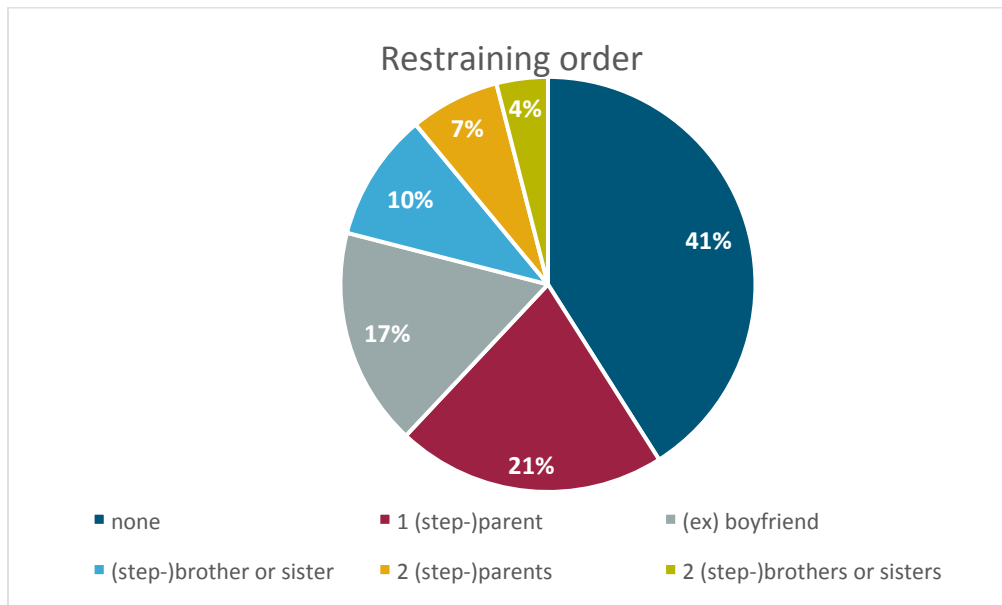
Vulnerable family composition. Most of the adolescents enrolled at Van Celst have a vulnerable family context (see Figure 6). With regard to family composition, the core family is intact in only 10% of the adolescents. In about one third of the cases, (step)brothers or (step)sisters are or have been placed in residential care. A parent in prison, or the absence of the father in the first year of life, are further possible vulnerabilities within the family context.

Figure 6. Vulnerabilities in the family in the files of adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29). Percentage of files of the participating adolescents reporting certain types of vulnerabilities in the family.



Restraining order. More than half of the participants have a restraining order against close relatives or acquaintances (see Figure 7). For 10% of the adolescents there is a contact ban with two persons in their close context. Most frequently, for more than one fifth of the participating girls, this involves a restraining order against one parent or stepparent (most frequently stepfather). For an additional 7% of the girls, it is a restraining order against two (step)parents. A restraining order against a friend or ex-boyfriend is also in place for 17% of the participating girls.

Figure 7. Distribution of types of restraining order in the files of adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29).



Together, these findings, based on file data about the context, contribute to the profile of the target population, in which contextual issues are also prominently present. Furthermore, the vulnerabilities and needs in the context of these adolescents clearly argue for an integrated approach, where attention is paid to both child and context, in which psychological vulnerability can be a guidance focus and whereby social integration and functioning are simultaneously pursued (Tausendfreund, Knot-Dickscheit, Schulze, Knorth & Grietens, 2016).

Parents with (Mental) health problems. In 55% of the cases, the files mention a father and/or mother with a psychiatric problem. In 24% of the participants, the files describe a chronic physical condition in one or both parents. For the mothers, in a little more than half of the cases the files mention mental health problems. In most cases it is a personality disorder type borderline (17%), followed by depressive disorders (14%). For fathers, psychiatric problems, most frequently substance-related problems (17%), are reported in about a quarter of the cases. In 30% of the files, a sibling with psychiatric issues is mentioned. Most often, they have a ADHD or intellectual disability diagnosis. Care must be taken when interpreting these findings, because they are based on the file data of their child in care, rather than on clinical investigations in parents.

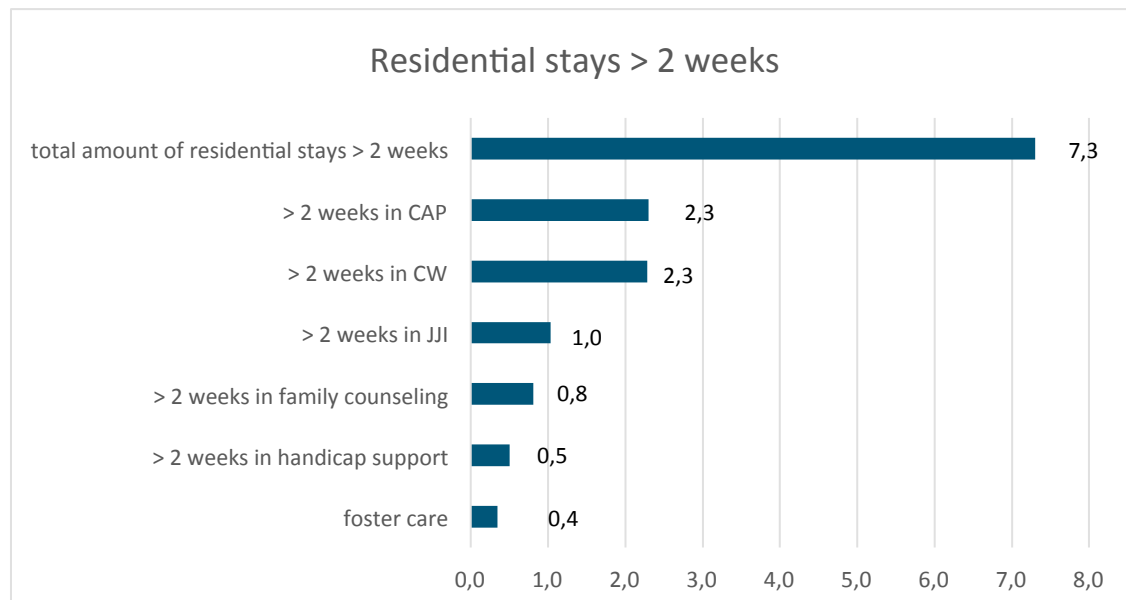
Care Delivery

Complex care delivery history. A very clear characteristic found in the files of participating adolescents is their fragmented care delivery history. They have had contacts with a large number and variety of professionals in different sectors and have had several placements before they came to Van Celst. The reports of previous treatments and stays were sometimes not complete (years missing), so this data could be an underestimation of the real number of different interventions.

Before their enrollment at Van Celst, these adolescents have had a mean of more than seven residential stays with a duration of more than two weeks. This is a very large number of placements, especially regarding the young age of these adolescents and the fact that short crisis placements are not included in these counts. The mean number of stays is more than two in CAP, and also more than two in juvenile justice institutions.

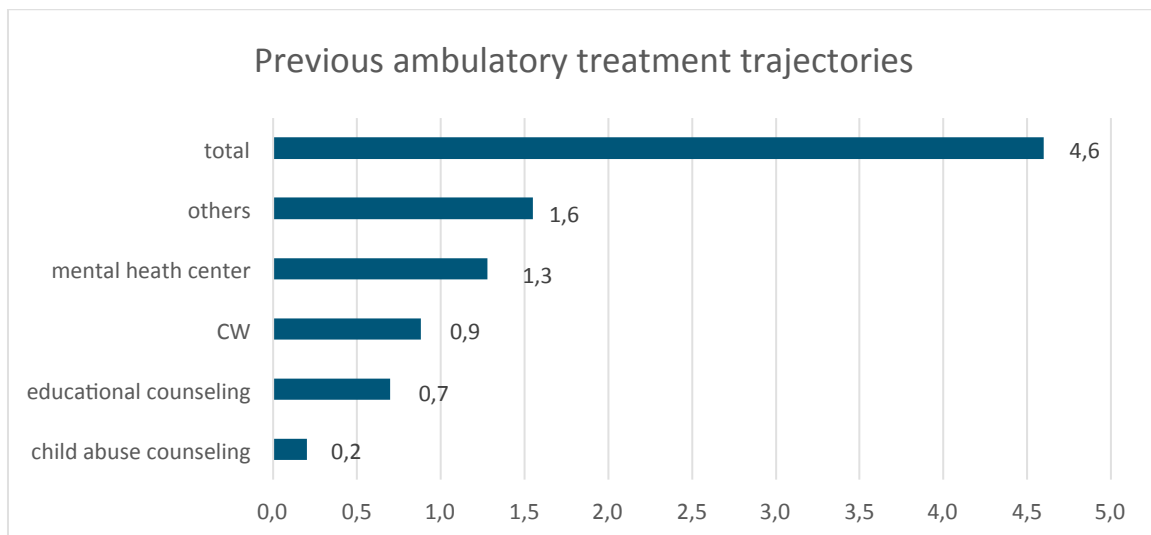
Taking into account the different sectors of prior residential stays, nearly 90% of the adolescents have had a previous stay in child welfare, and nearly 70% had a CAP residential treatment, before arriving at Van Celst (Figure 8).

Figure 8. Mean number of previous residential stays in the files of adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29)



Before the stay at Van Celst, these adolescents have had a mean of five non-residential treatment trajectories, defined as three or more contacts with the same instance or professional, with a diagnostic or therapeutic purpose (Figure 9). These contacts are quite diverse. Besides mental health and CW, participants have often been in regular contact with school counseling services or speech therapists. Caution is recommended in interpretation of these data, because the account of ambulatory treatments in the files is likely to be an underestimation of the real number of contacts with different professionals.

Figure 9. Mean number of ambulatory treatment trajectories in different sectors of care for adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29)



Another aspect that was looked for in the files is the age of onset of professional help. The mean age at first ambulatory treatment is 6.9 years, and for residential treatment 7.3 years. In both cases there is a large age range (from infancy to adolescence) for initial treatment.

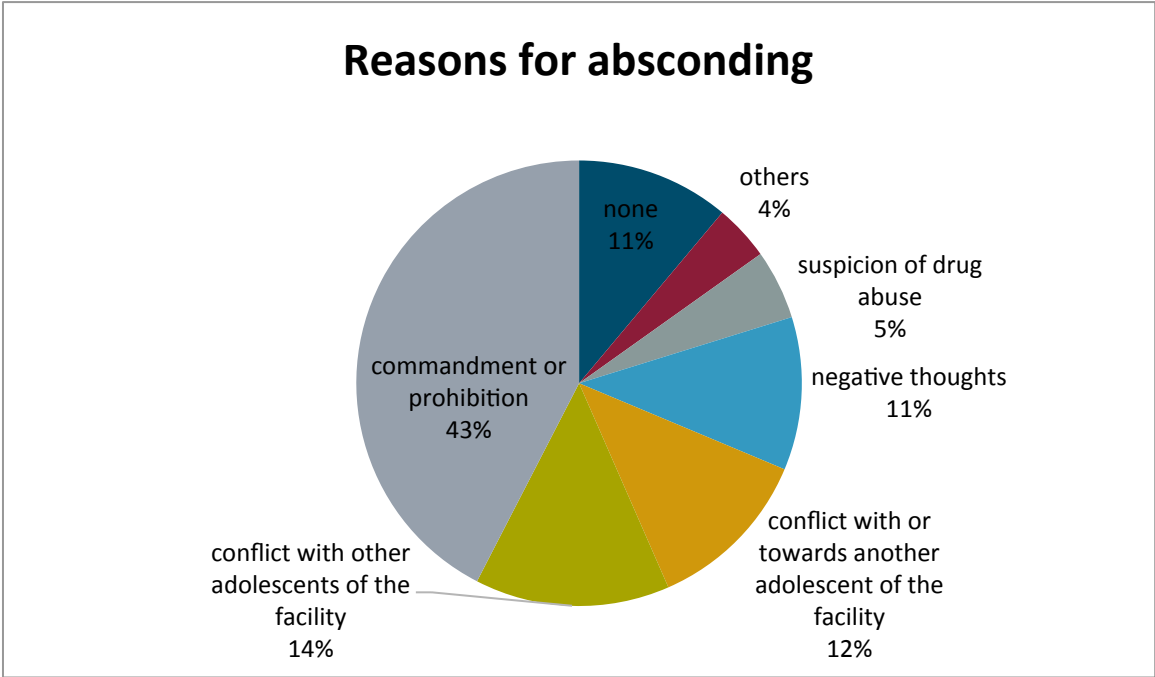
The number of sectors contributing to care delivery (residential or ambulatory) before enrolment at Van Celst is 3.2. The most frequent combination is CW and CAP.

Complex care delivery during the stay at Van Celst

Absconding. A possible indicator of the complexity of the care delivery trajectories while the participants are enrolled at Van Celst is the number of abscondings. This is quantified as the number of police signalizations of absconding. During the research period, for all participants together, a total of 286 absconding signalization documents were found. These involved 23 of the 29 girls (79%). Most often, the adolescents are leaving from the facility (75%) or their (parents'/friends') home (20%).

The most frequent reason (42% of cases), as noted by the person that signals the absconding to the police, is a reaction to a rule. Other reasons are conflicts or other influences of other adolescents at the facility. In 11% of the cases the absconding is even more worrisome because the adolescent has uttered suicidal thoughts (Figure 10).

Figure 10. Distribution of reasons for absconding (n= 286 abscondings) for adolescents present between March 1st 2015 and August 31st 2017 who participated in the file study of the research project Van Celst (n=29)



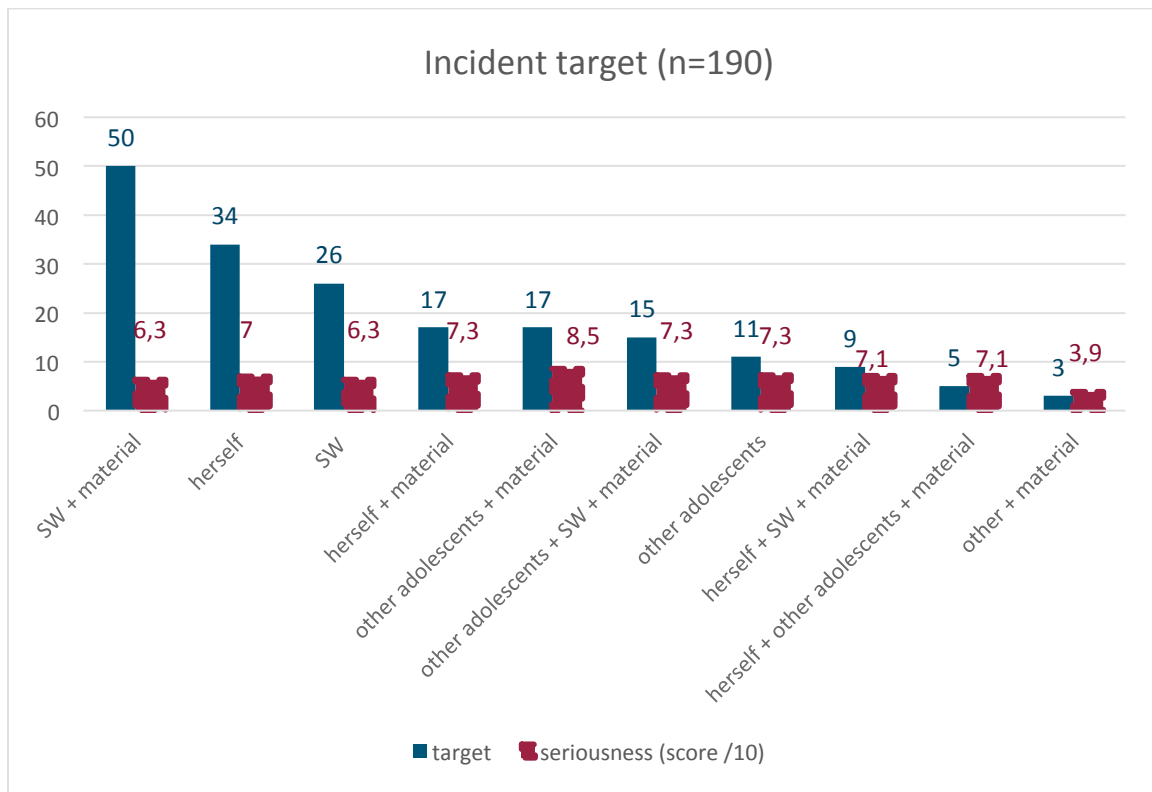
Incidents registered by staff. Severe incidents, most often adolescents' aggressive behavior directed against others, against objects, or against themselves, are registered by staff using the SOAS-R (Staff Observation Agression Scale – revised; Nijman, 1999). This tool allows the professionals to describe the cause and the actual situation (what happened? directed against whom? consequences?). They also register the actions that were undertaken (what was done to tackle the situation?). Moreover, this tool allows the professional to rate the severity of the incident. They can also make comments on whether there were premonitory signs, whether enough colleagues were present, and whether they wish to have a debriefing conversation.

For the entire research period, 190 of these incidents were registered, being a mean of more than 1.5 incidents a week. These incidents were related to 18 of the 29 girls included in the file study, representing a mean of 11.2 incidents per adolescent in this subgroup.

With regard to the actual problem behavior, verbally aggressive behavior (insulting or threatening) towards staff (34%), or a combination of physical and verbal aggression (30.5%) are most frequent. In 20% of the cases the reported incident is self-harm. The most frequent trigger was when the adolescent was confronted with the rules (38.4%), followed by a conflict with another adolescent in the facility (29%). In most cases the situation is handled at the facility, by ending the contact, treating minor injuries, repairing and replacing materials/objects. In 13.3% of these incidents, an ambulance was required and in 10% of them, police intervention was necessary.

The mean score for the severity of the incidents is 6.9/10. In 94% of cases the professionals report that there were enough colleagues present, to handle the situation. In 12% of the cases they ask for a debriefing meeting (that is subsequently organized with the team coordinator, other colleagues, and/or the child psychiatrist) (Figure 11).

Figure 11. Target (blue column) and mean severity as scored by professionals (red column) of incidents (n=190) registered during the study period between March 1st 2015 and August 31st 2017 for adolescents present who participated in the file study of the research project Van Celst (n=29) (SW=social worker)



Time-outs. The daily observations and registrations also give information about the time-outs the adolescents have from the facility. Time-outs can be initiated by the adolescent, the professionals at the facility, or by the juvenile judge. In this collaboration, the intent is to use time-outs as a part of the care delivery trajectory, allowing the adolescent and the professionals (and relatives or other girls at the facility) to take a break for self-reflection and to work on the relationship with professionals. The adolescents are always welcomed back in the facility after their time-out, the intent is not to change their placement. The time-out duration is variable, ranging from a few days in another facility or a foster family, to several months in juvenile justice institutions, followed by CAP and other CW institutions. The mean number of time-outs per adolescent per month is 0.8. The most frequent type of time-out is a short time-out in a juvenile justice institution. The number of long time-outs diminishes over time.

Doctor's appointments. The daily observations also record the doctor's appointments of adolescents enrolled in the program. In the files considered, the mean number of doctor's appointments (including visits to the ER) is 1.3 per adolescent each month. Most frequent are visits to the general practitioner, followed by specialists (most often orthopedics) and the emergency room.

In the daily observations and corresponding agendas, it was possible to evaluate all missed appointments that were noted for the adolescents enrolled. This seemed interesting as these appointments represent a considerable part of the efforts made by professionals of the collaboration project, but one that is not clearly visible. The mean number of missed appointments for this group of adolescents is 0.8 per month. The type of appointment that is missed most often is an appointment with CAP (i.e. diagnostic or therapeutical, child psychiatrist or psychologist) or a doctor's appointment. It goes without saying, the continuous investment of re-inviting adolescents and re-organizing consultations is demanding.

Questionnaires

Needs in Terms of Emotions and Behavior

Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997)

The SDQ measures psychosocial problems and skills among children and adolescents. It is a questionnaire that is completed in a separate version by relatives and the individual social worker, about the adolescent. The SDQ has 25 statements, generating scores for the following domains: emotional problems, behavioral problems, hyperactivity, problems with peers, and prosocial skills, as well as two general scores: the total problem score, and the score for impact of the problems on the functioning.

The questionnaire yields three outcome measures: “normal”, “moderately increased (borderline)” and “increased (clinical)” score. These scores are an indication of the adolescent’s level of functioning compared to what is expected in the general population for this age and gender. If the score is “increased” or “clinical”, it is comparable to the score of children/adolescents who need or receive professional help. The cut-off values used in this study are the Flemish standard data for the SDQ (Verpraet, Janssens, & Deboutte, 2011). The graph below (see Figure 12) shows the average scores on the SDQ questionnaire for the youth self-report, the questionnaire for (step)parents (‘context’), and the version completed by the individual social worker.

Figure 12. A. SDQ cutoff scores for self-report, parent/caregiver, teacher/professional

Domains/ interpretations	Emotional problems	Conduct problems	Hyperactivity	Peer problems	Prosocial problems
SDQ self-report					
Normal	0-5	0-3	0-5	0-3	6-10
Borderline	6	4	6	4-5	5
Clinical	7-10	5-10	7-10	6-10	0-4
SDQ parents/caregiver					
Normal	0-3	0-2	0-5	0-2	6-10
Borderline	4	3	6	3	5
Clinical	5-10	4-10	7-10	4-10	0-4
SDQ teacher/professional					
Normal	0-4	0-2	0-5	0-3	6-10
Borderline	5	3	6	4	5
Clinical	6-10	4-10	7-10	5-10	0-4

B. Average SDQ scores for adolescent self-report (n=23), filled in by the context (n=19), and completed by the individual social worker (n=23).

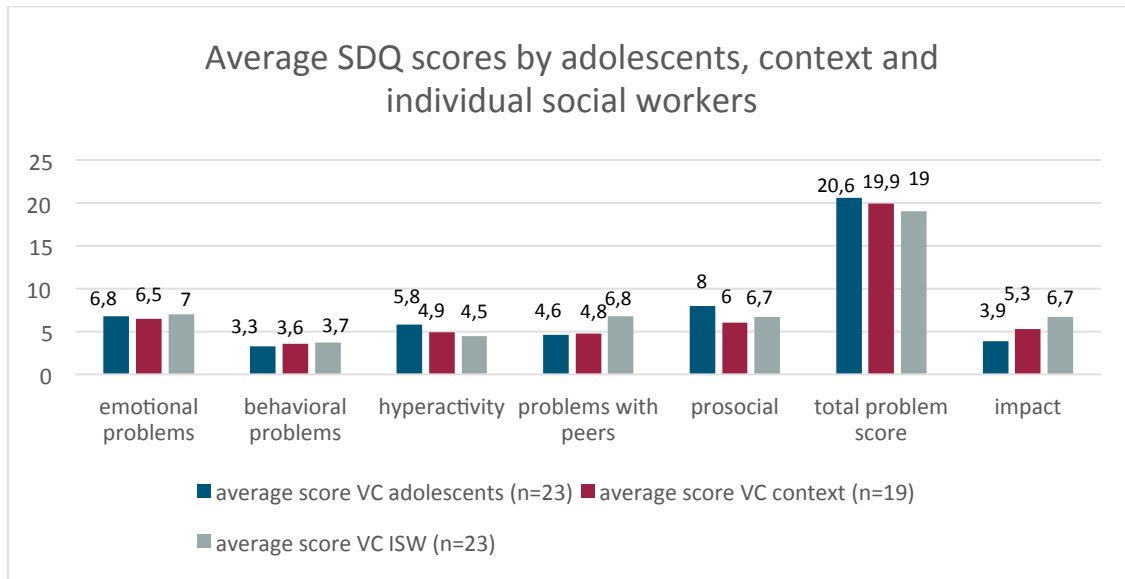


Table 5 shows the interpretation of the average SDQ scores for the self-report, relatives and individual social workers questionnaires. The total problem score and the impact score are on average “clinical” for the three informants. In the self-report questionnaires and in the data from individual social workers, only 10.3% of the adolescents at Van Celst have a normal total problem score (in comparison with Flemish standards). In the SDQ completed by (step)parents, only 5.2% of the adolescents have a total problem score that is not increased in relation to the general population, and so a larger proportion of the adolescents have a clinical total problem score.

Table 5. Interpretation of average SDQ scores compared to Flemish standard data (Verpraet et al., 2011). Adolescent self-report n=23, context n=19, individual social worker n=23.

	Self-report	Context	Professionals
Emotional problems	clinical (6.8)	clinical (6.5)	clinical (7)
Behavioral problems	normal (3.3)	clinical (3.6)	clinical (3.7)
Hyperactivity	normal (5.8)	normal (4.9)	normal (4.5)
Problems with peers	clinical (4.6)	clinical (4.8)	clinical (6.8)
Pro-social skills	normal (8)	borderline (6)	normal (6.7)
Total problem score	clinical (20.6)	clinical (19.9)	clinical (19)
Impact	clinical (3.9)	clinical (5.3)	clinical (6.7)

The average score for the self-report questionnaire is a normal score for a number of scales: hyperactivity, behavioral problems and prosocial behavior (friendly and helpful behavior). “Emotional problems” and “problems with peers” scores are in the clinical range on the self-report questionnaire.

The pattern in the questionnaires of parents and individual social workers is remarkably similar to that of the adolescents: the domains “emotional problems” and “problems with peers” are problematic compared to the general population, for all informant groups. The scoring profile is discrepant for behavioral problems, where the adolescents score “normal” and parents and individual social workers “clinical”. Also on the prosocial skills scale there is a small difference: parents score “borderline” (moderately increased), but individual social workers and adolescents’ scores are in the “normal” zone. In summary, the SDQ scores indicate that participants have, on average, greater needs in terms of psychological well-being and psychosocial problems than the general population. These difficulties are most pronounced in terms of emotions and contact with peers, and also appear to have a significant impact on their functioning.

In addition to this information about how the target population at Van Celst is situated in relation to the general population, it is also relevant to examine whether there are differences between the adolescents at Van Celst, and other groups of adolescents in (similar) service settings.

Thanks to data from earlier research using the SDQ among adolescents in CW in Flanders, the target population at Van Celst can be compared with other adolescents in CW (see Figures 13a, 13b and 13c). In the BIJPASS project (Janssens, Peremans, & Deboutte, 2010) the SDQ was filled in by adolescents (146 self-report questionnaires), parents (n=223) and care providers (n=263) in 16 facilities of CW (556 children and adolescents). In the graphs below, based on the adolescents’, (step)parents’ and social workers’ questionnaire, a comparison is made between the scores of the adolescents at Van Celst and the scores found in the aforementioned research for adolescents in CW.

Figure 13a. Average SDQ-scores for self report (adolescents), (step)parents and individual social worker, each time in comparison with the scores found in previous research in a group of adolescents, parents and care providers, representative of the Flemish CW. Adolescents n=23, context n=19, individual social worker n=23.

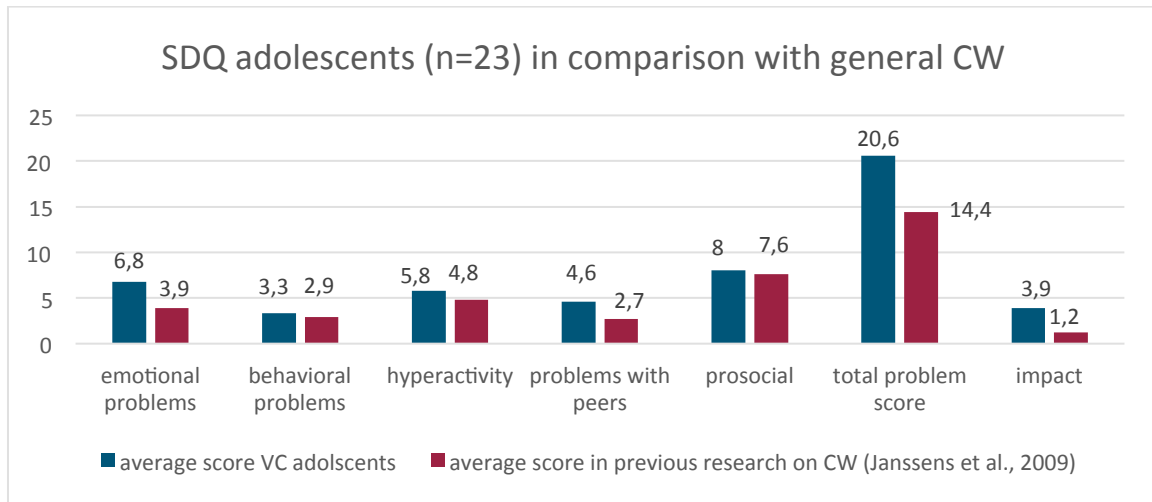


Figure 13b

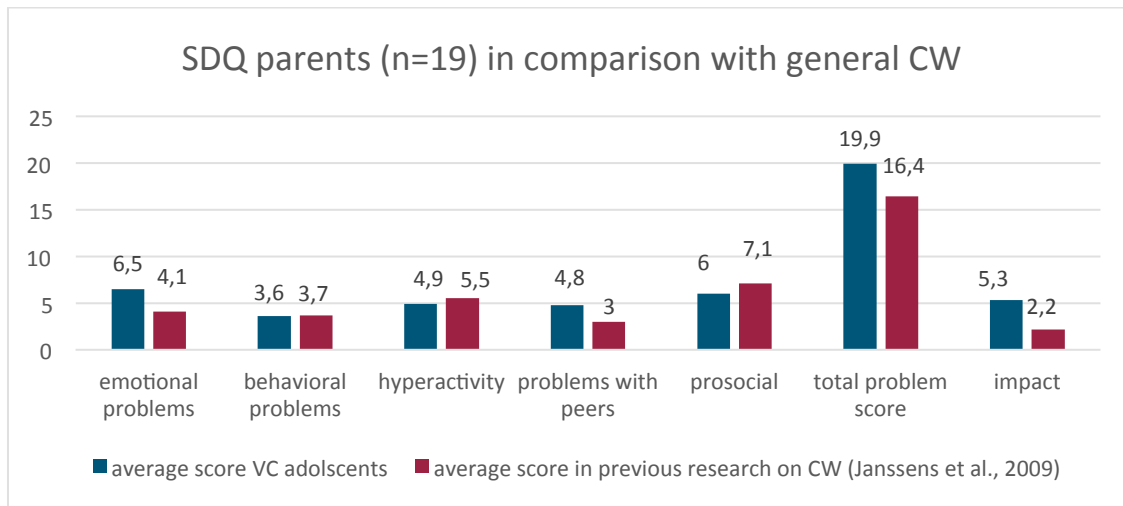
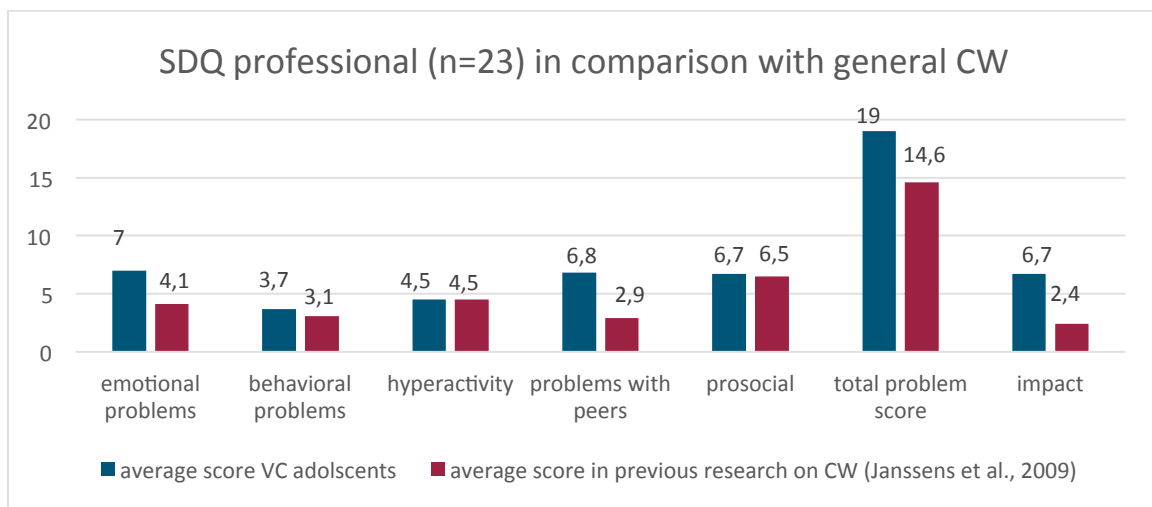


Figure 13c



When comparing the data of the adolescents at Van Celst with this group of children and adolescents who reside in a residential facility within CW in Flanders, the following applies:

- The participating girls at Van Celst have on average a significantly higher emotional neglect on self-report questionnaires (20.6 for the girls of Van Celst versus 14.4 for the sample of CW).
- Also on the parents' questionnaire the total problem score among the girls at Van Celst is significantly higher than the score of the sample adolescents from CW in earlier research (19.9 for the girls of Van Celst compared to 16.39 for the sample of CW).
- The total problem score that professionals attribute to the adolescent is also higher on average in the girls of Van Celst than in the sample of adolescents from CW (19 for the girls of Van Celst versus 14.6 for the sample of CW).
- The impact score for self-report and for the questionnaires for (step)parents and for individual social workers is higher at Van Celst (3.9 versus 1.2 for the self-report; 5.3 versus 2.2 for the context; 7 versus 2.4 for aid workers).
- All scales (including impact) are scored higher by the adolescents at Van Celst than by the comparison group from CW. This also applies to the prosocial behavior scale, which is a positive scale and reflects skills.
- (step)parents of adolescents at Van Celst score behavioral problems and hyperactivity lower than in the sample of youth in CW. They also give a lower score for prosocial behavior.
- Professionals score all scales (including impact, but also prosocial behavior) higher than the scores that the care providers gave in the sample of adolescents in CW in the previous study.

The above comparison gives an indication of how the target population of Van Celst relates to other groups of adolescents in CW. Total problems scores and impact, as well as different subscales, illustrate the severity of issues in the Van Celst target population.

Massachusetts Youth Screening Instrument-2 (MAYSI-2) (Grisso & Barnum, 2000)

The MAYSI-2 is a questionnaire that was initially designed for adolescents in juvenile justice institutions and that evaluates mental health needs (Figure 14). It consists of 52 yes/no questions. The problem scales that the MAYSI evaluates are:

- *Alcohol and drugs*: scale to identify adolescents who use alcohol and/or drugs to a significant extent and therefore may be at risk for substance-related disorder.

- *Angry/irritable*: scale to detect explicit feelings of anger and a general tendency to irritability (often accompanied by tension, touchiness, impulsivity ...).
- *Depression/fear*: this scale assesses (mixed) anxious-depressive feelings in adolescents.
- *Physical complaints*: this scale questions various physical complaints and pain, in addition to the specific physical anxiety equivalents.
- *Suicidal thoughts*: assesses (recent and current) suicidal thoughts (both thoughts of self-injury or suicide and depressive components that cause an increased risk of suicide).
- *Trauma score*: examines whether an adolescent has been exposed to traumatic events more than other adolescents. No cut-off value is used for the “trauma” scale.
- The scale “*thought disorders*” has not been validated for girls and was therefore not used.

Three possible outcomes are generated, depending on the scores. The score is described as “attention” if the score is higher than that of 2/3 of the adolescents in the juvenile justice institution. “Warning” applies to a score in the top 5-15% of adolescents in a juvenile justice institution.

Figure 14. Average MAYSI-2 scores for the adolescents at Van Celst, compared to the cut-off value for “attention” and “warning” (n=23)

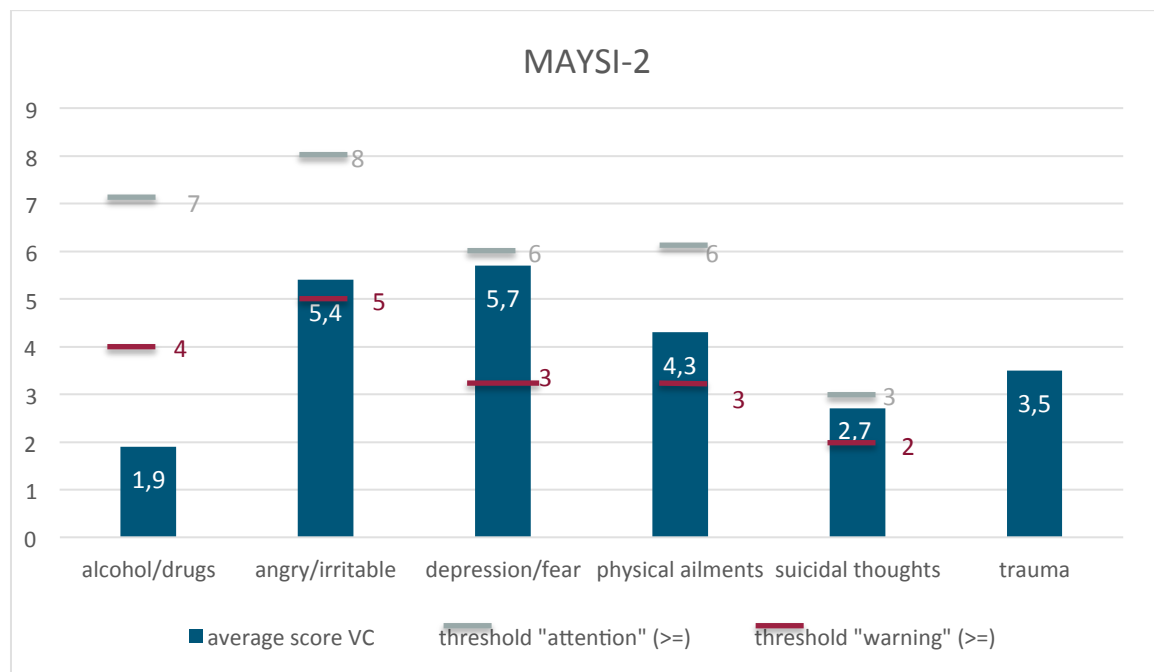


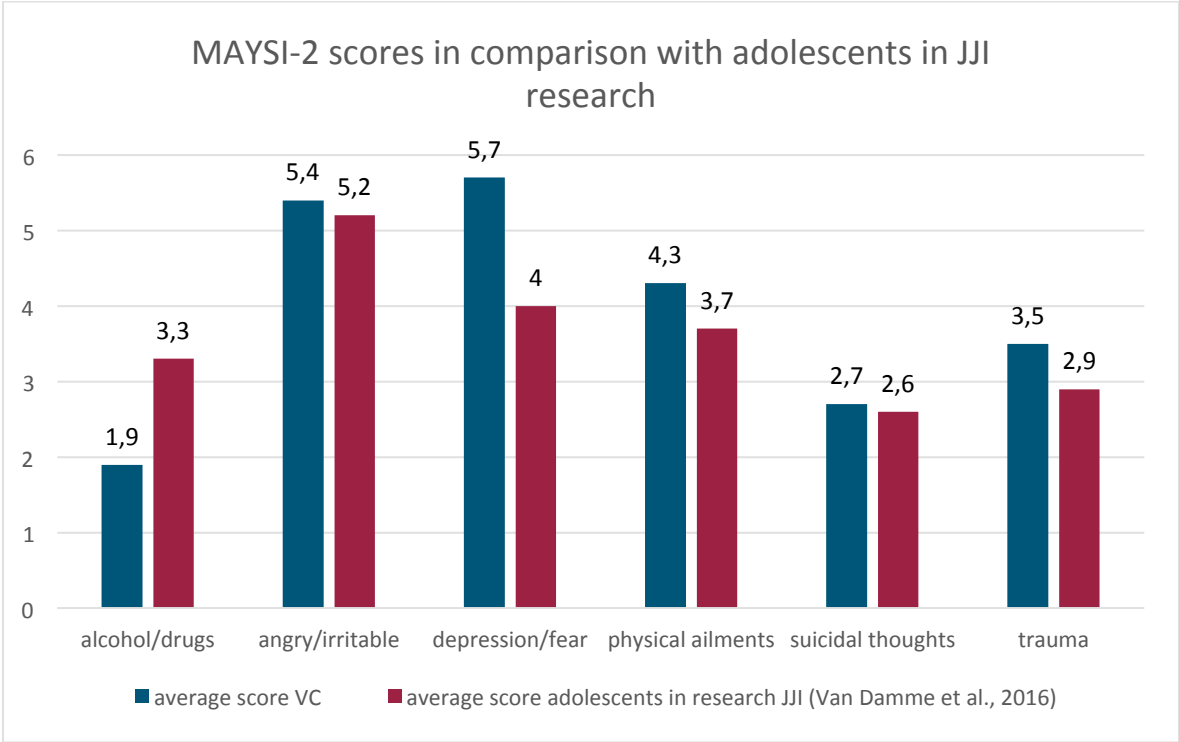
Figure 14 shows the average score for the various scales. The cut-off values for scores indicated as “attention” or “warning” are shown. On all scales, except the scale that assesses the excessive use of alcohol

and drugs, the adolescents in this target population score above the “attention” threshold and consequently show higher needs in the field of mental health care than 2/3 of the adolescents in the comparison group of the MAYSI-2 (juvenile justice institution).

From this MAYSI-2 questionnaire, the girls at Van Celst appear to have specific needs in terms of internalizing problems, when comparing with adolescents in a juvenile justice institution. For the scale of depression/fear, 57% of adolescents at Van Celst score in the “warning” zone, corresponding to the top 5-15% adolescents with the most problems in this area, in the norm group. For the scale of suicidal thoughts, 52% of adolescents at Van Celst score in the “warning” zone. For the physical complaints scale, 91% of the adolescents at Van Celst have a “warning” score. For the angry/irritable scale, which represents an externalizing dimension, scores for 48% of the adolescents at Van Celst are in the “warning” zone.

When comparing with the data for 307 adolescent girls during a stay in a juvenile justice institutions in Flanders (see Figure 15), collected in previous research (Van Damme et al., 2016), on all problem scales except alcohol/drugs, the girls at Van Celst have higher mean problem scores. However, both groups exhibit similarities in profile, in the sense that all scores are on average in the “attention” zone, apart from those on the alcohol and drugs scale.

Figure 15. Average MAYSI-2 scores for the adolescents at Van Celst, in comparison with previous research among girls in the Flemish juvenile justice institutions



The profile of the scores on the MAYSI-2 is similar to the findings from research in Flemish girls in the juvenile justice institutions. However, the adolescents at Van Celst have higher needs in the field of mental health care found in the field of externalizing and internalizing problems (including physical complaints, suicidal thoughts and trauma), but do not score higher for substance-related problems.

In a study in juvenile justice institutions in the Netherlands 64% of adolescents (n=133) had a “warning” score on at least one scale. This is the case with 74% of the population at Van Celst (Eichelsheim & van der Laan, 2011). Compared with Dutch adolescents in juvenile justice facilities, in the target population at van Celst, an additional 10% of adolescents have needs in the “warning zone” (= top 5-15%).

Need for a Trauma-Sensitive Approach.

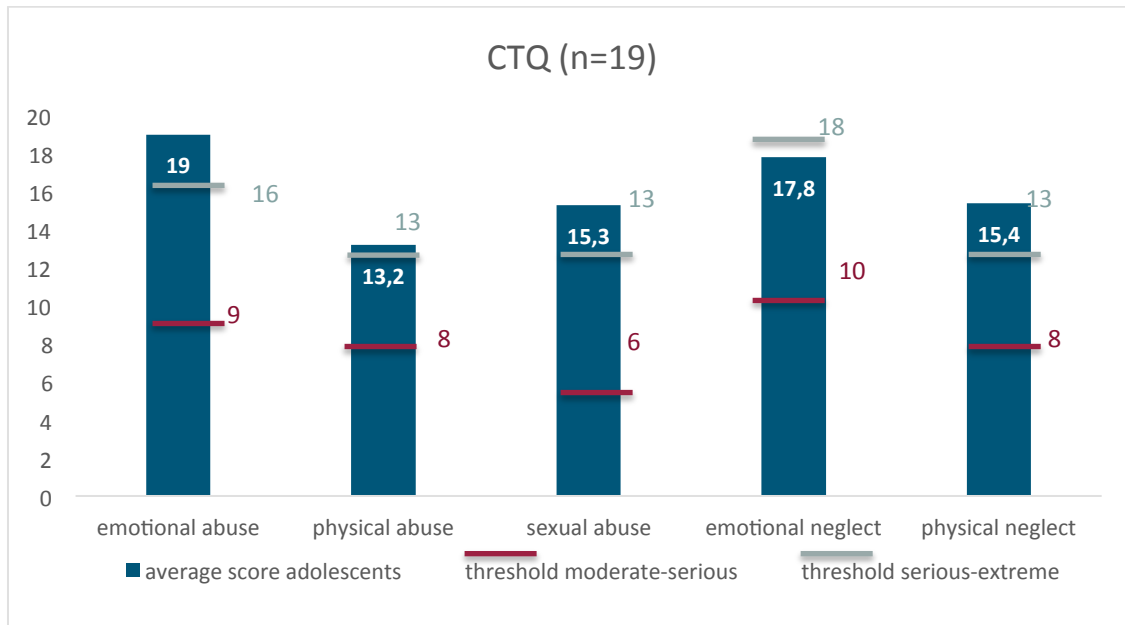
Childhood Trauma Questionnaire (CTQ) (Bernstein & Fink, 1998)

The CTQ assesses experiences of abuse and neglect. Scores on the five different subscales vary between 5 and 25 and provide a quantitative index of abuse experience in each of these domains. Depending on the score, the subscale is categorized as: no/limited, low, moderate, severe, and extreme with regard to the experience of each type of abuse.

The subscales are emotional abuse, physical abuse, sexual abuse, emotional neglect, and physical neglect.

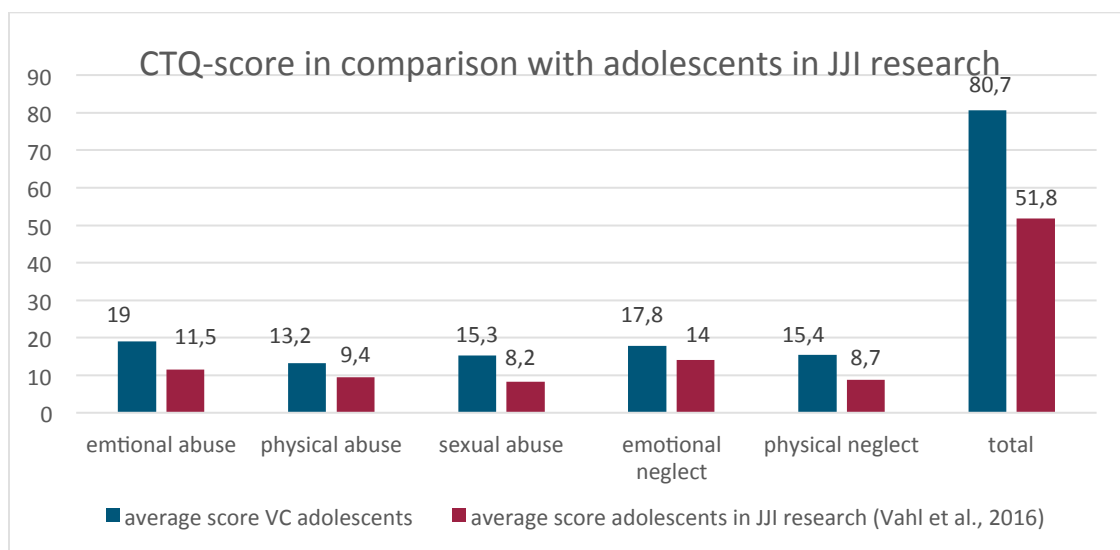
The average score of the CTQ among the adolescents at Van Celst is in the highest category with regard to experiences of abuse and neglect for each of the domains, apart from emotional neglect (see Figure 16). On the scale of emotional abuse, 79% of adolescents at Van Celst have a score in the “severe-extreme” zone. On the scale of emotional neglect, where the average score is just below the threshold for serious-extreme neglect experiences, 58% of the adolescents still score above the highest threshold. On the scale of sexual abuse, 89% of these adolescents have a score above the “moderate-severe” threshold. There is none of the forms of abuse or neglect for which the mean score for the adolescents at Van Celst does not fall at least within the “moderate-severe” range. On the basis of this questionnaire, there appears to be an extremely high incidence of the various forms of abuse and neglect among the adolescents in the facility.

Figure 16. Mean CTQ (Childhood trauma questionnaire) scores for adolescents at Van Celst (n=19)



In previous research, the CTQ was administered to 240 girls in Flemish juvenile justice institutions (Vahl, Van Damme, Doreleijers, Vermeiren & Colins, 2016). As indicated in Figure 17, the target population at Van Celst has more traumatic experiences on all scales, compared to the previous research by Vahl and colleagues.

Figure 17. Mean CTQ (Childhood trauma questionnaire) scores for adolescents at Van Celst, in comparison with previous research among girls in the Flemish juvenile justice institutions



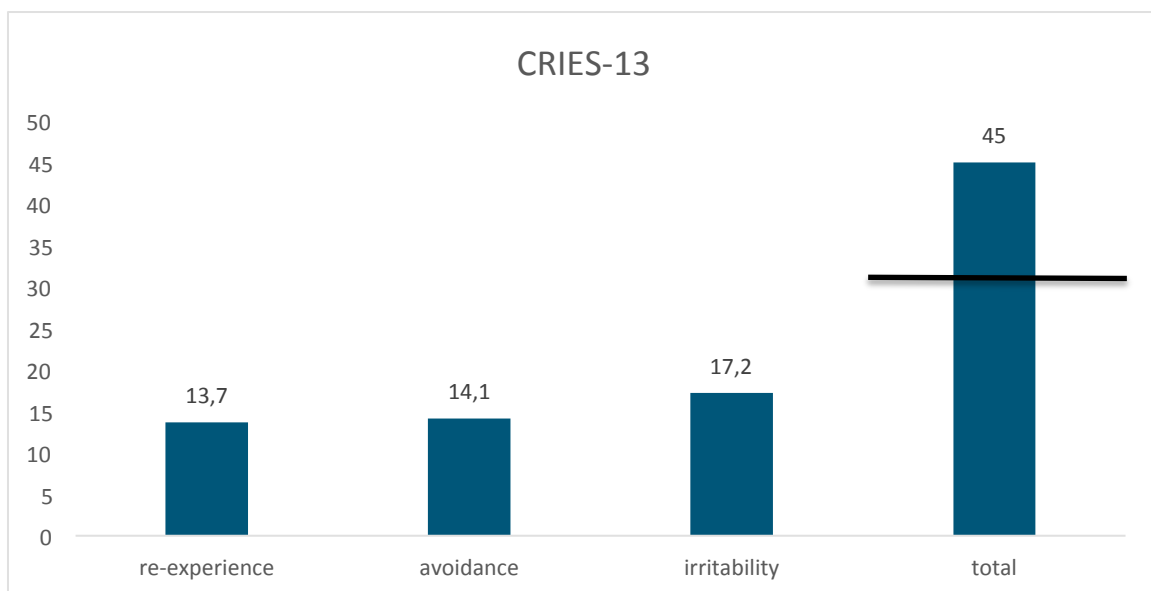
So, the girls of Van Celst have on average gone through more experiences of abuse and neglect than the girls in the juvenile justice institutions included in the previous research.

Children's Revised Impact or Event Scale-13 (CRIES-13) (Verlinden & Lindauer, 1998)

The CRIES-13 (Verlinden & Lindauer, 1998) is a 13-item screening questionnaire for post-traumatic stress disorder. This questionnaire evaluates intrusion, avoidance and irritability. The score on the CRIES-13 can be seen as a continuous score, that is: the higher the score, the more the adolescent suffers from post-traumatic stress complaints. With a total score of 30 or higher there is an increased risk of posttraumatic stress disorder (PTSD) and further diagnosis and/or treatment is recommended.

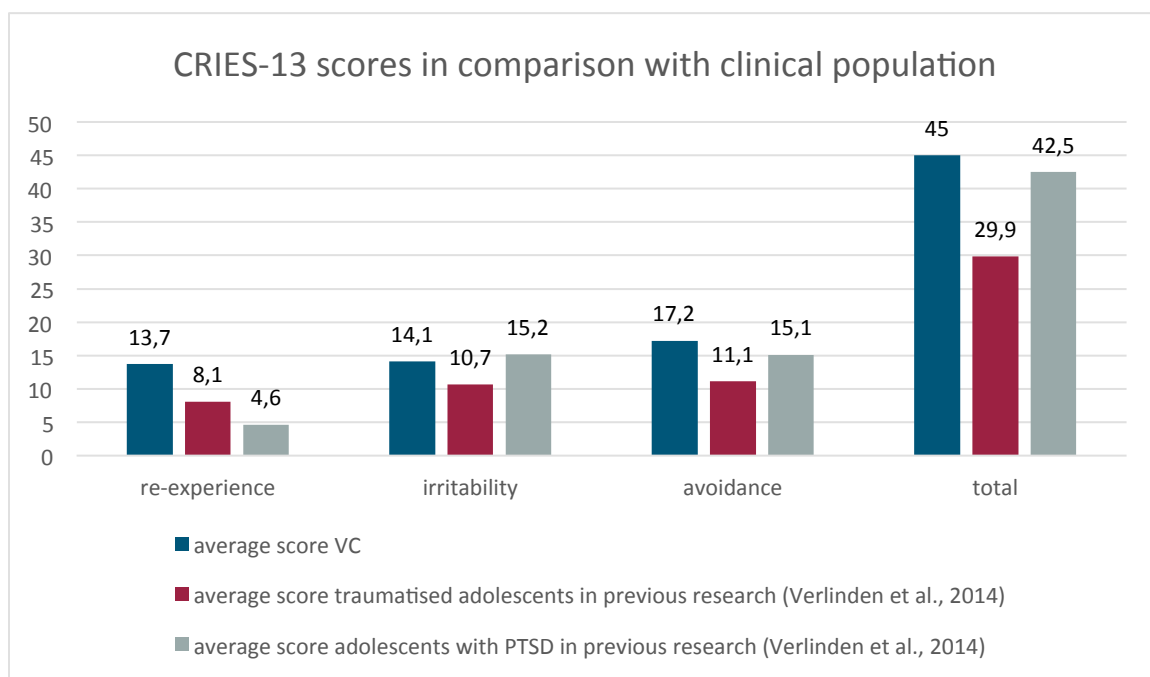
Figure 18 gives an overview of the CRIES-13 average scores of the girls at Van Celst. The average score of the completed questionnaires in the Van Celst research project is 45. This value is well above the threshold of 30, which represents a positive screening for PTSD. Eighty nine percent of the girls who filled in the CRIES-13 have a positive screening for PTSD.

Figure 18. Average CRIES (Children's Revised Impact of Event Scale-13) scores for adolescents at Van Celst (n=19)



In previous research in the Netherlands by Verlinden and colleagues (2014), the CRIES-13 was used among 395 adolescents who had been referred for trauma-related problems. In addition, a diagnostic interview about PTSS was taken from all these adolescents. Based on that interview, 178 of these adolescents had a DSM diagnosis of PTSD. The graph below (see Figure 19) shows the scores on the CRIES-13 for the girls at Van Celst, the entire group of adolescents, with known traumatic experiences, and the subgroup with PTSD (Verlinden et al., 2014).

Figure 19. Average CRIES (Children's Revised Impact of Events Scale-13) scores for adolescents at Van Celst (n=19) compared with group of adolescents referred to CAP because of known trauma



On all three scales of the CRIES-13, which represent the main characteristics of PTSD, the adolescents in the Van Celst research project have, on average, a higher score than the adolescents in the aforementioned research who have been clinically referred on the basis of trauma. When comparing with the group of adolescents in whom PTSD was diagnosed, the total score in the group of adolescents at Van Celst is higher, as are the partial scores for avoidance and intrusion. In 88% of the subgroup of adolescents with PTSD in the previous study, the total score was above the threshold value of 30; for the group of girls at Van Celst this is the case in 89%

Quality of Life

Kidscreen-52 (The Kidscreen Group, 2006)

The Kidscreen-52 is a questionnaire that maps the quality of life of adolescents, in different domains. The instrument has been developed and standardized for both healthy and chronically ill children and adolescents between the ages of 8 and 18. There are different versions for parent and child, but in the research project Van Celst only the self-report questionnaire for the adolescents was used. Although two shorter versions of the Kidscreen exist, this research project opted for the extended version with 52 items. This allows to assess well-being and needs on different domains, regardless of psychiatric diagnosis.

The scales of the Kidscreen-52 are

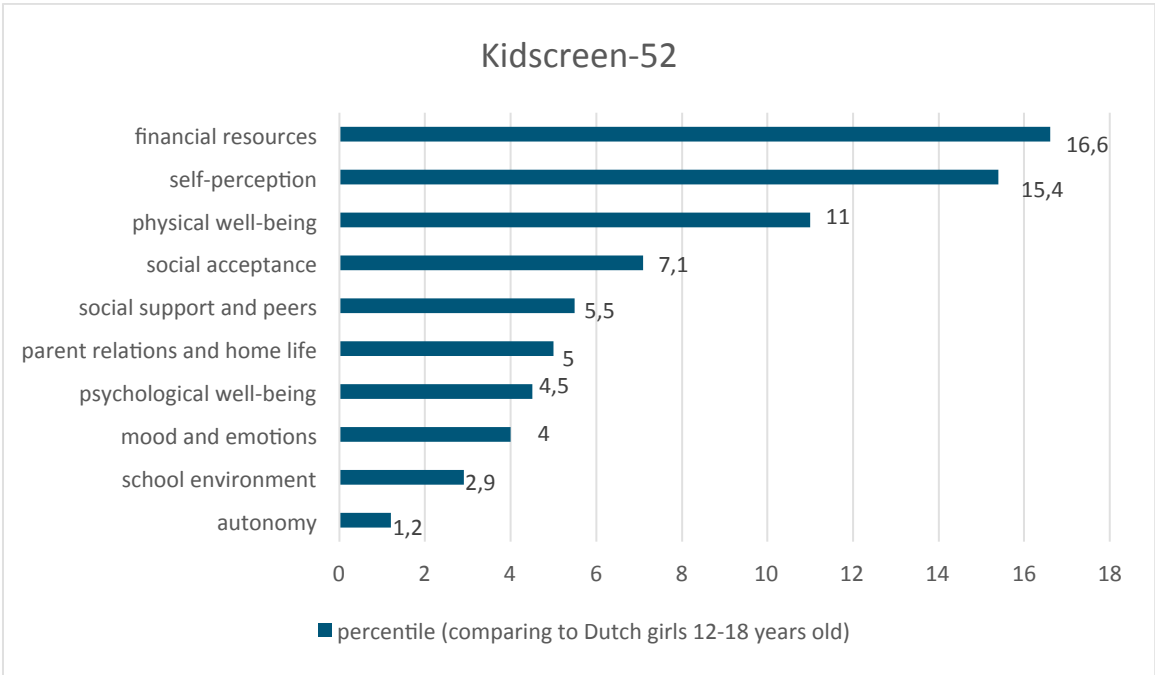
- *Physical well-being*: degree of physical activity, energy and fitness.
- *Positive feelings*: psychological well-being through positive emotions and joy in life.
- *Negative feelings/mood*: negative mood and emotions.
- *Self-image*: perception of oneself, including the body image.
- *Autonomy free time*: to what extent the adolescent can independently fulfill his or her free time and social life.
- *Family and home*: experienced relationship with parents, atmosphere at home.
- *Money matters*: perceived quality of financial resources.
- *Relationships with friends*: the nature of the relationship with other children and adolescents.
- *School and learning*: perception of the adolescent in the field of cognitive possibilities, learning and concentration, in addition to the feelings towards school.
- *Social acceptance*: examines to what extent the adolescent feels bullied or excluded at school.

Figure 20 shows percentile scores per scale of the Kidscreen-52. The 50th percentile is not reached in any of the ten domains, in the participating girls at Van Celst. The adolescents who filled in the questionnaires at Van Celst therefore have a lower quality of life compared to the expectation for adolescent girls in the general (Dutch) population.

On some scales, the quality of life among the adolescents at Van Celst is extremely low. For autonomy, school and internalizing symptoms (mood and emotions/psychological well-being) scores are below the 5th percentile. The highest average scores were found for the scales about financial aspects and self-perception.

It is possible that the low score in terms of autonomy is related to the fact that adolescents have less control over their free time due to their stay in a facility (or juvenile justice institution). The low quality of life in terms of school, mood and relationships (family and friendships) can be interpreted against the background of the further file and questionnaire data that indicate difficulties in these domains.

Figure 20. Average percentile scores for the participating adolescents in comparison with norm group European adolescent girls on Kidscreen-52 for adolescents at Van Celst (n=23)

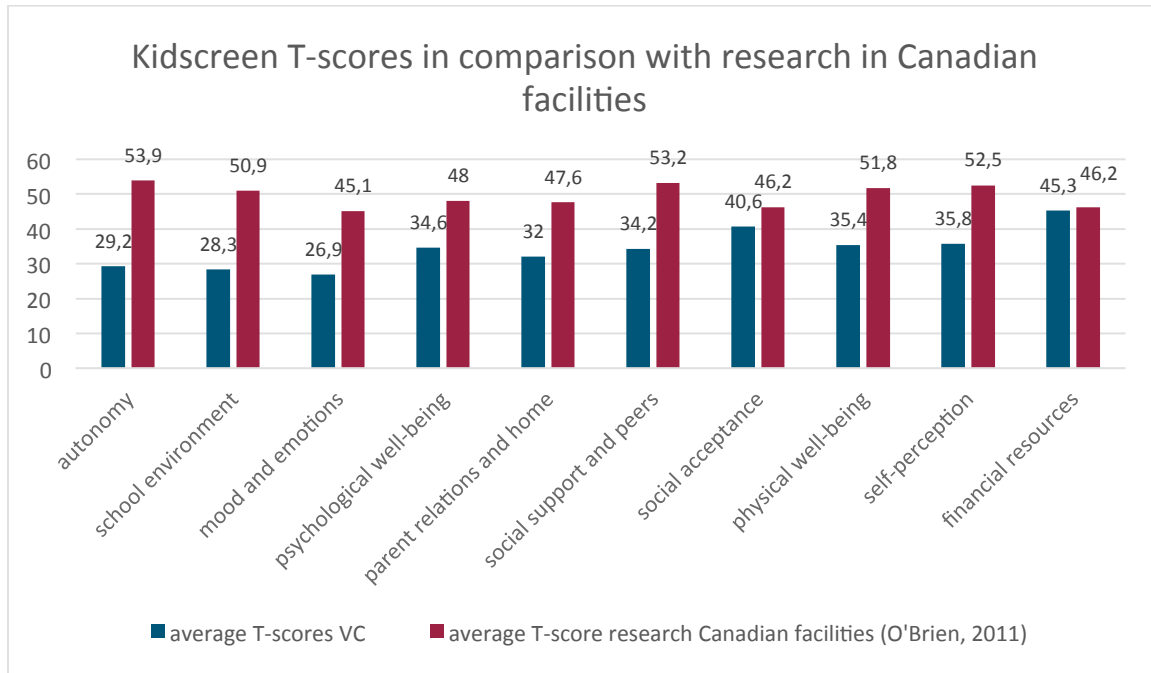


The Kidscreen-52 was used as part of a population screening for depression in children and adolescents in Germany. Characteristics of depression were checked in 1560 adolescents, and quality of life was evaluated on the basis of the Kidscreen-52. The adolescents were divided into groups, depending on their depression scores. There were 248 adolescents who were classified as “high depression score” (Burnside et al., 2008). When the T-scores for the ten domains of the Kidscreen in the latter group (adolescents with the highest depression scores) are compared with the T-scores of the adolescents at Van Celst, it is striking that in all ten domains the scores in the target population of Van Celst are lower. The adolescents at Van Celst therefore have a lower quality of life across the whole range than the above-mentioned adolescents with severe depression scores.

In a Canadian study of 80 adolescents who started in youth care, the Kidscreen-52 was administered (O'Brien, 2011). In all domains of the Kidscreen the target population at Van Celst has on average a lower

quality of life than the adolescents from the CW of the Canadian study (see Figure 21). The difference is most pronounced in terms of school and autonomy/free time; the difference is much smaller in money matters.

Figure 21. Average T-scores Kidscreen-52 scores for adolescents at Van Celst (n=19) compared to youth in youth care in Canadian facilities



In the context of the Youth and Health study, part of the “Health behavior in school-aged children” of the World Health Organization, health-related quality of life was measured in Flanders (Ghent University), among 9,566 pupils and students from the fifth year of primary education to the seventh year of secondary education (56.5% boys and 43.5% girls). The average percentage of Flemish adolescent girls aged 15 or 16 with a low quality of life, defined as a mean T-score below 38 on Kidscreen-10, is 15.7% in the years 2006, 2010 and 2014. On the contrary, this is 74% for the girls at Van Celst (Currie, Nic Gabhainn, Godeau, & Committee, 2009).

Personality

The Severity Indices of Personality Problems (SIPP) (Verheul et al., 2008)

The SIPP is a self-report questionnaire that measures the adaptivity of personality development. The SIPP-118 consists of 118 statements for which the respondent indicates on a four-point scale to what extent he/she agrees with the statement. Scores are generated in five domains and for 16 underlying facets. The 5 domains are:

- *Self-control*: the degree to which the person can tolerate, use and control his own emotions and impulses.
- *Identity integration*: coherence of identity, the ability to view oneself and one's own life as integrated and meaningful.
- *Responsibility*: the ability to set realistic goals and achieve these goals, in line with the expectations that the person created in others.
- *Relational aspects*: the ability to sincerely care about others and to feel valued by them; the ability to communicate personal experiences, and the ability to hear and interact with others' experiences.
- *Social concordance*: the ability to value the identity of someone else, to suppress aggressive impulses to others and to cooperate with others.

There are standard scores for the general population and standard scores for patients who are treated for personality problems. High scores on the facets and domains indicate better adaptive functioning. Low scores point to possible problematic aspects in the field of personality functioning, when compared with the general population or with patients in treatment for personality problems.

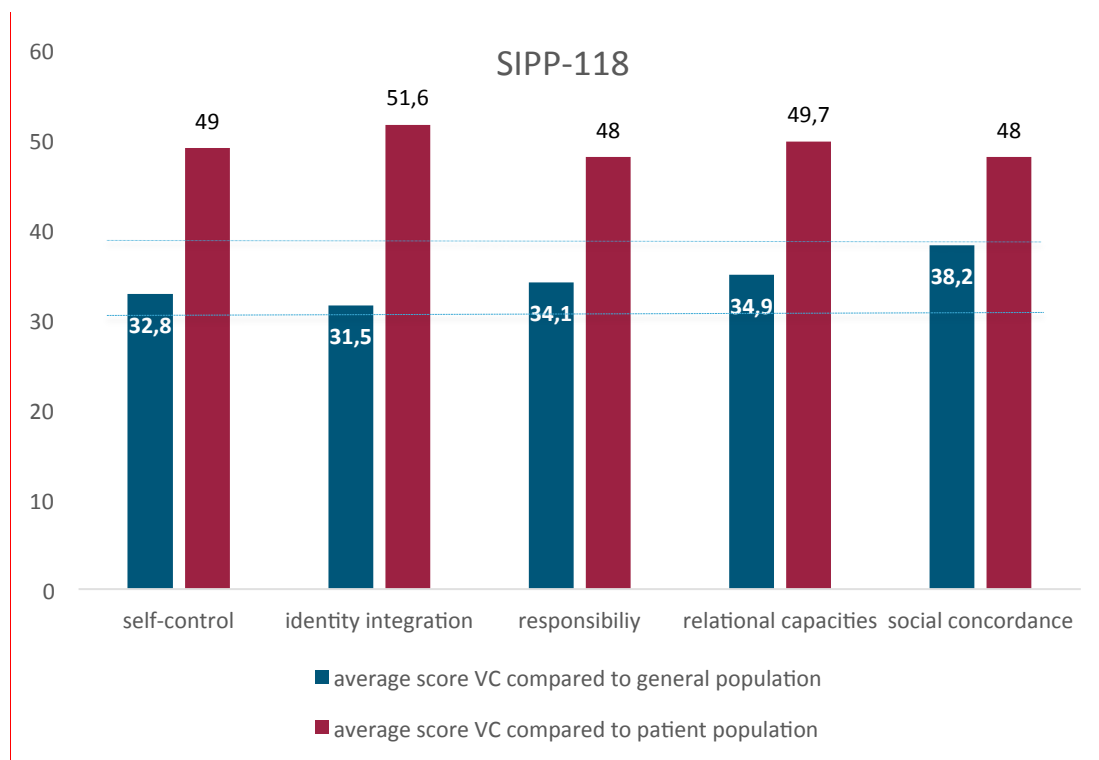
For the participating adolescents, the SIPP-118 scores for all 5 domains show reduced adaptive functioning, when compared with the norm group "general population" (see Figure 22). The domains for which a reduced adaptive functioning is most frequently observed are identity integration (43.5%) and responsibility (39.1%).

In comparison with the norm group of adolescents with diagnosed personality problems, the average score of the target population at Van Celst is not characteristic of impaired adaptive personality functioning. Indeed, when compared with patients with personality problems, the adolescents at Van Celst have on average a more normal, adaptive personality functioning. Only 1/5 of the adolescents have reduced adaptive personality functioning in at least two domains in comparison to the norm group of patients with personality problems (21.7% identity integration; 17.4% responsibility). Almost 1/5 of the girls (17.4%) do not have reduced (or severely reduced) adaptive personality functioning (comparing with norm group and with patients) on any domain.

The SIPP-118 scores in comparison with the general population also give an indication of whether in certain domains there is above average adaptive personality functioning. In the adolescents at Van Celst, however, this is the case for none of the domains.

In summary, the adolescents at Van Celst are vulnerable regarding personality development when compared with the general population, but not when compared with patients with personality problems. 1/5 of the group does not have problematic scores in any of the domains, but 1/5 of the group has a problematic score even in relation to a patient population in certain domains.

Figure 22. Average T-scores for the 5 domains of SIPP-118 (Severity Indices of Personality Problems) for adolescents at Van Celst (n=22), relative to the general population, and compared to a patient population in treatment because of personality disorders. T-scores below 40 correspond to impaired adaptive functioning, T-scores below 30 correspond to severely reduced adaptive functioning (blue horizontal lines)



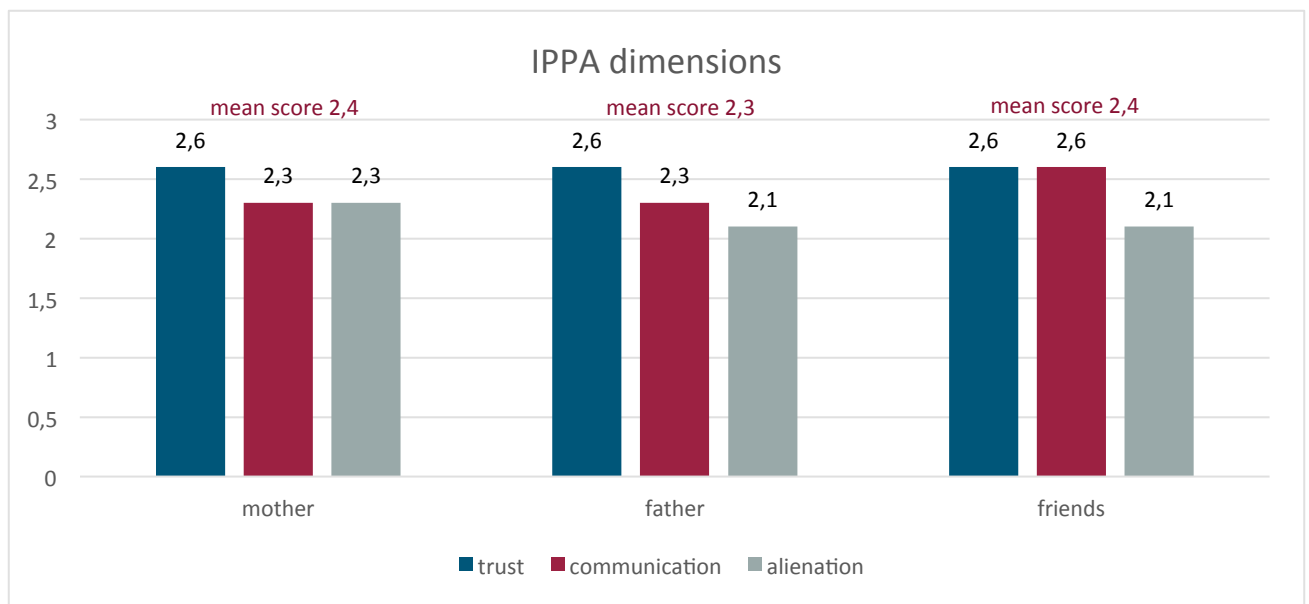
Attachment relationships

Inventory of Parent and Peer Attachment (IPPA) (Armsden & Greenberg, 1987)

The IPPA is a questionnaire that evaluates attachment relationships. The IPPA does not distinguish a certain attachment type, but measures a continuum of secure attachment, with a higher score representing a safer attachment. Attachment is hereby conceptualized as the quality of the relationship with mother, father and friends: the presence of communication and trust and the absence of alienation. The tool describes the

perceptions of adolescents about the affective and cognitive dimension of the relationship with their parents and close friends and gives an indication of how strongly these persons represent a source of psychological safety. The attachment relationship with each of these persons is measured in terms of trust, communication and alienation. For each descriptive statement, the respondents assess the extent to which it represents their current relationship with their mother, father and peers on a four-point scale. The dimensions communication and trust are described as a marker of security in attachment. The items that gauge alienation, on the other hand, give an indication of unsafe attachment (Armsden & Greenberg, 1987). When at group level for the adolescents at Van Celst the attachment relationships inquired into with the IPPA are plotted side by side, the highest score can be found for “friends”, followed by “father” and the lowest score for “mother” (see Figure 23). An important observation was thereby, that four of the adolescents (21%) indicated that they could not complete the questionnaire for their father or a father figure.

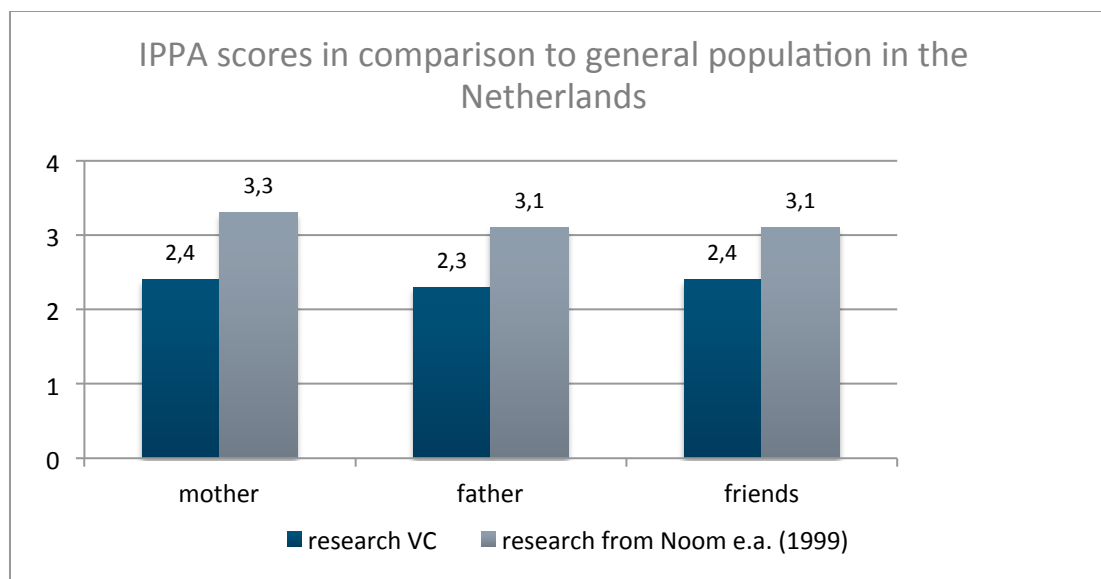
Figure 23. Average IPPA score for adolescents at Van Celst (n=19). for dimensions of trust, communication and alienation



Earlier research among 400 Dutch adolescents aged 12-18 years, in the general population, used the IPPA to study the connection between their attachment relationships and a number of characteristics in terms of well-being and functioning (Noom, Dekovic, And, & Meeus, 1999).

In Figure 24, the results (average score on IPPA, for mother, father and friends) of the adolescents at Van Celst, are compared with the results of that group of adolescents from the general population in the Netherlands.

Figure 24. IPPA scores (mean scores for “mother”, “father” and “friends”) among the adolescents who are enrolled at Van Celst, compared with adolescents in the general population in the Netherlands (511 boys and girls between 12 and 18 years old).

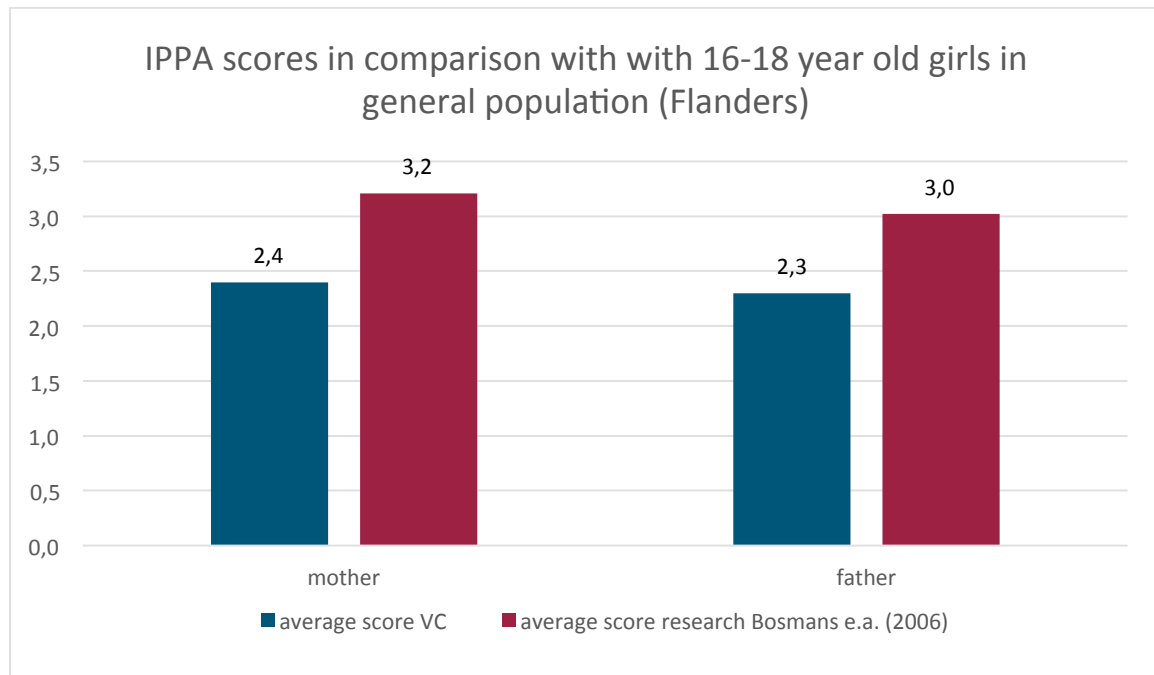


On all three scales, adolescents at Van Celst have lower scores than the comparison group of adolescents in the general population. In the study by Nooms et al. (1999), the attachment relationship with friends is given a lower total score than that with parents, whereas among the adolescents at Van Celst this is not the case. In the research by Nooms et al. (1999), a higher score on the IPPA dimensions “mother” and “father” are both related to better school performance and higher self-confidence. In this area, there may also be an additional vulnerability in the adolescents at Van Celst.

The research by Bosmans and colleagues (2006) in Flanders, also provides data on attachment of adolescents in the general population (Bosmans, Braet, Leeuwen, & Beyers, 2006). The aim of this research was to determine the role of attachment relationships, in the relation between parenting style and problem behavior among adolescents. In this study, both boys and girls (a total of 511 10-18 year olds) completed the IPPA questionnaire. Fifty-six of these adolescents were Flemish girls between 16 and 18 years old.

In the figure below (see Figure 25) their data are compared with those of the girls at Van Celst (the “friends” scale was not used in that study).

Figure 25. IPPA scores (average scores for “mother” and “father”) among the adolescents at Van Celst, compared with 16-18 year old girls in the Flemish general population (56 girls aged 16 to 18 years old)



The adolescents enrolled at Van Celst score the attachment relationship with both their mother and their father lower than their peers in the Flemish general population do. Bosmans et al. (2006) report that throughout all adolescence the quality of the attachment relationship with parents is related to the development of problem behavior. Adolescents who scored lower on the IPPA quality of attachment with their parents, scored higher on problem behavior. This connection may also offer a possible indication for understanding the vulnerability for externalizing problems, which is described in the adolescents at Van Celst.

Care Delivery Intensity

Child and Adolescent Service Intensity Instrument (CASII) (Dutch: IZIKA, Deboutte, 2014)

The IZIKA is an authorized translation of the Child and Adolescent Service Intensity Instrument (CASII) of the American Academy of Child and Adolescent Psychiatry (AACAP, 2005). The Child and Adolescent Service Intensity Instrument (CASII) is a standardized assessment tool that provides a determination of the appropriate level of service intensity needed by a child or adolescent and his or her family. In order to use the IZIKA

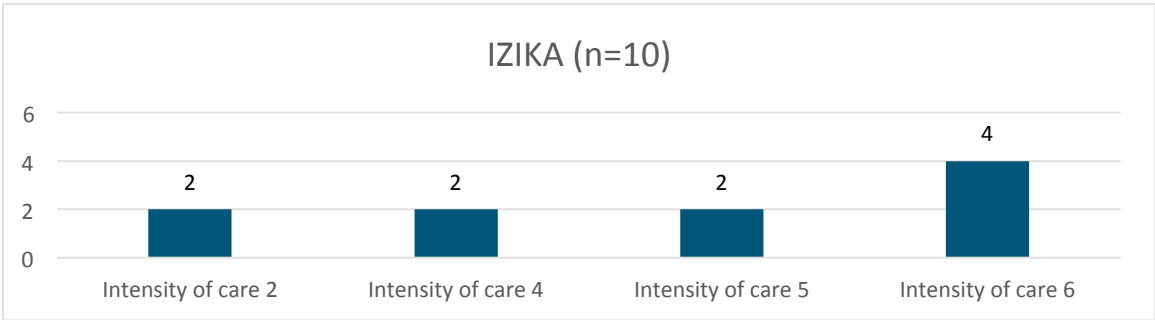
effectively, a good knowledge of the adolescent and his or her context is of great importance. At Van Celst, the IZIKA was scored together by psychologist, individual and family social worker. This happened, for example, at evaluation meetings. The IZIKA incorporates holistic information on the child within the context of his/her family and community by assessing service intensity needed across six key dimensions: Risk of Harm, Functional Status, Co-Occurring Conditions, Recovery Environment, Resilience/Response to Services, and Involvement in Services (Table 6).

Table 6. Care levels in the Instrument to determine the Care Intensity of Children and Adolescents (IZIKA) (AACAP, 2005)

Level 0: basic services for prevention and maintenance. This is a basic package of prevention and health maintenance services that are assumed to be available to all people in the community.
Level 1: recovery maintenance and health management. This level of service is usually reserved for those stepping down from higher levels of care, who need minimal system involvement to maintain their current level of functioning or need a brief intervention to return to their previous level of functioning. Examples of this level of service include: children or adolescents who only need ongoing medication services for a chronic condition or brief crisis counseling.
Level 2: outpatient services. This level of care most closely resembles traditional once/week visits.
Level 3: intensive outpatient services. This level of service can range from a couple of visits per week up to a few hours for three days per week, and may include multiple services (e.g. big brother, church services, mental health services) necessitating coordination (case management).
Level 4: intensive integrated service without 24-hour medical monitoring. This level of care best describes the increased intensity of services necessary for the “multisystem, multi-problem” child or adolescent requiring more extensive collaboration between the increased number of providers and agencies. A more elaborate wraparound plan is also required, using an increased number of formal supports. Additional supports may include respite, homemaking services or paid mentors. In more traditional systems, this level of service is often provided in a day treatment or partial hospitalization setting. Active case management is essential at this level of care.
Level 5: non-secure, 24-hour, medically monitored services. Traditionally, this level of care has provided a safe residence and has including group home, foster care or a residential facility, but can also be provided by a tightly knit array of wraparound services in the community.
Level 6: secure, 24-hours, medically managed services. Most commonly, these services are provided in inpatient psychiatric settings or highly-programmed residential facilities. If security needs can be met through the wraparound process, then this level of intensity of service could also be provided in a community setting. Case management remains essential to make sure that the time each child spends at this level of care is held to the minimum required for optimal care and that the transition to lower levels of care is smooth.

An IZIKA was scored for 10 cases (see Figure 26) during the data collection period. The most frequently recommended level of care was level 6, corresponding to secured, 24-hour assistance under medical/psychiatric management. This indication of care delivery intensity reinforces the impression that care delivery resources and expertise must be optimized for this target population.

Figure 26. IZIKA scores, filled out by professionals for 10 adolescents



Discussion

The Population at Van Celst

This chapter illustrates the profile of the target population of adolescent girls with complex needs enrolled in a collaboration project between CAP and CW. This description was made as a part of a PAR and with adolescents themselves, their relatives, and professionals. The findings were fed back on the group level to all stakeholders and were used to inform and ameliorate care delivery in the collaboration project. The information from the questionnaires was also used to guide individual counseling on the case level.

The needs of these adolescents are situated in varied intertwined domains and reinforce each other: vulnerabilities that can be qualified as “biological” (e.g. physical complaints), “psychological” or broader mental health issues (e.g. poor social network) resulting in difficult integration into society. These result in the need for specialist advice and support, in different domains (from different sectors), for adolescent and context, at the same time.

Regarding the “biological” vulnerabilities, treatment programs for these adolescents should have attention for physical illnesses and ailments. As part of the PAR in this thesis, the biological vulnerabilities were taken into account when planning and developing the medical expertise. Indeed, including medical expertise and coordination of (para)medical interventions including pharmacotherapy seem important.

With regard to the “psychological” needs, specialist expertise from mental health and related disciplines can help these adolescents with complex needs in their well-being and development. As part of the PAR in this thesis a trauma-oriented was valued for these adolescents, who for the larger part have had difficult and/or traumatic experiences in the past. Vulnerabilities in attachment relations and personality development, as well as suicidal thoughts and self-harm should also be addressed. Apart from mental health diagnoses, considering the global quality of life of these adolescents and making personal adjustments can enhance their well-being.

The “social” needs of these adolescents can be met by an extensive context-oriented support in order to help them build a strong and safe social network. (Family) social workers, but also professionals from justice, can assist them in building a support network and integrating into society in spite of the challenges brought about by broken homes, difficult socio-economic background or restraining orders. As part of the PAR, results of these findings were fed back to the stakeholders. Discussions that came out these feedback sessions suggested that input from school counseling services would also be very valuable for this group of adolescents, as the vast majority of them were found to have important difficulties regarding school.

A second aspect of the profile is the challenging interaction with services, with most importantly an impressive discontinuity in care delivery up to the enrollment in Van Celst.

The global profile described in this chapter indicates the intensity of needs of the target population at Van Celst. This profile was used to formulate focus points for the support of this population and to guide the further development and adjustment of the collaboration project at Van Celst. For professionals, this profile illustration acknowledged the complexity and intensity of needs they perceive. A finding that differed from clinical perception was the severity of trauma- related issues rather than personality disorders. As a consequence of this target population profile, a more trauma sensitive approach was installed.

Conclusion

The target population at Van Celst has important biological, psychological and social vulnerabilities. The needs are both from the adolescents themselves, and pertaining to their context and care delivery. This calls for collaboration between different sectors in order to address their needs.

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CHAPTER 3

A Multi-Perspective Exploration of the Service Needs of Adolescent Girls With Multiple and Complex Needs*

*Published as

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Abstract

The increasing population of adolescents with multiple and complex needs, who are at the extreme end of a spectrum of case complexity, poses an important challenge to child and adolescent social and health care. Adolescent girls with multiple and complex needs are especially vulnerable and suffer from fragmented care delivery. Yet, their service needs are not comprehensively covered in the literature, especially not from their own or their relatives' perspective. Better knowledge of the necessities of adolescent girls with multiple and complex needs could ameliorate service provision for this vulnerable population.

Our aim is a multi-perspective description of the needs of a group of adolescent girls with multiple and complex needs, as part of an overarching participatory action research. We conducted in-depth interviews with 9 adolescents and 12 (step)parents, and did focus groups with 44 professionals. All participants were involved in a collaboration project between a child welfare residential facility and a tertiary child and adolescent psychiatry hospital, aiming to optimize care delivery for adolescent girls with multiple and complex needs.

Combining all perspectives, we found that the main service needs were: 1. *focus on adolescent–professional relationship*; 2. *agency*; 3. *holistic and adjusted care delivery*; 4. *efficient coordination*; 5. *focus on the individual*; 6. *continuity of care*. Our findings enrich the knowledge about service needs of adolescents with multiple and complex needs and are found to be in line with the framework of needs-led child and youth care characterized by continuous focus on clients' needs, participation in the care process and professionals' displays of needs-led attitudes and skills. We also highlight the importance of integrating the voices of adolescents, their relatives and professionals in research, and care delivery planning and implementation.

A Multi-Perspective Exploration of the Service Needs of Adolescent Girls With Multiple and Complex Needs

Health and social services are challenged by the growing group of persons with multiple and complex needs (MCN). Existing care delivery fails to meet the needs of this population, that is situated at the extreme of a spectrum of case complexity (Burnside, 2012; Keene, 2001; Rankin & Regan, 2004; Rosengard, Laing, Ridley, & Hunter, 2007). Despite the lack of an agreed-upon definition of MCN in the literature, Rankin and Regan (2004) point out that in essence, persons with MCN have needs that are both “deep” (intense, severe) and “broad” (on several interacting domains) (Rankin & Regan, 2004). As such, the population, described in terms of “multitude” and “complexity” of their needs, is very heterogeneous. They span all health and social care sectors, but also the education or justice systems (Katz & Spooner, 2006; Keene, 2001).

Gender and developmental age influence the consequences of the problems that persons with MCN encounter. Adolescents with MCN may have a combination of some of the following issues: (mental) health problems, challenging and high-risk behavior (including aggressive behavior, substance abuse, self-harm, ...), difficulties in relationships and concerns about personality development, a history of trauma, a problematic family situation and/or worrisome contacts with peers, school or work-related difficulties and possible involvement in delinquent activities (Keene, 2001). These issues bring them into contact with a diversity of professionals and often lead to multiple placements (Burnside, 2012). A dimension specific to adolescents presenting MCN is the developmental impact of their issues, which is putting their personal development and integration into society at stake (Miller, Christenson, Glunz, & Cobb, 2016; Stalker et al., 2003). The family situation is of particular relevance in adolescents, as an “impaired protective system” that fails to meet their needs, can further aggravate the impact of existing difficulties (Child Welfare Information Gateway, 2006). Regarding gender, girls in care are known to be an even more vulnerable population than their male counterparts, regarding both psychosocial and physical health and their access to care delivery (Handwerk et al., 2006; Hussey & Guo, 2002).

Residential care can have an important role to play in providing a safe environment and the opportunity to address areas of difficulty for many of the most vulnerable children and adolescents. However, the reality is that adolescents with MCN often face complex and fragmented care trajectories that fail to meet their needs (Burnside, 2012). For decades, there has been an increasing call for the development of a care system that is driven by the needs of the child and his or her family, aiming to respect their dignity and

individual goals, and maximizing self-determination in the planning and delivery of care (Stroul & Friedman, 1986). The three main characteristics of needs-led child and youth care are: 1. a continuous focus on clients' needs, 2. client participation in the care process and, 3. needs-led attitudes and skills displayed by professionals. Needs-led services base provision of care on the users' needs, revolving around the idea that a service has quality when it is able to satisfy the needs of its customers. This approach to services strives for more effective care delivery based on personalized, specific, flexible, multifaceted and differentiated care delivery (Axford, Green, Kalsbeek, Morpeth, & Palmer, 2009; Metselaar, van Yperen, e.a., 2015). Although there is a clear call for the assessment of needs as the basis for developing specific residential care services, the actual situation for young people with MCN falls short of the ideal (Axford et al., 2009; Axford, 2010; Calheiros & Patrício, 2014; Metselaar et al., 2015).

When taking "needs" as a starting point, and when conducting "needs-led" youth care, it is imperative to aim for adequate participation by adolescents and their parents (Calheiros & Patrício, 2014; Currie, 2003; Gal & Duramy, 2015; Soenen, D'Oosterlinck, & Broekaert, 2013). This means actively involving them in treatment decision making, and in planning and assessing services (Koren & Paulson, 1997; Nix, Bierman & McMahon 2009; Metselaar et al., 2015). Participation of service users has the potential to ameliorate care delivery outcomes and to enrich research findings. Indeed, higher levels of participation in residential care are associated with positive outcomes for the placed children as well as their families (Metselaar et al., 2015; Thoburn, Lewis & Shemmings, 1995). Also, service users' views can provide important research insight into mechanisms of care delivery that are not captured in either clinical outcomes alone, or professionals' perspectives alone (Cooper, Evans, & Pybis, 2016; van Bijleveld, Dedding, & Bunders-Aelen, 2015). Yet, specifically the most vulnerable populations, such as adolescent girls with MCN and their relatives, are at risk to be overlooked regarding participation in their own care delivery trajectories, on the policy level (regarding organization and evaluation of services) and when it comes to research projects (Head, 2011).

A concurrent multi-perspective analysis of needs of service users is valuable, as different stakeholders each have unique expertise regarding those needs. The involvement of young people themselves, as well as their families, is essential, since they are the true "experts" in terms of their own needs (Clark & Moss, 2001). Involvement of professionals is equally important, since the manner in which they perceive service users

influences the care delivery practices. Indeed, earlier research in related fields has shown disparities between the perspectives of adolescents, parents and professionals, stressing the value of an all-round evaluation (Garland, Lewczyk-Boxmeyer, Gabayan, & Hawley, 2004; Mason & Gibson, 2004). A multi-perspective evaluation of needs specific to the extremely vulnerable population of adolescent girls with MCN has, to our knowledge, not yet been performed.

The purpose of the present research paper is to describe the needs of a group of adolescent girls with MCN in residential care through the use of in-depth interviews and focus groups and the involvement of adolescent girls with MCN, their (step)parents and professionals in the context of a participatory action research.

Methods

Study Design

This study is a part of a participatory action research (Reason & Bradbury, 2008) aiming to improve care delivery for adolescent girls with MCN. The impetus for the project was the fact that the needs of this population are not comprehensively described in the literature, nor met by currently available services. In line with the participatory action approach, adolescents, their (step)parents and professionals were involved in each phase of the project: deciding goals, choosing methodologies, collecting data, discussing findings (Reason & Bradbury, 2008). Our goal was explorative, aiming to describe the needs of these adolescents as they were expressed by themselves, their (step)parents and the professionals involved in this collaboration project. We aimed to collect extended and in-depth descriptions relevant to our research question by using interviews and focus groups. We opted for in-depth interviews with adolescents and (step)parents, because the aim was to understand the individual meaning of given phenomena for them. Also, researchers and participants agreed that individual interviews would prevent participants from being restrained or influenced by the opinions of others, or inhibited by the fact that other participants could hear their contributions (King, 1994). For the professionals, we chose to use focus groups, because after discussing the data collection methods with all stakeholders, we believed the group interaction in these multidisciplinary groups would add depth to the data collected (King, 1994).

Setting

The adolescents who were interviewed in this study reside in a residential child welfare (CW) facility located in Belgium. An innovative collaboration program with a tertiary child and adolescent psychiatry (CAP) service was specifically designed to meet the needs of adolescent girls with MCN. It offers treatment and support to girls aged between 14 and 21 years. Each of these girls has a combination of needs in different life domains (difficult family situation, psychiatric symptoms or disorders including trauma and internalizing and externalizing difficulties, contacts with justice, learning and behavioral difficulties at school, ...). Professionals from CW and CAP take joint responsibility for planning and implementing treatment and support for this population. Table 1 gives additional information about the collaboration project and the center where this study took place.

Table 1. Description of collaboration program following the reporting standards by Lee and Barth (2011)

Characteristics	Description in collaboration project
Outcomes	Treatment: intensive services for mental health and social needs. Providing a stable living environment, offering continuity of care.
Population	Adolescent girls with multiple and complex needs. Referrals in a majority from juvenile court, but also from child and adolescent psychiatry and social services. Ages 14-21. 2 group-based, and 2 independent living programs.
Setting and location	Urban, freestanding home.
Program model	Innovative: Collaboration between child welfare and child and adolescent psychiatry. Milieu: the events of daily living provide opportunity for growth and change. Child welfare approach guided by principles of New Authority ^a and Institutional Pedagogy ^b , whereas Empowerment theory is guiding the overarching organization ^c . Some of the child and adolescent psychiatry interventions are inspired by Dialectical behavioral therapy ^d .

Practice elements	Mental health services offered through very intensive collaboration between child welfare and child and adolescent psychiatry. Independent livings skills, family involvement, educational programming, recreational programming, psychiatric diagnosis and treatment tailored to individual needs.
Staffing	Shift staff, specific training (by child psychiatrist).
System influences	Oversight from child welfare and mental health. Initially project funding.
Restrictiveness	This residential care facility is gated, not locked.

Population

After discussing the participatory action research project during multiple meetings and providing written information, we did interviews with adolescents and (step)parents, and focus groups with professionals who volunteered to participate. All adolescents, all (step)parents and professionals present/involved at the time of the interviews were invited. In this convenience sample, we included 9 adolescents and 12 (step)parents (9 biological parents and 3 stepparents of those adolescents) for the interviews that were conducted in January and February 2017. The mean age of the participating adolescents was 16.8 years (range 14-19 years) and they had been in the facility for a mean of nearly 2 years. The parents were (step)parents of 8 adolescents and were seen in 4 couple interviews and 4 interviews with single mothers.

We did 6 focus groups with 44 participating professionals. We started in January and February 2016 with focus groups involving the CW and CAP professionals participating in the collaboration project on a daily basis, and continued in September 2016 with the professionals who were referred to as external partners, as a next step in the participatory action research and stimulated by discussions of previous findings with all stakeholders. The sample reflected the variety of professions involved in the collaboration project: residential care workers, family social workers, child psychiatrists, psychologists, team coordinators CW, dietician in CAP, juvenile judges, residential care workers from juvenile court, workers from juvenile justice center, general practitioners, and policy makers in youth care. All but two of the professionals closely involved in the project, and 14 out of 20 persons designated by the professionals in the facility as being important external partners, participated. Reasons for not participating were practical impediments (time restrictions, illness).

Data Collection

Data for this study were gathered through interviews with a mean duration of 1h and 15min, conducted by the first author (CAP trainee), with a second researcher (clinical psychologist) present as an observer taking field notes. Focus groups with a mean duration of two and a half hours were conducted by the first author, along with a second researcher (anthropologist) in the observer role, taking field notes; a third researcher joined them for the two focus groups with external partners. Interviews and focus groups were structured around a series of open-ended questions. A literature search and discussions with professionals, adolescents and (step)parents helped in the design of the interview and focus group guide. The interview topics were centered on the needs from care delivery, for adolescent girls with MCN. Example questions were: “What is most important for services to support you?” (adolescent interview); “Are the needs of your daughter met adequately, and what is determining the extent to which this is the case?” (parent interview); “What attitudes and actions are useful in meeting the needs of adolescent girls with MCN?” (focus group).

Interviews and focus groups were audiotaped and transcribed verbatim. We invited each participant to provide any additional information or clarifications that they wished after reading a copy of their transcript, although no changes were suggested. When we had interviewed 9 of the adolescents, we decided that the interviews were rich in details of personal descriptions of their situations, also referred to as “thick description” (Malterud, 2012), while there was considerable variation in the kinds of experiences described, and several participants expressed similar views independently. For (step)parents this was the case after 12 participants (8 interviews). For the focus groups, we had invited all involved professionals after 6 focus groups. For both the interviews and focus groups, interim analyses were done, in order to assess data richness and to guide further enquiry. We increased verification of findings in different ways: the researchers were familiarized with the local culture in the collaboration project (prolonged engagement); the interview guide was discussed between researchers, and interviews were done with one researcher asking questions, one observing and taking field notes (triangulation); interviews were continued until achieving a detailed and in-depth description (thick description); debriefing occurred after the interviews (peer review and debriefing); themes and interpretations were negotiated between researchers (negative case evaluation and peer review); participants had the opportunity to check the transcripts (member checking), and continuous discussion between researchers and with participants in the context of the participatory action research supported researcher reflexivity (author

reflexivity) (Creswell, 1998; Creswell, 2017). With these steps in the research project we also implemented the strategies for rigor as described by Padgett (2011).

Data Analysis

The researchers involved in data collection, and one additional researcher, did the analysis. We used systematic text condensation, as described by Malterud (2012). We followed the four steps described in this approach of qualitative analysis: (a) all three researchers read and re-read the transcripts to obtain an overall impression and find preliminary themes; identification of themes was conducted separately by the three researchers who then met to discuss and agree on the final themes; (b) each of them identified units of meaning characterizing diverse aspects of the (step)parents' perceived burden and needs, and coded for these, whereas parts of the transcript not relevant to the research question were removed from the analysis; (c) researchers summarized the contents of each of the code groups into a condensate, and (d) re-contextualized the data, writing an analytic text and adding useful quotations. Re-reading the original transcript ensured goodness of fit with the final code groups and themes. Synthesized condensates and their illustrating quotes were translated from Dutch to English and language equivalency was assured through review by a researcher fluent in both languages. We used NVivo-11 (QSR International, Doncaster) to assist with management of data.

Ethical Standards and Author Reflectivity

This study was approved by the ethical advisory board of the University Hospital Antwerp/University of Antwerp. Written informed consent was obtained from all individual participants included in the study. All potential participants received a comprehensive information letter and verbal information explaining the purpose and method of the research project, as well as data handling and participants' rights. They had the opportunity to discuss their potential involvement in the project with a member of the research team.

Involved researchers were a PhD student in CAP training, and two clinical psychologists, a child psychiatrist and an anthropologist. As a part of the participatory action design, all researchers were familiarized with the way of working in the residential facility, without being involved in individual cases. Multidisciplinary discussions and close collaboration with all professionals of the CW center throughout the project helped to minimize the potential bias of the authors who have more experience in CAP than in other sectors of youth care.

Results

In this section, the needs of adolescent girls with MCN, that emerged during the analysis of the interviews and focus groups, are discussed. Within these large themes that appeared in each of the three perspectives we assessed (adolescents, (step)parents, professionals), the different accents brought about by each of the participant groups are put forward. Table 2 gives an overview of the main themes. This section is built on analytical texts representing synthesized condensates and illustrated by quotes.

Table 2. Needs

Needs	
Focus on adolescent-professional relationship	<i>Attention and quality time, trustworthy and genuine professionals, feeling respected, bonding activities, focus on attachment, trust</i>
Enabling youth to have agency	<i>Control and power with regard to decisions, information, developing a shared plan of action, empowering, adapting the degree of decision making depending on the case</i>
Holistic and adjusted care delivery	<i>Support for psychological or psychiatric difficulties and daily living skills, broad and holistic focus, collaboration between agencies in order to benefit from their combined skills and expertise</i>
Efficient coordination	<i>Coordination and collaboration between services, briefing of information, planned and coordinated care, efficient and transparent communication, cross-sector coordination</i>
Focus on the individual	<i>Care about the individual, respect their individuality, adapt to the individual needs, needs instead of agencies' offer guide care delivery</i>
Continuity of care	<i>Relational aspect of continuity, placement stability, collaboration between services supports continuity in care delivery</i>

Focus on Adolescent–Professional Relationship

Adolescents. When discussing the service needs of these girls with MCN, “*adolescent–professional relationship*”, referring to the relationship between adolescents and professionals, is a prominent theme for adolescents, (step)parents and professionals alike. From the viewpoint of the adolescents we interviewed, cornerstones in this relationship are the time and attention they get from professionals, the trust they can have in them and the mutual respect in the interaction between adolescents and professional. The adolescents explain that they need *attention, and quality time* with residential care workers, for their wellbeing and in order to process difficult issues. Residential care workers should have enough time to engage in conversations and activities with the adolescents, aside from their administrative tasks. One of the participants suggests that all residential care workers should have one day “without computers” a week, enabling them to spend more time with the adolescents.

When I’m having a hard time, I go to the residential care workers and say “I don’t feel OK at the moment, would you mind having a chat with me?” But they don’t always have the time. And that is hard for us, of course. I can understand it, when they don’t have the time. But it’s hard ... They do, however, try to arrange a moment to spend together that same day. (adolescent interview 1)

To be able to build a good relationship with professionals, they have to be *trustworthy and genuine*. One adolescent explains that all professionals have to “be themselves” and “show what they really feel” in contact with adolescents.

It is so important that you can trust the residential care workers. Because we come from bad situations ... And here you have a really big house, material luxury, but it’s only when you have nice people you can trust, who are genuine, that you can go on in life, progress. (adolescent interview 6)

Feeling respected, valued and cared about is important for the youth–professional relationship and enhances the well-being of the adolescents on a day-to-day basis. One of them explains how the fact that she feels respected and “heard” in the residential unit, lowers her distress.

[The most important thing is] Being respected. Because in my home situation, they didn't really listen to me. It felt like I was talking to the wall. Here, I can ask questions, at last someone's listening to me. That puts me at ease. (adolescent interview 7)

Adolescents name different forms of respect that are important in order to build and maintain a strong relationship between adolescents and professionals.

It is very important that they respect the limits we set. If I say: stay out of my room, they should stay out. (adolescent interview 8)

Some of the participants also mention the importance of respect for their confidential information, which is sometimes difficult to establish in a multidisciplinary team functioning. Whereas some of the adolescents find it beneficial that at team meetings different professionals discuss their case (residential care workers, but also the psychologists and the child psychiatrist), others feel like their privacy is put at stake by such meetings. Another adolescent explains that she feels annoyed because in spite of an area to write down information that is "private" in the files, this information is still available to a large group of professionals.

There is a file "private", but everyone from this service can read it. Then I feel like I'd better keep quiet, because otherwise they're going to broadcast it everywhere. (adolescent interview 5)

(Step)parents. (Step)parents also attribute a lot of importance to the relationship between the youth and their "individual residential care worker" whom they describe as a confidant. Parents underscore the adolescents' ideas in stating that this personal residential care worker should undertake *activities* with them in order to strengthen their relation.

Yesterday, for example, X [daughter] went out, to drink a coffee and eat an ice cream, with her personal residential care worker. That way, they have, like, "bonding moments" with the girls. (parent interview 5)

Besides that, a father told us he finds it very valuable that in the institution there is an adult the young people can turn to anytime, thus also ensuring a more continuous monitoring than would be possible at home.

Being there for them, monitoring, that's valuable – you know in the morning someone's here, in the evening when they're coming back from school someone's waiting for them, at night someone's here. We can't do that at home. (parent interview 1)

Professionals. The importance of the relationship between the adolescent and professionals, as well as the crucial role of *trust* in this relationship, is emphasized in the focus groups as well. The importance of having stable and reliable contacts with professionals as well as a *focus on attachment relationships* in the treatment program are highlighted by professionals. They explain that in spite of knowing how important it is for these adolescents to build a trusting relationship with the people caring for them, personal and contextual difficulties of these adolescents can also complicate this relationship.

The relation, having an attachment figure, is really important for all young people in an institution. But especially so in this group, characterized by attachment difficulties, risk for personality disorders ... It is typical that they seek rejection. But then that's the challenge; we have to keep investing in that relationship. (focus group professionals 3)

Enabling Adolescents to Have Agency

Adolescents. Besides having stable and genuine contacts with professionals, adolescents also emphasize the importance of having *control and power with regard to decisions* made in care. Adolescents wish for services to help and support them to progress towards independence. They want professionals to trust in their ability to contribute to the planning of their care delivery and to offer them support as their independence and self-determination grow. They especially emphasize the importance of talking to the adolescents directly, and of giving them enough information, so they can really participate in the decision-making process. One of the participants told us that she “fought to follow her own path” and wanted professionals to support her during that process.

I never stopped fighting for myself. I was strong, I found my own balance ...Of course, they can help sometimes ... At that time, I called it nagging, when the residential care workers told me what to do, but now I see that it has been useful in some way. (adolescent interview 9)

What is very frustrating to adolescents, is when they do have a forum to report their opinion and vision, but feel that their voice doesn't really have an impact on the decision-making process. Several adolescents describe the experience that their point of view is asked, and that what they have to say is listened to, but that it doesn't change the course of decisions that are made by professionals.

Sometimes, we don't have a lot to say. We can say "In my opinion this should be that way" or "I think that's a good idea", but in reality, you don't have so much impact. (adolescent interview 3)

In order to be able to make their own decisions and be a true partner in the decision-making process, the adolescents have to be well *informed*. For example, to have the opportunity to attend every meeting where their progress is discussed, and to know what is said about them by the professionals on the team meetings.

It helps when I know what they say about me. I want to know if what they say is true. Because if it weren't true, I couldn't defend myself or point out what I want, if I don't know. I need to have all the information about myself in order to decide what's best for me, that makes sense, doesn't it? (adolescent interview 5)

(Step)parents. (Step)parents confirmed the importance of asking the opinion of their daughters and informing them, but put the emphasis on coming to a *shared plan of action*, between adolescents, parents and professionals.

That's the goal, having a shared plan with X [daughter] and everyone around her; we, and all the professionals. (parent interview 1)

For the (step)parents, in analogy with what their daughters mentioned, being involved in decisions about treatment planning is very important in ensuring their agency and motivating them for therapy.

They explain the possibilities to the adolescents who might benefit from therapy or from seeing a nutritionist for example. Those who want to engage themselves go to some sessions, but they're not forced to ... Having a choice and being involved in the planning helps lowering the threshold for therapy and giving them some decision power. If they don't want to go they don't, but the door is open and they know that. (parent interview 2)

A few of the (step)parents highlighted that they prefer a *strict approach*, leaving less room for decision-making by the adolescents, especially about sanctions. One couple of (step)parents illustrates this with regard to the decisions of the juvenile judge.

- In our opinion, the juvenile judge and the facility should be stricter, not giving them [the girls] so much space to do their own thing. Like "if you run away one more time I guarantee you'll be locked up in the juvenile justice facility for three months"

- Yes, and not saying "you get to choose an alternative", because the girls know that very well. (parent interview 3)

Professionals. The professionals describe how adolescents can be *empowered* when care delivery reinforces them in making their own decisions about their care trajectory, or when they can be engaged in evaluating care delivery. Thanks to the involvement in care delivery decisions and the agency over care delivery that is gradually built, some of the adolescents are strengthened enough to start investing and taking more control in other aspects of their life as well, e.g. building a supportive social network.

They take their life back in some way. They get to decide to start doing things themselves, figuring out what they want to do in life, start making plans again. (focus group professionals 6)

An exchange between a psychologist and the CAP illustrates that some of the professionals stress the importance of staying aware that the *degree of decision-making* must always be considered in each specific situation and with the best outcome for the youth in mind.

- *Most of them, if you let them decide, they wouldn't go to school, that's not in their best interest.*

- *That's true, but that behavior is kind of age-appropriate in a way ... And you can let them join the decision-making on certain aspects of the topic school. (focus group professionals 3)*

Holistic and Adjusted Care Delivery: Psychiatric Difficulties and Integration into Society

Adolescents. These adolescents need support for dealing with *psychological or psychiatric difficulties* in order to feel better and to cope with difficult situations in the past. Equally important, they need help for *daily living* skills to facilitate their integration and functioning in society. One of the participants explains from her personal experience that psychiatric assistance is not available everywhere.

[We need] Psychological or psychiatric support, because all children who have lived this kind of life, have psychological difficulties. And not every residential facility can offer the right support. The last institution I stayed at, they didn't understand these issues and they didn't know what to do. They couldn't understand that I needed help with the panic attacks and stuff. (adolescent interview 6)

Another girl details some of the domains in which practical assistance from the CW staff is useful. She feels it prepares her for the rest of her life.

Everything that you learn here is useful. I mean living alone, finances, documents, to make your appointments; they help you with these things (...). If we didn't have that and would go straight to living alone, we wouldn't cope. (adolescent interview 2)

The close collaboration that exists with the general practitioner is also important in this holistic approach of needs. Some adolescents explain that they have different illnesses or aches, and take medication from several different doctors. Another girl points out that at home, they were sometimes afraid to go to the

doctor, while now they have a good contact with the general practitioner associated with the residential center.

I think they are better off here, because the girls who, when they are ill – I think also in their home situation – were a bit scared to ask to go to a doctor ... Like me, I was always scared to ask that, and now I have so many ailments, so much pain that I take painkillers that aren't even prescribed. (adolescent interview 5)

(Step)parents. A *broad focus* for treatment and support regarding both psychological well-being and societal integration is essential in order to ameliorate their current well-being and their chances in future life. Some (step)parents explain that help with daily living tasks, as well as psychotherapy and medication, is sometimes needed for their daughter. A father explains that his daughter benefits from the fact that in this facility, help from both CW and CAP are combined.

At this moment, it wouldn't work with only CW and it wouldn't work with only CAP. Because she needs the psychiatric support and she needs a stable living environment. (parent interview 2)

One of the mothers highlights the importance of tailoring services to accommodate the multiple needs of these adolescents and gives an indication of the balance between providing enough monitoring and learning independent living skills.

They have to do their best to offer them the tailored help they need, therapy or medication for example. X [daughter] for example got a new medication recently. But I don't know if she takes it every day. Now that she is learning more independent living skills, they don't check that every time I think. But maybe they should (...) I feel when she doesn't take it, she has more negative or aggressive emotions. (parent interview 5)

Another mother puts the emphasis on the benefit of not focusing only on the psychiatric issues, but rather on strengthening these adolescents and teaching them to integrate into society.

It is important not only to look at the problems, but also to teach them how to cope with their psychiatric vulnerability. Teach them to accept it and to integrate into society, rather than hiding behind the problems. They should teach them to take each other into account, and to take responsibility for their actions and the consequences. (parent interview 6)

Professionals. This population is extremely challenging for care delivery. In order to be able to meet the interrelated and intense needs of these adolescents, the *expertise and skills of different agencies* are necessary. When needs guide the development and implementation of services, every agency can contribute in order to establish a complete, holistic care delivery for the adolescents. In this respect, the fact that the CW residential unit collaborates with CAP is a major advantage.

The fact that CW and CAP are working together is really valuable, because it can offer these girls what they really need. They can have stability and the whole CW support, staying here in the facility residentially and not in psychiatry, yet they are also offered intensive psychiatric care. They need a stable living environment because they can't reside at home, and they also need psychiatric support, but it doesn't have to be chronic psychiatry in a psychiatric institution. Then it is a lot better to keep them in a more "normal" living environment, from where they can go to school, learn to live together, learn the daily living skills, and thus try to build their own and normal trajectory. (focus group professionals 3)

Efficient Coordination

Adolescents. *Coordination* between the residential facility and other agencies is of great importance. For example, the close collaboration between the facility and the general practitioner, or having special educators in school who are assigned to manage the coordination between school and residential facility, are perceived as helpful. One participant explains the benefits of having a reference person managing the communication between the school and the institution.

That would be great to expand further, that every youth in an institution automatically has a pupils' coach at school. Via such a pupils' coach the collaboration between school and institution is automatically better. This means that there is more communication between institution and home and school and that in school, they can better understand where we come from and what we need.
(adolescent interview 3)

Accurate *briefing of information* between professionals is very important in order to avoid practical difficulties such as missed appointments, or negative outcomes for health (e.g. wrong medication scheme) or well-being (e.g. incorrect information about contacts with family).

If they report the information correctly, then there is no problem. I have the biggest issue with the fact that they don't pass on information correctly. Like, when my mum needs to be here, half of the time she knows it through me. Or when they come and say hey, you have an appointment and I'm like "what appointment?" (adolescent interview 4)

(Step)parents. (Step)parents also call for efficiently *planned and coordinated* care along with clear communication. It is reassuring to them, to feel there is a solid theoretical base for the decisions made by professionals. The plan needs to be sufficiently proactive in order to maximally avoid the need for urgent decisions.

You want to know their reference frame, from what theoretical or maybe philosophical base they start (...). They should ask in advance, like, if we were in that situation, what would be your wishes or what do you think should happen ... because up to now we've had brusque changes and then everything has to be decided quickly and you don't have the time to think about it. (parent interview 8)

Efficient and transparent communication is associated with having a good relationship with professionals. A mother explains that she can communicate openly and efficiently with her family residential care worker, because she has built a trusting relationship with her. Another aspect of what parents label as efficient care, is *collaboration between the different agencies* that are involved. The need for this coordination

is related to the complexity of service needs in this population. A mother explains how she feels that one “common plan” should be made, involving the adolescents, their (step)parents, and all different professionals who are involved. She says that such a “common story” is necessary to centralize all information. Another couple of (step)parents is disappointed and say they don’t understand why information is lost in between agencies.

We thought that a comprehensive file of X [daughter] existed and every place she went to, the file would be taken along. But that is not the case! “We didn’t have that information”, they said a few times, because they don’t have access to the files of previous placements. In that perspective, I find that the collaboration should improve. (parent interview 1)

Professionals. Due to the problems of these adolescents and the variety of sectors involved, cross-sector coordination and collaboration is necessary in order to achieve good care delivery. A residential care worker from the CW institution explains how working together can minimize the information loss.

I think if the care is not coordinated, a lot of information is lost. And that happens here also, but I think the loss of information here is less than in other agencies, where they don’t collaborate and don’t have joint team meetings. Here the communication is easy, on the phone or via mail. It’s not going perfectly, but the threshold is lower. (focus group professionals 1)

A juvenile judge notes that from her perspective, when services across sectors work together in a planned manner, this really helps to meet the complex needs of these adolescents.

For us, as juvenile judges, it gave us hope that they work on collaboration and coordination, because a lot of adolescents have pedagogical, behavioral and parenting issues in their context, but also psychological, emotional problems. Before, it wasn’t coordinated; it was more like referring to each other and also trying to shift the responsibility to each other. (focus group professionals 5)

Focus on the Individual

Adolescents. The adolescents highlight the importance of care delivery that is focused on the specificities of each person and their needs. Feeling respected as an individual is important in this needs-led approach.

Here, it's not the same approach for everyone. I think that's positive, because we all have our own problems and we have different family situations. So, I think it is important that they focus on what every one of us needs in particular. (adolescent interview 5)

(Step)parents. In order to tailor care delivery to the needs of their daughter, several professionals from different agencies have to be involved at the same time. (Step)parents also emphasize it is very important to *adjust the care to the individual needs* of each girl. Also, adolescents and parents should feel that professionals are interested and believe in each specific girl as an individual.

Most important is that they believe in the individual child, that they see the individual that she is, not give them all the same treatment. That was a really good thing. (parent interview 7)

Professionals. A common and highly integrated approach, where the *individual needs of each of these adolescents guide the care delivery*, is most valuable. Needs, instead of the agencies' offer, determine how care delivery is organized. Professionals want to form a joint network around each of these adolescents, in order to achieve a tailored care. This focus on each girl as an individual is motivating and creates a sense of shared responsibility and engagement.

Everybody who's working here is truly engaged to help these girls. That is what is bonding between professionals. Putting all pieces together for a girl, every caregiver coming from their trajectories and discipline and expertise and tasks. And I find it works out fine when you're working with that common goal: the well-being of these girls with very complex problems. (focus group professionals 1)

Continuity of Care

Adolescents. The *relational aspect of continuity* of care, the importance of continuity in contacts with people they know is put forward. The participating adolescents emphasize it causes distress when they have to get to know new professionals and learn to trust them. New professionals need some time to “adjust” to them and to “know how they function”. Interruption of contact with professionals is distressing, for example when they change psychologists or individual residential care workers, or when students or people with temporary contracts leave the facility.

When new residential care workers first start working here, that is ... more difficult of course, because you have known the others for years. So, they have experienced your whole trajectory. New residential care workers, in the beginning, they don't know how we function, all that stuff. (adolescent interview 1)

Along with this, more continuity in contact with caregivers helps them to make decisions in the young persons' best interest.

At each team meeting, someone from CAP is attending, and she [child psychiatrist] has known me for a very long time. So, it helps that she knows all that, and can have an input when they decide things. (adolescent interview 5)

Adolescents explain that an important moment where this continuity of care is put at stake, is during the time-outs, periods of time the adolescents spend in a juvenile justice institution, or any other facility, in case of a difficult situation (running away, aggression, conflict) in the residential facility. Some of the adolescents relate the experience that professionals come to visit them and find this very positive, others have missed out on this continuity of contacts and found it distressing.

Contact during time-out is important, because – I've also been a few times in time-out – the residential care workers came to visit. They came to see how I was doing and I could call them also. I found that very good. (adolescent interview 8)

(Step)parents. (Step)parents mostly highlight this last aspect and talk about the longer stay in one facility, *placement stability*, and relate this to the residential facility “not giving up and throwing them out”.

It has been two years, no, three – because they don’t give up. She’s been in 32 facilities before ... That is the positive thing here, they don’t give up on the adolescents. Where others give up, they keep on going, and I appreciate that. (parent interview 5)

Professionals. Professionals put the emphasis on *continuity of placement*, but also include *relational aspects*. They explain that the collaboration between CW and CAP enables them to enhance the continuity of care, by sharing resources and responsibilities. One of the professionals explains how continuity of care, resulting in longer trajectories in the same setting, is beneficial to the adolescents, as it provides them with a safe basis from which they can proceed to therapy when necessary.

The fact that we can offer long trajectories, thanks to the collaboration, makes that we can work towards creating a safe haven here. It is a safety that they experience from the residential care workers – in fact you are trying to give the youth a safe base (to go to therapy). (focus group professionals 2)

Continuity of care can contribute to enhancing control and agency. By offering adolescents stability, their sense of control seems to increase.

We notice that these are the girls that are really damaged and hurt. In the past, before you knew, they were gone again, so you couldn’t establish that connection. Whereas now, we see that a lot of these girls have been here for 3–4 years now. Nearly adults, you see them become proud and take control. Like, hey I can do it, I’ve been in so many residential facilities but this one will be the last one, I really go for it this time. (focus group professionals 6)

Discussion and Concluding Remarks

The aim of this study was to explore the perception of adolescents, (step)parents, and professionals regarding the needs of adolescent girls with MCN. Interviews and focus groups yielded the following themes: 1. *focus on adolescent–professional relationship*, highlighting the importance of contact, trust and respect in the relationship between adolescents and professionals; 2. *agency*, pointing out the importance of giving the adolescent a sense of control, by providing transparent information and letting their voice have an impact on decision making in care delivery; 3. *holistic, adjusted care delivery*, tailored to the multiple and specific needs of this population, namely the domains of stability and focus on daily living skills, together with support for psychiatric and medical issues; 4. *efficient coordination* between services, with transparent communication and a clear plan of action; 5. *focus on the individual*, with the well-being and development of each youth with their specific needs as the core of the common efforts of all involved professionals; 6. *continuity of care*, aiming for avoidance of ruptures in contact with professionals, and striving for placement stability.

Starting from these findings, it is interesting to consider the contrasts between the perspectives of adolescents, their (step)parents, and professionals; to consider the analogy between our main themes and the principles of needs-led youth care; and to reflect upon shifts in the care delivery approach that could be valuable in optimizing services for the most vulnerable populations.

Contrasting Findings from Different Perspectives

Globally, the same themes were mentioned by each of the participant groups. However, for some of the themes, they discussed different aspects and their perspectives diverged.

For example, regarding agency, the adolescents wanted to maximize their input and influence on the decision-making process. They viewed the care delivery system as useful when it supports them while they “follow their own path”, rather than taking control. Professionals acknowledged the value of increased agency for the development of these adolescents, but also insisted on a case-based approach where the extent to which decisions could be made by the youth, vary depending on the specific situation. Some of the (step)parents would prefer the care delivery or justice system take more control, whereas others shared the opinion of the adolescents.

Although the importance of achieving more continuity of care was emphasized from all perspectives, different aspects of this concept were highlighted by adolescents, (step)parents or professionals. The

adolescents mainly stress the importance of continuity in contacts with people they know (also while residing in the same facility), while (step)parents emphasize the aspect of placement stability and professionals mention both aspects.

Analogy with Needs-Led Youth Care

Our findings are found to be in line with the concept of needs-led youth care (Metselaar et al., 2015). Therefore, our findings could assist in planning and implementing needs-led services for this specifically vulnerable population

Focus on Clients' Needs. The themes *holistic and adjusted care; focus on the individual; continuity of care, and efficient coordination* reflect different aspects of the necessary focus on the adolescents' needs. Concerning the need for *holistic and adjusted care* and the *focus on individual needs*, all parties agree that it is specific to this target population that needs exist both in a "CW" and a "psychiatric-medical" domain, and that due to the diversity and variability in needs, services should be tailored to every specific situation. Overall, the literature certainly endorses this need for a full range of service options for those with MCN. While good practice has emphasized the value of community-based models of care, residential care services may be relevant for some of the most troubled groups (Rosengard et al., 2007; Burnside, 2012).

All parties also point out the importance of *continuity in care delivery*. Earlier reports state that the importance of continuity is greatly underestimated, for example in maintaining links with previous caretakers and other people who matter to the child. Jackson (2002) describes that wider issues of stability have been confounded with the question of placement breakdown, and warns that confounding of the need for stability with issues around placement breakdown, can be argued to have been a major impetus in the move towards permanency planning (Jackson, 2002).

In our findings, all parties agree on the necessity for *efficient coordination*, including fast and clear communication and designing a proactive care delivery plan. Earlier research relates this need for clear and efficient service delivery to the agency of adolescents. Indeed, unreliability in terms of commitment to appointments, and unclear communication about expectations, make a considerable contribution to young people's feelings of powerlessness (Mason & Gibson, 2004).

Participation. Our findings regarding the need for agency are in line with the growing literature and policy attention directed at participation and agency of adolescents in care. The right of children and young

people to have this need for agency met through participating in decision-making about their own lives, has long been recognized by children's rights advocates (United Nations, 1989) and is an integral part of the policy of needs-led youth services (Metselaar et al., 2015). Earlier research found that children take seriously their right to be involved in decisions that affect them, as reflected in the research project of Mason and Gibson (2004), in a high attendance at decision-making meetings for children in care (Mason & Gibson, 2004). In line with the vision of professionals in our study, Scannapieco, Connell-Carrick and Painter found that engaging youth as planners for their own lives is important because it embraces their ability to make decisions and affirms their capacity for self-sufficiency (Scannapieco, Connell-Carrick, & Painter, 2007).

Significant benefits are attributed to increased client participation and agency in youth care (Metselaar et al., 2015; Vis, Strandbu, Holtan, & Thomas, 2011). Vis et al. (2011) describe a strong link between the potential benefit of enhanced decision-making by adolescents, and another of our themes, *relationship between adolescents and professionals*. In order to benefit from increased participation, children need to successfully form a relationship with someone who can explain, give information, and is open to the child's own agenda (Vis et al., 2011). As such, the relationship between child or youth and residential care worker is one of the main factors facilitating agency and participation (van Bijleveld et al., 2015).

Professionals in our focus groups also highlighted the importance of adapting the degree of participation to each specific situation, in the best interest of the adolescents. Indeed, full participatory roles and responsibilities are not feasible or necessary in every situation (Head, 2011).

Needs-led attitudes and skills of professionals. The statements regarding the importance of the *adolescent-professional relationship* in residential care are in line with earlier research reporting about the contact between adolescents and professionals in residential care. In a study on young people's and caretakers' perspectives on the mental health needs of adolescents in care, young people emphasized the importance of availability and continuity of staff in describing what they valued in their relationship with professionals (Stanley, 2007). Soenen and colleagues (2013), who explored the perspectives of children and adolescents in a residential center for emotional and behavioral disorders, confirm this importance of close and stable contact with professionals (Soenen et al., 2013). They report that relationships can be built through, on the one hand, doing fun activities with staff, preferably on an individual basis, and on the other hand, attention and communication as a way to address issues that are difficult for them.

Another theme relating to the attitude of professionals was the wish of adolescents and (step)parents that professionals would focus on their *individual needs* and be interested in them as a person. Adolescents, (step)parents and professionals alike describe that care delivery has to be flexible and tailored to their specific situation. Especially in the care delivery for those with MCN, a comprehensive mapping of strengths and difficulties and a focus on the individual as a whole is very valuable (Burnside, 2012; Keene, 2001).

Practical Implementations. These findings gathered from different stakeholders, fit in the framework offered by “needs-led” child and youth care as described among others by Metselaar and colleagues (2015) and illustrate its principles specifically for the vulnerable population of adolescent girls with MCN. Truly using service users’ needs, rather than agencies’ resources or offer as a starting point, seems the most important recommendation in meeting all needs that were mentioned.

An implication for practice suggested by the different participant groups is the benefit of interagency and cross-sector collaboration in order to meet the needs of these adolescents and their families. They mention collaboration as a strategy to provide holistic care, to enhance efficient coordination, and to enhance continuity of care. But one can also imagine that the adolescent–professional relationship can receive more attention if residential care workers get the necessary support. Even “agency”, can benefit from collaboration, because professionals who have more insight into the functioning of other services, can give the adolescents information that enables them to be more engaged in their care delivery trajectory. The literature highlights that joint working is required at different levels in order to meet MCN (Keene, 2001; Kodner, 2002; Burnside, 2012): at the service planning level (knowing the overall population with needs, and what services are required), and at the level of implementation of care delivery (Keene, 2001; Rankin & Reagan, 2004). Besides needs-focused collaboration, other shifts in the care delivery system may be valuable in order to accommodate the needs of this vulnerable population.

Participation of adolescents, (step)parents and professionals in planning and evaluating services both on the case level and in research, can assist in tailoring services to their needs by combining the unique expertise of each of these groups. In this respect, it is important to be aware that in earlier research youth in care often described that in spite of the existing processes for listening to young people, they felt like their view did not count (McNeish & Newman, 2002) or that their right to express their opinion and influence decision making is not genuine (Mason & Gibson, 2004).

In order to meet the needs on the level of the relationship with professionals, or in a broader context

the stable and fulfilling contact with a reliable adult, and the related need for continuity in care, this must be a specific focus of the care delivery (Soenen et al. 2013). It seems important to limit disruptions in placements, but also disruption of contact during a stay in the same facility (due to work load, reorganizations, professionals' absence, ...). Ensuring sufficient practical and emotional support for social workers could make a contribution in this regard.

Limitations of our study are the fact that our findings may be biased because the adolescents and (step)parents who chose to participate, may not represent the opinion of all those involved. Furthermore, we focused on the needs of the youth in care, but the needs of their (step)parents and siblings need to be assessed and attended as well. The methodology used does not allow for a broad generalization of findings, but rather aims to stimulate reflection processes. A strength is the fact that we could bring together different perspectives about underexplored needs of a very vulnerable population.

In conclusion, in care delivery for adolescents with MCN, the relationship with professionals, enabling participation, and enabling continuity of care delivery in a holistic and coordinated approach, are found to be important from the perspective of adolescents, their parents, and professionals.

In future research and planning of care delivery, it is valuable to involve adolescents and their (step)parents in the exploration of their needs and the evaluation of services.

Compliance With Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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CHAPTER 4

Needs and Preferences of (Step)parents of Adolescents with Multiple and Complex Needs in Residential Care*

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Abstract

The perspective of parents whose children are in residential care, has received only minor attention in the literature, despite evidence pointing out the value of parental involvement in care delivery for their child.

This exploratory study draws upon in-depth interviews with 12 parents of adolescent girls with multiple and complex needs enrolled in a collaboration between residential child welfare and child and adolescent psychiatry. It describes parents' own needs and preferences with regard to care delivery.

Parents of adolescents in care describe their own needs and wishes towards services: (1) to have a true partnership between parents and professionals (involvement), (2) to feel respected by professionals (respect), (3) to have the information and mandate necessary for joint decision making (agency), and (4) to receive consideration and (emotional) support, besides advice on how to handle the challenges their family faces (support).

Their plea draws attention to an aspect of the dimension of "parent-caregiver partnership" in family-centered residential care that deserves more emphasis. Indeed, being attentive to the needs of parents can contribute to the optimization of services for the most vulnerable families.

Needs and Preferences of Parents of Adolescents with Multiple and Complex Needs in Residential Care

The literature about child serving agencies has increasingly recognized the important role of parents when their child is in residential care (Geurts, Boddy, Noom, & Knorth, 2012). First of all, a residential care approach that involves parents is shown to improve both short and long-term placement outcome. Research consistently reports the importance of working with the child and his or her parents and wider family in terms of improving the effectiveness of residential care during the stay (Curry, 1991; Harder & Knorth, 2014; Williamson & Gray, 2011). Studies show that involvement of parents in family therapy is linked to more positive outcomes – e.g., children’s developmental progress, lower problem recurrence, and better transition (adaptation to life after services) – than the residential treatment alone (Frensch & Cameron, 2002; Knorth, Harder, Zandberg, & Kendrick, 2008; Walter & Petr, 2008; Wilmshurst, 2002). Involvement of the adolescent’s family is also considered important for achieving successful outcomes after leaving care, leading to, for example, larger after-discharge stability (Landsman, Groza, Tyler, & Malone, 2001). Regarding child outcomes, the overarching advantage of involving parents in decision-making and implementation of residential care is that it can serve the ultimate goal of reintegration in the family and/or in society (Underwood, Barretti, Storms, & Safonte-Strumolo, 2004).

Second, close involvement of parents can ameliorate the reciprocal perception that parents and professionals in residential care have of each other. Staff attitudes towards parents are shown to become more positive as parents become more involved in close communication, decision-making and day-to-day activities of the children in care, along with viewing parents more as “partners” and valuing their expertise on their child (Carlo, 1988). The other way around, parents are more motivated and engaged in the care for their child if they are invited to share responsibility and to be involved in care delivery (Tam & Ho, 1996).

Third, on a policy level, parents’ perspective may inform policy changes towards more family-oriented approaches in care. Indeed, policy in many countries has highlighted the importance of parental involvement when children are in care, but also recognizes its complexity (Boddy, McQuail, Owen, Petrie, & Statham, 2008; Geurts et al., 2012; Williamson & Gray, 2011). Hence the importance of investigating the parental perspective, that may give valuable insights into the impact of this aspect of care delivery that are not captured in clinical outcomes alone or professionals’ perspective alone (Cooper, Evans, & Pybis, 2016).

As such, the literature clearly demonstrates that parents and close caregivers have a very important and multifaceted role in the residential placement of a child.

Overall, in the light of the implications of family involvement discussed above, there is a need to enrich our thinking about parents of adolescents with MCN in residential care. Authors point out that it is essential to assess the perspective and well-being of parents with children with special needs and to provide interventions to improve health and functioning for both the parents and the children who have these needs (Calheiros, Patrício, & Graça, 2013). To date, research on residential care has focused on treatment outcomes for placed children, considering parents in terms of their impact on the outcome for the placed child, without assessing their own needs (Frensch & Cameron, 2002; Kiraly & Humphreys, 2015).

In Flanders, approximately 0.74% of the population under age 18 is placed in residential services from different sectors of care delivery (among others youth protection services, or services for persons with a handicap) (Agentschap Jongerenwelzijn, 2017). The general vision is that parents and other caretakers must be involved as much as possible when children are in residential care (Departement Welzijn, Volksgezondheid en Gezin, 2012), but to the best of our knowledge there are no guidelines nor comprehensive registration on how parents are exactly involved when their child is in residential care.

As the population of adolescent girls with multiple and complex needs (MCN) is among the most challenging in residential care, investigating the perceptions of these parents seems interesting in order to enrich the knowledge on parents' expectations towards services. Adolescents with MCN have profound and intertwined needs on different domains, such as a family situation that lacks safety and stability, different psychiatric problems (including emotional and behavioral difficulties and substance abuse), severe school problems, and peer contacts that negatively influence their safety or development (Burnside, 2012). These adolescents are at the extreme of a spectrum of case complexity and have contact with a variety of professionals and agencies. As their needs exceed what each individual sector can provide, these complex cases are passed on from one agency or facility to the next, resulting in very fragmented care delivery (Burnside, 2012; Keene, 2001).

The aim of this research project is to add to the understanding of the perceptions of parents of adolescents with MCN in residential care, exploring their own needs from services in a series of in-depth interviews. Enhanced knowledge of parents' needs and preferences in care delivery can inform practice and policy making regarding this aspect of family-centered care delivery (Law et al., 2003).

Methods

Study Design

This study is a part of a participatory action research that aims to improve care delivery for adolescents with MCN. Adolescents, their (step)parents and professionals were involved in each stage of the project, guided by the different phases of participatory action research (Reason & Bradbury, 2008). We draw upon in-depth interviews in order to explore the perceptions from 12 (step)parents of these girls. As our interest was to gain insight into the needs of these (step)parents, a qualitative descriptive approach was chosen, amenable to obtaining straight descriptions of events, and suitable to explore questions of special relevance to practitioners and policy makers (Sandelowski, 2000).

Setting

We recruited the (step)parents who participated in this study in a child welfare residential center located in Antwerp, Belgium. This facility offers residential care for girls aged 14-21 years who have MCN. All of them have been placed by juvenile court multiple times before this placement.

Population

Potential participants were (step)parents or other non-professional caregivers of adolescents with MCN. We used convenience sampling and included 12 participants (9 biological parents and 3 stepparents; 4 of them in couples and 4 single mothers). All of them were (step)parents representing 8 girls enrolled in different intensity levels of the residential care. In total 8 interviews were conducted, four of them with a couple of (step)parents and 4 with single mothers. The mean age of the (step)parents we interviewed was nearly 39 years.

Data Collection

Data for this study were gathered through interviews with a mean of 75 minutes in duration, conducted by the first author (child and adolescent psychiatry trainee) and a clinical psychologist. No themes were predefined in the interview guide. Examples of interview questions are: what is helpful in care delivery for you, as a parent? What is important for professionals to know, concerning the needs of parents who are in your situation (having a child in residential care)? Interviews were audiotaped and transcribed verbatim. We invited each participant to provide any additional information or clarifications that they wished after reading a copy of their transcript. Nevertheless, no additions or changes were made. When we had interviewed 12 informants, we stopped the sampling, because the interviews were rich in details of participants' descriptions

of their situations, referred to as “thick description” (Malterud, 2012), while there was considerable variation in the kinds of experiences described and several participants expressed similar views independently.

Data Analysis

Two researchers performed the data collection, and a third researcher (last author) joined them for data analysis. We attempted to increase verification of findings (Creswell, 1998) by using different procedures: the interview guide was discussed between researchers; interviews were done with one researcher asking questions, one observing and taking field notes; debriefing occurred after the interviews; themes and interpretations were negotiated until agreement was achieved and member checking was made possible.

We used systematic text condensation, as described by (Malterud, 2012). We followed the four steps described in this approach of qualitative analysis: (a) all three researchers read and re-read the transcripts to obtain an overall impression and find preliminary themes. Identification of themes was conducted separately by the three researchers who then met to discuss and agree on the final themes; (b) each of them identified units of meaning characterizing diverse aspects of the (step)parents’ perceived burden and needs, and coded for these, whereas parts of the transcript not relevant to the research question were removed from the analysis; (c) researchers summarized the contents of each of the code groups into a condensate; and (d) researchers re-conceptualized the data, writing an analytic text and adding useful quotations. Re-reading the original transcript ensured goodness of fit with the final code groups and themes. Transcripts were translated from Dutch to English and language equivalency was assured through review by a researcher fluent in both languages. We used NVivo-11 (QSR International, Doncaster) to assist with management of data. We performed interim analysis after three and after five interviews in order to shape the focus of the ongoing data collection and to provide information on data saturation.

Credibility was enhanced by prolonged engagement of researchers in the facility, by researcher, method and source triangulation, member checking; whereas an audit trail and negative case analysis enhanced dependability (Lincoln & Guba, 1985). The audit trail, detailing context and rationale for all research decisions also enhanced conformability.

Ethical Considerations and Author Reflectivity

This study was approved by the ethical advisory board of the University Hospital Antwerp/University of Antwerp. All potential participants received a comprehensive information letter and verbal information explaining the purpose and method of the research project, as well as data handling and participants' rights. They had the opportunity to further discuss their potential involvement in the project with a member of the research team and signed a consent form before participation.

As part of the participatory action design of the overarching project, all researchers were familiarized with the way of working in the residential facility, without being involved in the individual cases.

Results

Four themes emerged when (step)parents described their needs towards services: involvement, respect, agency, and support. This section is built on analytical texts representing synthesized condensates and illustrated by quotes.

Needs and Preferences of Parents Regarding Residential Care Delivery

Involvement. Most (step)parents insisted on the importance of a “partnership” with the residential care workers, being closely involved in the care planning and delivery for their daughter. Good collaboration, as equal partners, and joint decision-making using a common reference frame, benefits both adolescents and the (step)parents themselves. Some participants even describe the collaboration between parents and professionals as the cornerstone of a good residential care. Participants want a “joint planning”, whereby (step)parents and all different professionals together assess strengths, difficulties and needs of the adolescent, and plan care delivery.

I think the match and collaboration with the social workers, that is what really determines if the placement works or not. That collaboration determines if it is going to work out fine for parents and for kids. It has to become one integrated story, with the parents also. (interview 1)

Participants explain how this involvement can take place in practice. An example is the exchange of information about the daily functioning of the adolescents. Most parents appreciate to have a lot of information about what is going on with their daughter in the residential facility. This makes them feel involved

and reassures them that they can ask for advice when necessary. Besides the exchanges with social workers (often by phone), (step)parents further concretize a close collaboration with the examples of frequent meetings and good agreements about all aspects of the youth's life. A mother and stepfather explain:

-Yearly, or every six months, a meeting with really everyone involved, my daughter, team leaders, social workers, psychologist, director, juvenile judge, doctors, really everyone.

- Yeah, a yearly meeting where everyone can explain his or her point of view. Then everyone is on the same page. If someone doesn't agree, it can be discussed during that same meeting. (interview 1)

Participants describe many benefits of a true partnership between parents and professionals. A major advantage of having a good collaboration is that clear and joint agreements offer the adolescent clarity, facilitating a joint and consistent approach from all parties. Explicit expectancies, shared by all those who care for them, help the girls in regulating their behavior and makes them more inclined to obey the rules. Several (step)parents described "standing strong" when working in close collaboration with the professionals in the residential care center.

It gives the social workers a bit more power to get the adolescent to obey, when they collaborate with parents. For example, if everyone is working together and is saying that the girl has to stay ... It also clarifies the situation for the youth, like "OK, they're all working together here". (interview 3)

Also, it is necessary for (step)parents to have close contact with the professionals in the residential facility in order to look at events from different perspectives. Two mothers tell us how important they find it to hear how an incident was perceived by their daughter, but also by the professionals. Not having this information, could lead them to have negative feelings towards the residential care staff (following the emotions of their daughter).

It hurts me when my daughter is upset; it makes me angry at the facility. But at times her story isn't the truth or isn't complete, so I wouldn't have to be angry with them. So therefore also, I keep stressing the importance of close collaboration and communication. (interview 5)

An aspect emphasized by two mothers is, that parents should be allowed to choose for themselves to what extent they wish to be involved in the care delivery.

I am a mom who wants to be very closely involved with it all – I know mothers who are OK with it if the residential care workers and the youth are able to fix things by themselves, without involving parents ... For me, it is not because my daughter doesn't live with me – because she is still in the juvenile justice system – that I must get to know everything as the last person, after everyone else. Sometimes this is the case and I find that very frustrating, because I am her parent, I should be the first to know everything concerning her. (interview 7)

While most participants insisted on being involved as much as possible, one of the mothers explained that she preferred another way of being involved, where she would only be directly contacted for important decisions and not for daily hassles.

Respect. To feel respected is very important for parents whose children are in residential care. This respect is described on different levels and encompasses the respect for them as a person, respect for their role as a parent, respect for parents' rights along with the child's rights; but also on a very practical level, respect for the parents' agenda when fixing appointments. Feeling respected and accepted as a person is very important to these (step)parents. Some participants describe that they have had the impression of being judged and blamed by professionals in the past. Two couples explain that at times, they felt like no solid explanation for the difficulties of their (step)daughter was sought, and "bad parenting" was directly pointed out as the culprit.

What I find important is that they dig deeper and investigate the situation instead of sticking a label. Here, they didn't stick a label but they analyzed the situation instead: what are the problems? We had the feeling they listened to us. (interview 6)

Second, (step)parents want to be respected in their parental role. Despite their child being in care, they want professionals to acknowledge the fact that they still are their daughter's parent, and have to be

respected as such. Participants feel this respect when their opinion and expertise concerning their child is considered, and when professionals stimulate the child in care to ask and respect a parent's opinion.

It is important that they appreciate our feedback also. They say "you know her best as a parent". After all, the goal is that part of the daily issues are handled here, because it was not bearable in the family anymore, but what you don't want is to be only "half a parent" after a while. That is a feeling that care delivery can give you, having no control, and failing. (interview 3)

One father and stepmother mentioned a third aspect. Some parents who have full parental rights feel like these are not respected. They feel like it is unfair that, while they asked for support themselves, being worried about their daughter's well-being, when care delivery agencies become involved, they are set aside as a parent.

You feel that the vast majority of files here are under juvenile court, forced. So often, they will inform us, but in fact the decisions are already made. (interview 7)

A fourth point regarding respect that some of the (step)parents make, is that they feel like professionals don't take their agenda enough into account when planning meetings. It feels disrespectful to these (step)parents when their schedules are not taken into account, or when a vast majority of professionals have to leave a meeting prematurely.

We make time for these appointments. You know the doctor is there, the family therapist, maybe a social worker, ... And then they say "I cannot stay very long, I have another appointment". And then I think, "you are paid for this! We give up our time to come and listen". (interview 8)

A fifth point regarding respect that different participants mention, is that the huge emphasis put on children's rights and agency in care delivery, sometimes obscures that (step)parents too, should have rights. At times these parents have felt like they had only obligations.

At a certain point, there was yet another girl that came to see us, a lot of explanations again – nothing against her, I mean that girl can't help it, they only have the tools they get – but she puts two little booklets on the table "rights of the child" and "obligations of the parents". Well, I said, and now the rights of the parents? But they didn't have such a booklet. (interview 1)

Agency. Parents want to have the information and mandate necessary for (joint) decision-making regarding their daughter. Depending on the specific (legal and family) situation, the exact manner and extent of the (co)decision-making by parents can vary. Some (step)parents felt the circumstances were not created for them to make their own decisions, due to fragmentation of information or not being informed in a timely way. In other instances, they felt great about the joint decision-making and tell about good cooperation, in particular with the social workers.

When parents have to invest a lot of time and energy to get the right information, this doesn't allow them to be in control as much as they feel they should be. A stepmother explains how in each institution or hospital where her daughter resided, they had to make huge efforts in order to have access to enough information to feel involved and be part of the care delivery process as a (step)parent.

It has been like that in all institutions, in all psychiatric hospitals: as a parent, you have to ask for everything yourself. Recently, the nutritionist for example, we had to put a lot of effort into contacting them and explaining them we want to know what they discuss and decide about our daughter and how we can be part of that. (interview 8)

Another reason why parents feel that they sometimes lack mandate over the care for their daughters, is that they're often not allowed to take part in the process that precedes important decisions. They feel professionals only contact them to give their agreement with a care delivery planning that was established without consulting them in earlier phases, or even after decisions have been made.

What was very frustrating to us, was that they didn't take us along in the process. That was a big mistake. The decisions they have made, we've never had issues with those. It is not that we don't

agree, it is the fact that they have to let us be part of the decision-making. Very often, we get informed, but only after the decisions are made. That leaves us feeling discouraged. (interview 6)

It is not only about giving (step)parents the opportunity to make a difference in the decisions made about their child, but also about enabling them to fully understand the situation, plans, and options by clarifying the frameworks and reasoning used by the professionals involved. By working in a planned and proactive manner, parents have more opportunities to fully take part in the decision-making.

It's not just letting you decide or say "go" or "no go". If you don't know what the framework is, or why they make certain choices ... You are just guessing what is happening. Whereas, when you have insight into the whole decision-making process and you know what motivates the decisions they make, that helps you to have enough information to make informed decisions by yourself, and makes you feel stronger. (interview 8)

Support. (Step)parents, and other family members, need to receive practical advice, but also consideration and emotional support. Parents want to feel this support in interaction with the residential professionals. One of the mothers describes the residential care facility as a place where support is available to parents and adolescents.

I call it a "help institution", a support for me and for my daughter ... Yes, they should provide help and support for parents who are ... well ... indecisive, who have difficulties. (interview 7)

The (step)parents expect support for questions about raising and helping their child, and want help from the institution in dealing with specific parenting issues. Knowing they can always reach someone at the facility when their daughter is at home and has difficulties, is very helpful. Discussing possible approaches to the challenges they face, with the residential care professionals, strengthens them and makes them feel supported and empowered.

It was really helpful that we could just grab the phone and call when it was difficult at home and say “help”, and that they really listened and helped us out, looked with us for things we could try. Then we knew how to handle it. It made us feel stronger. (interview 2)

Besides support in dealing with the difficulties their daughter faces, parents also expect emotional support. This is necessary in order to help (step)parents and siblings deal with the difficulties related to the MCN of their daughter or sister. Professionals have to be aware of the emotional impact of the frequent crisis situations (running away, suicide attempts, involvement in juvenile prostitution) on (step)parents. Participants asked for a more considerate and supportive attitude towards them, and wish they would receive more support in dealing with these difficult situations as a family. They also wish professionals would take a parent’s perspective in a crisis situation and understand why a situation – such as an attempted suicide – that residential care workers may find “ordinary”, is shocking to (step)parents. If professionals listen to them, offer advice and show they care about their feelings, especially in or after crisis situations, that helps them cope.

Our daughter has attempted suicide. I think they took the necessary actions, they did everything well, but they completely forgot about us. They did call us that night, but afterwards, the care for parents – how to come to terms with this as a parent – they completely forgot that. (interview 8)

Yet another aspect regarding “support” is that professionals in residential care for girls with MCN should also take into account the other children in the family. The parents we spoke to, stress the fact that they need support as a family, and consequently several parents view family therapy positively.

We talked to X (family social worker), because we felt like our youngest was having a hard time since this all happened. She said, what would you think about going to see someone in child psychiatry who works with families? And we said OK. And at first our youngest said what a “busybody”, why is he so nosy? But then my son’s attitude changed and now he says “in fact it helps, mum”. (interview 1)

Family social workers have a close contact with (step)parents and invest a lot in the relation between youth and parents and institution and parents. They can also help parents to rebuild the contact with their daughter if that relationship has been under tension.

We have had periods when it was all too much for us, and then we hadn't heard from X [daughter] for weeks. When your daughter is in an institution, you think "I have some peace at last, she probably is fine over there" and then you lose contact, you grow apart. And the family social worker is the one who is in between and can help to rebuild the relation. (interview 3)

Feeling supported and being in contact with social work and (mental) health care professionals lowers the threshold towards services. Two of the parents told us that the contact with residential care for their adolescent girl has prompted them to look for further therapy for themselves.

I feel that, after a family therapy session, I feel lighter. Like I'm another person when I come back from therapy. That is why I've asked for a psychologist for individual therapy for myself. (interview 4)

Discussion

Drawing upon in-depth interviews with (step)parents of girls with MCN, the aim of this study was to identify (step)parents' needs and preferences in care delivery. (Step)parents' perspective and own needs remain a secondary consideration in discussions of residential services, in spite of research pointing at the impact on parents of having children in care.

(Step)parents asked (1) to have a true partnership between parents and professionals (involvement), (2) to feel respected by professionals (respect), (3) to have the information and mandate necessary for decision making (agency), and (4) to receive consideration and (emotional) support, besides advice on how to handle the challenges their family faces (support).

Our findings concerning the difficulties these (step)parents encounter and their wish to be involved, align with the literature on family-centered residential care (Affronti & Levison-Johnson, 2009; Dunst, Boyd, Trivette, & Hamby, 2002; Geurts et al., 2012). As an added value, our findings emphasize that it is important to expand the rationale for (step)parental involvement with residential children's services beyond its benefits for the placed child (De Boer, Cameron, & Frensch, 2007). Indeed, it seems imperative to consider ways to assess

and accommodate the needs of the (step)parents themselves in order to achieve effective care delivery that empowers families as a whole in dealing with the difficulties they face.

The (step)parents we spoke to, ask to be *involved in care delivery* and wish for an equitable partnership with the professionals involved in the care delivery for their daughter. In earlier research, a strong alliance between parents and service providers is associated with positive service outcomes (Horvath & Bedi, 2002). While our findings emphasize the benefits for adolescents, of consistency and clarity brought about by better collaboration between parents and professionals, earlier studies found that when agencies work closely with parents, this decreases the likelihood that parents themselves would be distressed by contrasting demands (Green, Rockhill, & Burrus, 2008).

It is interesting that some of the barriers to interagency collaboration pointed out by professionals when referring to interdisciplinary contacts, are mentioned by the participants too, when they refer to the difficulties they encounter in contact with services (Cooper et al., 2016). For example, participants are struck by the fragmentation of files and the loss of information when their child moves from one placement to another. Also, they highlight the importance of being enabled to understand the reference frame used by the professionals caring for their child, in order to be real partners in the care delivery.

Participants also told us about *respect for their parental role*. Analogous to findings in a recent research report investigating the perceptions of parents whose children were placed in out-of-home care, the parents we spoke to continue to clearly identify themselves as parents of their children who are in care (Ross et al., 2017). Parents ask to be respected in this role by professionals engaged in services for their children. The participants in the study of Ross and colleagues also pointed out how challenging the parenting role was, and how many barriers they faced both improving and maintaining their parenting while their children were in out-of-home care. Our participants pointed at the importance of services to support them in their parenting role and not to label them as “failed parents” without giving them a chance to prove their good intentions. This is in line with parents of children in care interviewed in a research project on family contact in kinship care. In those interviews, parents pointed out the need for services that are empowering and respectful, rather than oriented towards them as failed parents (Kiraly & Humphreys, 2015).

The theme “*agency*” is a reflection of the fact that parents want to maintain to some extent control concerning care delivery planning and implementation for their daughter. To enable them to have a certain degree of agency over the care delivery process, it is important that professionals provide parents with timely

and comprehensive information about the care delivery planning process, and allow for as much input in the decisions as possible (Dunst, Trivette, & Hamby, 2007).

With the theme *support*, (step)parents express their own need for advice and for emotional help when facing the difficulties brought about by the problems of their daughters. One of the parents gave a very valuable advice by stating professionals should always be aware that a situation they may have gotten “used to” in time, is very distressing for the (step)parents confronted with these issues in their own child. Therefore, events such as a suicide attempt or a fugue should always be communicated in a respectful and considerate manner to parents (Affronti & Levison-Johnson, 2009). Moreover, as our findings additionally emphasize, parents should also be offered assistance in dealing with these situations.

Findings of De Boer et al. (2007), who explored parents’ perceptions of the benefits of psychiatric residential treatment for parents and siblings, are promising. They reported that, when a child is in a psychiatric hospital, this can also lead to improved personal and family functioning as perceived by the parents (De Boer et al., 2007). The vision that effective and humane residential care is best seen as a support to families who are struggling, rather than as a substitute for families who have failed, is strongly supported in the Consensus Statement of the International Work Group on Therapeutic Residential Care (Whittaker et al., 2016).

The needs and preferences expressed by these (step)parents have several organizational implications for residential services. They could guide planning and evaluation of the dimension of “parent–caregiver partnership” in the concept of family-centered care (Geurts et al., 2012; Law et al., 2003). Indeed, respecting and addressing parents’ concerns and providing them with tailored care and support corresponds to the aims of needs-based family-centered care delivery, as opposed to the less intensive forms of professional–family alliance (Dunst et al., 2002; Martone et al., 1989). Potential concretizations of our findings in service delivery are related to the partnership that is built between parents and professionals and to helping parents deal with the distress brought about by the difficulties their child encounters. A focus on active participation of service users in achieving the desired outcomes, is known to be essential for optimizing the empowering effects of care delivery (Dunst et al., 2007). Strengthening the family as a whole, is crucial in optimizing the long-term outcome of placed children, whether they return to their family or stay in out-of-home care (Geurts et al., 2012).

Investing in (re)building the relationship between parents and children is another important focus. Indeed, amelioration of family relations is one of the possible positive achievements of residential care (De Boer et al., 2007). This may be of particular importance for the target population in this research project, as a more adaptive parent–child relationship is found to promote resilience in the face of multiple personal and familial risks factors in early life (Flouri, Midouhas, Joshi, & Tzavidis, 2015).

Furthermore, it can be valuable to facilitate the process of (step)parents seeking help for their own issues by having a family therapy offer and collaborating with adult services. A concrete example in our study stresses this possibility: parents who were engaged in family therapy and found that useful, went on and were motivated to look for a therapist for themselves. Such collaboration between child-serving agencies and adult mental help services has proven beneficial in other vulnerable populations (Drabble, 2007). An interesting option is to include parent mentors, who have past experiences as a parent of a child in care, as members of the care delivery team (Affronti & Levison-Johnson, 2009). These persons can raise the awareness of professionals for the parental perspective, both in a policy and on the case level. Mentors can also assist parents by facilitating the communication of their needs and provide them with support. Another promising approach in order to meet the parental needs, is to organize parenting groups designed specifically for parents whose children are in care (Salveron, Lewig, & Arney, 2009).

Finally, having family functioning as an outcome measure in residential care, could further direct attention to the needs of families as a whole. Harder and Knorth describe that to date this is seldom the case, in spite of the fact that family problems often seem to contribute to the admission of youth to residential care (Harder & Knorth, 2014).

A limitation of this study is, that this qualitative data from these 12 (step)parents, representing 8 adolescents, cannot yield findings that are generalizable to all (step)parents of adolescents in care in this setting, or in other populations or other forms of residential care. Moreover, the one's who chose to participate in the interviews may have another vision than the (step)parents with whom there is no contact, of who did not participate. However, our exploratory study does provide a thick description of these participants' experiences that could inspire policy and practice workers to take the needs of parents into account. Moreover, as parents pointed out, the importance of siblings whose needs are often not assessed or "left out" when a brother or sister is in residential care, future research should take their voice into account.

Conclusion

The findings of this study in a collaboration between residential CW and CAP, drawn from in-depth interviews with (step)parents, point to an important consideration: attending the needs of (step)parents alongside with those of the placed youth. They could have a wider relevance, usefully informing work with children across diverse placements within the care system, pointing out the importance of attending (step)parents' needs by involving them in a respectful partnership, with attention to both agency and support needs. Optimal use of (step)parents' perspective and expertise as part of a needs-led family-centered care delivery, could be valuable for program development and implementation (Williamson & Gray, 2011) and will optimize the chances of a favorable short and long-term outcome for vulnerable families as a whole (De Boer et al., 2007).

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CHAPTER 5

A Model of Intensive Cross-Sector Collaboration Between Child and Adolescent Psychiatry and Child Welfare: Guiding Principles from the Professionals' Viewpoint*

*Under review at *Social work in Health care*.

Abstract

This paper explores the guiding principles of a collaboration project between child and adolescent psychiatry (CAP) and child welfare (CW), that aims to help adolescents with multiple and complex needs (MCN).

Handling the most complex cases requires services that trespass the boundaries of individual agencies and sectors. However, collaboration is known to be challenging, due to organizational and so called “people factors”. Literature accounts of collaboration projects between child serving agencies are scarce and offer little guidance for the development of new collaborative initiatives. Comprehensive descriptions of collaboration models, with attention to “people factors” are needed.

In this paper, after illustrating the collaboration model Van Celst, engaging CAP and CW, its guiding principles are described drawing upon focus groups with 44 professionals.

Participants report the following characteristics: 1. needs-led focus; 2. intensity of collaboration; 3. balance between integration (merging) and differentiation (specialization), 4. two collaborating partners integrated in a larger network. These ideas could inform reflections about collaboration projects addressing complex needs.

Multiple and Complex Needs Challenge Care Delivery and Urge Collaboration

Persons with multiple and complex needs (MCN) pose an increasing challenge for different health and social services. They have needs regarding (physical and mental) health, social functioning, justice and integration into society (Rosengard, Laing, Ridley, & Hunter, 2007). Children and adolescents with MCN suffer from cumulative harm that puts their well-being and development at stake. Gender and developmental age make adolescent girls especially vulnerable regarding both psychosocial and physical health, and put them at risk for poor physical and mental well-being, poor social integration or criminal activities, entailing considerable costs for society (Handwerk et al., 2006; Leve & Chamberlain, 2004; Van den Steene, Glazemakers, & van West, 2016).

From a service use perspective, persons with MCN typically encounter difficulties in access to services, have multiple and long term service use, and face fragmentation in care delivery (Burnside, 2012; Katz & Spooner, 2006). MCN set great challenges to service provision, as services required by these persons cannot be granted by a single agency or sector and individual services are failing to offer the individualized, longitudinal, in-depth and coordinated support needed (Davidson, Bunting, & Webb, 2012; Katz & Spooner, 2006). The severe and intertwined needs they have on several life domains overwhelm the capacity of regular services (Burnside, 2012; Carter, Cummings, & Cooper, 2007).

Collaboration between sectors of care is put forward as a potential strategy to better meet MCN, thanks to more diverse expertise, less treatment disruptions and more tailored care delivery (Fay Mitchell, 2012; Keene, 2001; Robertson, 2011; Rosengard, 2007). The hope is that this could minimize sequential or parallel interventions. Continuity in care delivery and a holistic approach are hoped to optimize the developmental chances of children and adolescents with MCN (Burnside, 2012; Katz & Spooner, 2006; Keene, 2001; Robertson, 2011).

Although collaborative care models are promising, several authors warn for the “feel-good rhetoric” and stress that interagency collaboration is challenging and does not automatically confer benefits for service users or organizations (Miller & Ahmad, 2000). Besides organizational factors, ‘people- factors’ such as valuing, respect, trust and confidence, or positive relationships, influence the success of collaborations (Cooper, 2016; Horwath & Morrison, 2007). Authors highly recommend that collaboration models should be described and studied for their effect on case and organization level (Lee & Barth, 2011; Wong & Sumsion, 2013). To date, there are few collaborative programs detailing their concept or examining their outcomes. The literature is

especially scarce regarding children and adolescents with mental health needs (Puura et al., 2002; Richardson, McCauley, & Katon, 2009).

The Van Celst Project: Intensive Collaboration between CAP and CW

Core aim of the project. Van Celst is an innovative collaboration between CAP and CW. Together, they take responsibility for a target population of adolescent girls with MCN. The collaboration project aims to provide these adolescents with the services they need, when and the way they need them. This with the hope to achieve a service delivery that is seamless and devoid of overlaps or gaps (Fabbricotti, 2003), with the purpose to maximally address MCN. An additional aim is to empower professionals to whom the confrontation with MCN can be overwhelming and frustrating.

Initial conditions. A university CAP center and a CW facility, which both perceived the urgent need to ameliorate services for adolescent girls with MCN, initiated this collaboration. Both agencies were confronted with young people with multiple needs, who were repeatedly referred from one facility to another, putting their personal well-being and societal integration at stake. Their needs could not be met by any available care delivery program. For CAP, the breadth and chronicity of problems (including school, self-care, administration, justice, ...) along with the lack of a safe and nurturing living situation, complicated the provision of services. For CW, psychiatric issues, including high-risk behaviors (suicide, self-harm, traumatic dissociation), were very hard to handle in a regular facility. Other professionals involved (school, juvenile justice institutions) could not meet the varied and intertwined needs of this population either.

Besides the concerns about the jeopardized well-being and development of adolescents with MCN, services were overwhelmed by these needs, and professionals felt frustration and helplessness. Teams were worn out by the magnitude of their needs and the lack of resources to address them, leading for example to stress, absenteeism, burnout or strikes among professionals.

Starting from the shared aim to ameliorate services, and the expectation that joining efforts in an integrated cross-sector approach would be beneficial, an innovative collaboration project was initiated, integrating CAP and CW on both the case level and the organizational level.

Case-level. This collaboration model is specifically set up for adolescent girls with MCN. The majority of them are referred by juvenile justice (apart from an occasional referral by CAP), and all of the girls have had multiple placements (CW, psychiatry, juvenile justice facilities) in the past. After the adolescents are referred to this collaboration project, the intake – the first contact with care providers from the project, aimed at clarifying

everyone's goals and expectations – is done together by a CAP and a CW professional. This clarifies the integrated approach for the adolescents and their families and allows professionals to share goals, information and responsibility from the very start.

All the adolescents enrolled reside in the CW facility. The frequency of their contacts with CAP varies from case to case. CW provides a safe and stable daily living environment, in a group care setting, divided in three levels with increasing independence, and outpatient based aftercare. The CW approach is aimed at improving independent living skills, providing social guidance (family relations and building a stable social network), handling high-risk behaviors and stimulating integration into society (school work, administration, ...). The focus of CAP is to provide mental health care and to coordinate broader medical care. This includes diagnostic testing, ambulatory therapy and counseling (individual, family, group, nutrition), residential or semi-residential (crisis) treatment, and (psycho)pharmacological treatment. Diagnostics and therapy are mostly done on an outpatient basis in the CAP hospital, but therapists can also come to the CW facility. The CAP assistance is not mandatory, but is available to all girls, with very limited waiting lists.

Organizational level. On the organization and policy level, a far-reaching integration and a shared goal, vision and mission characterize this collaboration. Information about the adolescents is centralized and shared between the professionals of both agencies, with the exception of information that resides strictly under professional confidentiality. The responsibility for all adolescents enrolled for the entire duration of their trajectory is shared, and all decisions are discussed by CAP and CW professionals together. The integration takes place on all levels of both organizations, involving professionals with all different backgrounds and functions in both agencies. Continuous exchange of information and advice takes place via formal, structural contact moments, additional contacts on indication, and informal exchange.

In a broader perspective, the integrated core of CW and CAP is part of a larger network of agencies involved in the care delivery for youths with MCN, such as juvenile court and juvenile justice institutions, medical experts, school counseling, or therapists.

Practical input. Both partners have a different but equally important role in the collaboration project. The CW team in the facility where the adolescents reside, is composed of administrators, team coordinators (social workers), psychologists, family social workers, and social workers. The CW facility offers a safe and stable group-care environment and assures the practical coordination of the care delivery (e.g. helping the adolescents to make and get to all appointments). The focus in CW is on independent living and societal

integration. (Family) social workers and psychologists assist the adolescents in strengthening family communication, school selection and school work, leisure time, building a strong social support network, and reducing high risk behavior.

From CAP, a team of persons employed in a tertiary university CAP center are involved in the collaboration project. The team is composed of a coordinating child and adolescent psychiatrist, a second (substituting) child and adolescent psychiatrist, psychologists, social workers and a dietician. The CAP input is varied and concerns both supporting professionals, joint meetings with CW professionals and direct services for the adolescents and their relatives. CAP offers (2 hour 2-weekly) low-threshold 10-minute consultations. The tertiary CAP center also offers extensive diagnostic testing that can be done in the facility or in the CAP center. There is the possibility of ambulatory and residential treatment (individual, group or family therapy, residential crisis treatment, ...) as well as psychopharmacological treatment, for a wide variety of emotional and behavioral issues. For some of the adolescents with school problems, the hospital school in the CAP center can offer a solution. On the level of the professional, the CAP team offers a multidisciplinary (medical, psychological, speech therapy, ...) perspective on all cases. The psychiatrist coordinates all medical issues and consultations, does supervision and intervision (1.5 hours every second week), and provides training on CAP-specific topics on demand (approx. 3 hours every two months).

Both CW and CAP also take on a lot of tasks together. As mentioned, the intake is done by professionals of CW and of CAP together. All subsequent evaluations of the adolescents, discussing progress and planning further care delivery with adolescents (and family) are also done together. There is a 24/7 permanency by CW supervisors and child and adolescent psychiatrist. There are joint team meetings where care delivery is planned and discussed for all adolescents enrolled (2.5 hours every 2 weeks). Decisions and progress regarding the collaboration project itself are made at management meetings (1.5 hours every month). Communication with external partners in the care delivery (schools, adult services, ...) as well as external stakeholders takes place at meetings to evaluate the project together with other partners in youth care or related domains (every 6 months).

For a good understanding and insight in the concrete and people factors (Horwath et al., 2007), experiences from professionals are crucial (Calheiros et al., 2013). In this paper, we want to enrich the description of this cross-sector collaboration model drawing upon answers from professionals involved in this project, to the research question: what are the characteristics and guiding principles of this collaboration

model? They give insight into guiding concepts and principles in this innovative collaboration project. These findings are reflected upon against the background of the literature on interagency collaboration for complex cases in child serving agencies, but also in the context of data from public administration literature.

Methods

Setting for the Study

Focus groups exploring the professionals' perspectives on the collaboration project Van Celst were conducted as part of a larger participatory action research project (Reason & Bradbury, 2008) by a multidisciplinary research team (clinical psychology, CAP, anthropology).

Data Collection

A literature review on MCN and collaboration, as well as in-depth discussion between researchers, assisted in the design of an interview guide. Six focus group interviews were conducted with a total of 44 professionals. Each focus group lasted for about 150 minutes, was audiotaped, and subsequently transcribed verbatim. Focus groups were done by the first author (CAP trainee and doctoral student) moderating, and a second researcher (anthropologist, professor) observing and taking field notes; a third researcher joined for the two focus groups with external partners. A supplementary researcher (clinical psychologist, professor) joined them for data analysis.

Participants and Recruitment

A purposeful sampling strategy was used in order to achieve a multidisciplinary in-depth description of the collaboration. Professionals from CAP and from CW and external partners of the project were included. Potential participants were approached verbally and via email. In January and February 2016 30 "internal" professionals (out of the 32 persons from CAP and CW working in the collaboration project), and involved in the collaboration project on a daily basis, were assessed. As a next step in the participatory action research, and stimulated by discussions with stakeholders, in September 2016, two additional focus groups explored the vision of 14 "external" professionals (out of 20 potential candidates). These participants are a part of the larger care delivery network, and play important episodic roles in their care trajectories. Reasons for not participating were time constraints or illness, for both series of focus groups. Table 1 details the composition of the focus groups.

Table 1. Composition of the focus groups

Focus number	group	Number of participants	Background of participants
1		8	CW: administrator, psychologist, social worker
2		8	CW: administrator, psychologist, team coordinator, social worker, family social worker
3		8	CAP: child and adolescent psychiatrist, psychologist, social worker, dietician (n=1)
4		6	CW: team coordinator, social worker, family social worker
5		6	External partners: social worker juvenile court, policy maker youth welfare, psychologist/social worker juvenile justice institutions, juvenile judge
6		8	External partners: social worker juvenile court, juvenile judge, social worker CW facility, policy maker youth welfare, psychologist juvenile justice institution, general practitioner

Data Analysis

Data analysis was done with systematic text condensation, following Malterud (2012). NVivo 11 (QSR International, Doncaster) assisted with data management.

Condensates were translated from Dutch to English and language equivalency was assured through review by a researcher fluent in both languages.

In order to increase verification of findings (Cresswell, 2017; Tong, Sainsbury, & Craig, 2007), interviews were done in pairs: one researcher asking questions and another observing and taking field notes; findings were summarized by participants at the end of the focus group and discussed with the participants after coding; debriefing between researchers occurred after the interviews; interim analyses were performed to inform further data collection; and themes and interpretations were negotiated until agreement between all three researchers was achieved. Credibility was enhanced by prolonged engagement of researchers in the facility, by researcher, method and source triangulation, member checking; whereas an audit trail and negative case analysis enhanced dependability (Lincoln & Guba, 1985). The audit trail, detailing context and rationale for all research decisions also enhanced conformability.

Ethical Considerations

This research project was subject to appropriate ethical review by the ethics committee of the University Hospital Antwerp/University of Antwerp. All participants received a comprehensive information

letter and had the opportunity to discuss their potential involvement in the project with a member of the research team. They gave written informed consent prior to participation.

Results

This section reports the guiding principles of this collaboration from the perspective of professionals involved in this cross-sector collaboration between CAP and CW. This section is built on analytical texts representing synthesized condensates and illustrated by quotes.

The Adolescents' Needs as a Starting Point

The entire care planning and delivery is led by the needs of the target population. The necessary expertise is put together from both sectors. Both partners share the motivation to ameliorate the care delivery for these adolescents with MCN. The needs of the target population are described as a central anchoring point in this service organization.

The stimulus for starting this collaboration project was the fact that no one agency or sector of care could meet the needs of adolescent girls with MCN. Both CAP and CW observed suboptimal, fragmented care delivery for these adolescents – being sent from one institution to another and having compromised well-being and functioning – and a difficult situation for the professionals involved. Joining expertise, resources and efforts was seen as the best chance to better meet the needs of adolescent girls with MCN and at the same time was hoped to be beneficial for both organizations. Professionals explain how clearly the shortcomings of services for this vulnerable population were felt, and how collaboration between CAP and CW seemed promising.

These adolescents have been in so many institutions ... Because of their problematic behavior and family issues they didn't belong in psychiatry; and they cannot stay in a normal CW institution because of the problematic behavior and the psychiatric issues. So where could they go to get proper help? Nowhere! (social worker)

I do not think psychiatry alone is a solution, or that we alone are a solution, but I think both are really needed for these girls. (CW administrator)

When professionals involved in the project on a daily basis or as an external partner describe the collaboration model, a lot of importance is attributed to a needs-led approach. The needs of these adolescents are the shared and central focus point of both collaborating partners, and guide the efforts of the collaboration on the level of the professional and the organization. Having this shared focus anchors the collaborative efforts, strengthens the ties between professionals, and structures the needs-led approach.

Our girls are at the core of this collaboration. They are connecting us. At first, we were confronted with “it’s two different worlds” [CAP and CW], but we were able to create a unified vision with at its center the care for the girls. We do that by putting their needs first, and by investing a lot of energy. (child and adolescent psychiatrist)

External partners also point out that it is specific to this collaboration project that the entire approach revolves around the needs of the girls served, and not around the agencies’ offer. They explain how this prevents “passing on” complex cases from one facility to another, based on the fact that their needs do not fit certain selection criteria for treatment.

High Intensity of Collaboration, yet Maintaining Each Partner’s Identity

When discussing the collaboration project, the intensity of collaboration on the level of the organization and the professional is highlighted as characteristic.

On the level of the organization, the intensive, structural character of the collaboration links both agencies and reinforces their commitment to the common project. Professionals insist on the structural, binding character of the collaboration.

When you organize this in a structural way, like here, you have partners that are – to put it negatively – obliged to build something together, in a longitudinal way. The budget is allocated for some years;

we've got the research project, ... Building a collaboration that way makes it stronger (...) that is true partnership, and searching for solutions together. (juvenile judge)

In this collaboration project the final responsibility is shared for each of the adolescents enrolled, and for their entire trajectory. This commitment of the CAP for the entire organization (and not just a few cases) and in the long term (and not episodic), differs significantly from temporary case-dependent consultation. This approach is also compared to the situation where a budget would be allocated to each complex case, allowing them to “choose” how to best meet their needs, but without the different services involved feeling this joint responsibility.

The joint intake has an important role in this approach that emphasizes the shared responsibility. From the very start all decision-making regarding care delivery planning is done together by professionals from both CAP and CW.

Starting from the very beginning, the intake, they are thinking together. Right from that moment on they already start, together with the psychiatrist, to explain the joint approach to the adolescent and to decide what is needed (...), instead of pointing at each other, passing on responsibilities. (social worker juvenile court)

To external professionals, this far-reaching joint responsibility is also very characteristic for this project and linked to increased continuity in care delivery.

The responsibility is shared and the burden is carried together, whereas in other files in juvenile court we see that they easily refer adolescents to each other because they do not feel such shared responsibility: “that’s a behavioral issue, she can’t stay in psychiatry”, or “that’s too psychiatric, not for us”. And then you get the ping-pong between agencies referring responsibility to each other, even when they are sitting at the same table. (juvenile judge)

The integration between agencies is not merely top-down or bottom-up, but involves all disciplines and all hierarchical levels in both agencies. This is found to enhance the commitment towards the collaboration

in both agencies, and the interdisciplinary non-hierarchical exchanges are found to be very fruitful for thinking “outside the box” and in the best interest of service users.

It's really working together across all levels here – people in all functions actively engage in this collaboration, want to build a true partnership. (...). It's not only the social worker, but also the person in charge of the unit and the management – as we often say here: from the cleaning lady to the manager. This is important to make it succeed – the commitment should exist at all levels. (team coordinator)

Also at the organizational level, exchange between both partners is maximized by investing in getting to know each other's way of working and understanding each other's reference frame. Formal and informal communication is encouraged. Of particular importance for optimizing the care delivery approach and for empowering professionals is the cross-training. This training, for example when the CAP discusses how to deal with certain psychiatric behaviors or crises, is entirely adapted to the specific situation and cases in the facility, and is therefore described as more effective than a generic course.

Because she [child and adolescent psychiatrist] also knows the girls personally, (...) she links the case to the theory and then it all seems logical and clear. Then you go to the facility and give it a twist, but you've got the theory, that background – you know how to react, and feel much more confident when you act. (social worker)

Characteristics on the level of the professional, or regarding the “people factors”, are equally important determinants to the intensity of this collaboration as the organizational factors. All professionals involved are reported to be motivated to be a part of this collaboration project, and have a respectful attitude towards professionals from the other agency.

I think every single professional here has the personal goal and motivation to do something positive for this population, and we're interested in each other's vision. (...) Wanting to collaborate in a horizontal, equivalent relationship is important. (CW administrator)

Getting to know each other on a personal level, building trust and supporting each other are important values when collaborating. It seems that knowing you can count on each other and helping each other deal with the (emotional) impact of working with a very challenging population, is what makes the difference.

You can deal with a lot more if you know you can trust your collaboration partner. We know they'll be there. If we need advice, if we need a CAP time-out, if there's a crisis, the social workers can call the CAP and that helps you deal with an intensity of problems you were maybe not trained to deal with – instead of the despair and frustration before. (team coordinator)

Besides the emphasis on the intensity of the collaboration between CAP and CW, professionals also highlight the importance of maintaining the identity of both collaborating agencies, and to safeguard the benefits of working from two different locations. In fact, professionals describe how intensive collaboration could also be a threat to the original organizational identity. They stress the importance of keeping expertise, values and ways of working specific to each of the collaborating partners. This benefits the service users, as the complementarity in expertise and resources of both partners can be used to the maximal extent, when they continue to function as separate entities. It is also important for professionals to feel valued for their specific knowledge and way of working. Especially the CW professionals report how important it is that their expertise and focus is safeguarded despite the far-reaching integration.

As we are a residential CW facility, we try to stay out of this “hospitalizing” care. If we would think a bit more “medically” like them, we would really just be a piece of CAP at another location. But the fact that we are not, and that we tackle these other things, like focusing on school and daily living skills, that makes us able to provide those long-term and tailored care processes. (psychologist)

The current design of the collaboration model – a residential CW institution, collaborating with a completely equipped CAP setting (outpatient care, crisis unit, therapeutic units, ...) and associated with a somatic hospital, at a bridgeable distance from one another – is perceived as beneficial. While the need for a

high intensity of collaboration is continuously stressed, several advantages of having two separate settings, rather than a complete co-location of services, are described. They include: promoting social inclusion and stimulating basic problem solving skills, by letting the girls reside in a “regular” rather than “psychiatric hospital” setting; contributing to continuity of care, as the therapist from CAP is separated from the CW institution and can still provide therapy when the girls are on a time-out from the institution (e.g. a short stay in a juvenile justice institution); a therapeutic benefit of creating some distance between the therapy and the daily hassles at the institution; providing access to a wide range of psychiatric and medical resources with a very limited waiting list, as the psychiatrist works in the CAP setting; and having an “external perspective” on team meetings, which facilitates a meta-reflection.

I think there should be a very close collaboration and that meetings should be held together, but the girls should also know that you as a psychiatrist or psychologist are independent of the facility. That you continue to support them, independently of the CW facility – that the girls themselves are the most important and not the institution where they stay at that moment – they need to really feel that. And the professionals too, knowing that it's not just that psychiatrist, it's the whole CAP setting which is behind it, and actually even collaboration with the general hospital. (...) If you're not on-site frequently enough, and reachable in permanence, you cannot get this job done (...), but I think if you have a psychiatrist in the institution, then you actually are going to lose that good collaboration with the whole CAP setting those girls need to function. (child and adolescent psychiatrist)

Larger Collaboration Network

In this collaboration model, CAP and CW engage in a very intensive and multilevel collaboration, but do not work in isolation. On the contrary, different partners from a variety of sectors (school counseling, juvenile justice, adult mental health services, agencies helping teen prostitutes, general practitioners, administrative services, social housing, ...) contribute to the care delivery. The expertise and resources of these partners are necessary in order to provide holistic services for the girls enrolled. Depending on the individual case, the involved partners vary, and so does the intensity of the interagency collaboration.

We are building a network around them, around us. The more partners you work with, the better you can help the girls. (social worker)

Engaging external partners is facilitated by the close CAP–CW collaboration. Together, CW and CAP invest in these external contacts, e.g. by developing communication pathways, or by organizing trainings. These external partners clearly describe how the CAP–CW collaboration had a positive influence on their own way of working and on the whole of the care delivery systems: more expertise is shared (e.g., by organizing trainings); communication is enhanced; “passing on” difficult cases to each other has been replaced by enhanced interagency trust.

External professionals illustrate the network structure in this collaboration model and explain benefits they perceive.

What is interesting and effective in this model, is that you have two partners, working together very intensively, and that core is incorporated into a larger network. (...) That reinforces the connections you can make with other partners, by providing more expertise, sharing information and showing you can count on them. That makes the network stronger. I think that that connection is what makes the difference in care delivery, that’s what you need in order to have everyone sharing responsibility and providing continuity of care. (...) And the trust, and sharing of information. (CW administrator)

Yes, the collaboration here not only stimulates multi-sector, but also intra-sector collaboration, and is not only multidisciplinary, but also reinforces intra-disciplinary work over agencies. And that exchange and integration makes that a much heavier problem load can be handled. (policy maker CW)

Discussion

Drawing upon focus groups, the perspectives of a variety of professionals involved in an innovative collaboration project between CAP and CW were explored. Their perspectives and description of guiding principles of this collaboration model allows for an interesting consideration in the context of the literature on interagency and cross-sector collaboration and could contribute to the reflection process when planning interagency collaboration in child serving agencies.

Four guiding principles are discussed:

1. needs-led focus;
2. intensity of collaboration;
3. balance between integration (merging) and differentiation (specialization);
4. a core of two collaborating partners integrated in a larger network.

A first observation is that the joint focus on the target population's needs and the high degree of collaboration between CAP and CW are fundamental for this collaboration. The specific combination of needs of the adolescents entering the program, guides the input of both collaborating partners, instead of services directed by the agencies' offers and resources. All professionals involved in both partner agencies share responsibility and decision-making (for every girl entering the program, and for their entire care trajectory). This is a different degree of collaboration compared to working together only for certain cases, or for certain episodes in the course of a treatment, or in the case of consulting one another, when one of both agencies retains the final responsibility.

The literature on facilitators and barriers towards interagency collaboration in child serving agencies confirms the idea that a shared focus on the youth's needs could reinforce collaborative efforts (Cooper, Evans, & Pybis, 2016). Discussing interagency collaboration in child serving agencies, Horwath and Morrison describe how important it is, when engaging in higher order collaborations, to keep a joint focus on uniting factors and common goals, rather than on factors that divide the partners (Horwath & Morrison, 2007). They suggest to do so by paying enough attention to people factors, such as working relationships and outcome. A needs-led approach, focusing on service users and validating their own view of their needs may indeed contribute to achieving a consonance of values. This is in analogy with the fact that a focus on business customers has helped in resolving problems of quality faced by customers (Morgan, 1997). The concept of a shared value base acting as a "glue" to strengthen and guide collaborative efforts, is also put forward by Walter and Petr in their template for family-centered collaborative care. These authors emphasize that without anchoring objectives, goals and other dimensions of collaborative efforts in a shared value base, interagency collaboration is futile. They present a model with a shared focus on service users' needs, more specifically family-centered values, as the core value system for interagency collaboration (Walter & Petr, 2000). As such, the shared needs-led focus seems a key to the strength of collaboration in the Van Celst model.

The other way around, the professionals in this collaboration project explained how the very intensive interagency exchange served the goal of providing needs-led care, and could ameliorate services for those with MCN. The joint efforts enlarge the spectrum of available services and resources and increase continuity of care, allowing for a better adjustment to the individual needs of each adolescent enrolled in the program. In the literature, the potential of interagency collaboration in meeting the needs of those with MCN (Keene, 2001; Rosengard et al., 2007) and in serving complex public (health) goals in general (Bryson, Crosby, & Stone, 2006) is widely highlighted.

Thus, starting from this collaboration model and consulting the literature, there seems to be a bidirectional beneficial relationship between this intensive type of interagency collaboration and providing needs-led care as a part of optimizing the care delivery for youths with MCN. Indeed, having the adolescents' needs as a shared focus, anchors and guides collaborative efforts, facilitating intensive interagency collaboration. The other way around, far-reaching interagency collaboration, combining resources and expertise from different sectors in a structural and coordinated way, seems very valuable to realize needs-led services.

Second, the intensity and comprehensiveness of collaboration is important. In the literature on factors facilitating interagency collaboration in agencies for child mental health (Cooper et al., 2016), the most important facilitators are: good interagency communication, joint trainings, good understanding and knowledge of each other, but also mutual respect, trust and valuing, and senior management support. All of these facilitators can be put in place by an intensive collaboration model like the one described in this paper, wherein a lot of effort is put into integration and exchange of information on the level of the organization, and integration on the level of the professionals, leading to trust, knowing each other and each other's working frame, joint trainings adapted to the daily practice, and a top-down as well as bottom-up integration. In a broader perspective, it is interesting to see that some principles of this collaboration model are also in line with what the public administration literature puts forward as guidance for cross-sector collaboration in general (Bryson et al., 2006). Stronger cross-sector relations are formed when single efforts to solve a public problem have failed, when partners share the problem vision, when formal agreements support accountability, and when cross-sector collaborations use each sector's specific strengths and confer mutual gain. Other important conditions include investing in continuous trust building and regular reassessment.

While most findings regarding intensity of collaboration in our study are in line with earlier literature on intensity of collaboration in child-serving agencies, the collaboration model described here differs in two ways. First, in this project, the CW and CAP staff are employed in two different settings, although the CAP staff goes to the CW center for a certain number of hours per week. As mentioned, this design has benefits for both the adolescents and the professionals: ensuring continuity of care, the benefits of separating therapy from daily life activities, offering an external perspective and access to an entire CAP service as well as other medical specialists. In the literature however, some authors point out that interagency collaboration was – or could be – facilitated through co-location: for instance, through sharing an office but also by spending time at the same site, as was the case in our model (Cooper et al., 2016). In interviews with statutory child mental health workers, co-location was said to be important for effective collaboration (Spong, 2013), and being based in the same location was also said to facilitate joint working between mental health and schools in a survey and case studies (Pettitt, 2003). However, as studies mostly do not detail the actual extent of co-location that is meant, it is difficult to compare to our collaboration model.

Another potential tool or strategy for intensive collaboration, described by some authors in the literature, that was not used in this collaboration project, is assigning a case manager who can help ensure good communication and service receipt by children involved with multiple agencies. For example in a project on integration in child serving agencies in CW, school and mental health sectors, assigning a care coordinator was associated with a greater use of mental health services by vulnerable young people (Chuang & Lucio, 2011). Another project revealed that a model with a single case coordinator who collaborated across service providers was effective with court-referred clients and their families for increasing family intimacy and child well-being and for decreasing family danger and conflict (Coll, Stewart, Morse, & Moe, 2010). In our collaboration model however, thanks to the intensity of collaboration, and the design with two closely collaborating agencies building a broader network, partners did not feel the need for such a case manager position: the two partners take and share this role of coordinator together. When even more partners are involved, or less intensive integration occurs, a case coordinator may well be very valuable.

A third interesting point made by the professionals in this study is the fact that a very far-reaching integration is beneficial, but that at the same time autonomy, identity and differentiation of each of the collaborating partners should be safeguarded. Keeping the original focus, roles and expertise of their agency makes the best use of the complementary resources and expertise that both partners have. Completely

merging CW and CAP approaches, leaving part of the resources and vision of each behind, would make the uniqueness and specialized expertise of both less available for service users. By keeping the expertise that differentiates them, the collaboration has more potential than a multidisciplinary team, because two sectors are truly collaborating. This idea put forward by the professionals engaged in this collaboration model shows analogy with guiding concepts in the literature about inter-organizational collaboration. Indeed, by introducing the concepts of integration and differentiation in organizational structures, Lawrence and Lorsch published a foundational work in organizational contingency theory (Lawrence & Lorsch, 1967). For collaboration to be effective, organizations must balance the somewhat antagonistic conditions of differentiation and integration (Willumsen, Ahgren, & Ødegård, 2012). Differentiation retains organizations' or sub-organizations' specialization, the differing forms of practice, culture, and relationships. Differentiation has been viewed as the primary means of promoting the diversity needed in organizations in order to meet complex environmental demands. The organization should be differentiated enough to match the degree of differentiation and complexity of its environment. At the same time, the more differentiated (and thus complex) an organization is, the more it needs to be integrated and coordinated in order to be effective. Integration refers to the unity of effort, to aggregation and/or homogenization (Toubiana, Oliver, & Bradshaw, 2016).

The balance and optimization of both differentiation and integration in order to be effective, is not only true for organizations but also for networks of organizations, where meeting complex goals in an effective manner requires a dimension of differentiation (specialization), at the same time as integration (coordination) (Buck, Seale, Leiter, & Taylor, 2011).

An extensive review of the literature on collaborative public management also points to the importance of focusing on distinctive competencies of the collaborators, and highlights the importance of building on such distinctive capacities for efficient cross-sector planning (Bryson et al., 2006). These inputs from different perspectives or disciplines can make those planning interagency collaboration in child serving agencies aware of the fact that both a high degree of integration, and at the same time attention for differentiation, are important keys to success.

Fourth, besides the intensity of collaboration, it is also interesting to consider the network structure of this collaboration project: a CW facility and CAP hospital services engaged in a very intensive collaboration in order to provide adequate care delivery for adolescent girls with MCN. However, other "external" partners are also involved in service delivery for this population, but on a less intensive and more case-dependent basis, and

form a larger network around the CAP–CW partnership. The literature on network structure and governance provides some arguments to support such a design of an intensely collaborating core, embedded in a broader network. Two influential studies in the field of network structure and governance researched the overall effectiveness of networks in the adult mental health policy field in achieving desired outcomes from the client perspective (Provan & Sebastian, 1998; Provan & Milward, 1995). They described how a centralized network organized around a leading core and more loosely related to other agencies in a network, is beneficial for service delivery to users and professionals, rather than aiming for the same degree of integration throughout in strong and densely tied networks.

Limitations of this study are the fact that no detailed observational data is included and, as with any in depth description of a particular setting, attention must be paid when generalizing findings. A clear strength is the fact that nearly all involved professionals from very different backgrounds and positions in the project were included. Also, there were different backgrounds and reference frames in the researchers' team.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conclusion

Collaboration is put forward as a promising strategy for ameliorating care delivery for the most complex cases in child serving agencies. In this paper, the structure and guiding principles of a cross-sector collaboration model between CAP and CW are presented. By means of a high intensity collaboration regarding both structural and people factors and with a focus on the youths' needs as a shared value base, this collaboration aims to optimize services for adolescent girls with multiple and complex needs. The high extent of integration and the needs-led approach may have a bidirectional beneficial effect. Attention must be paid to both integrating and differentiating services. The core of CAP–CW forms the center of a broader collaboration network. Comparing this model to literature on interagency collaboration in child serving agencies, but also considering the key principles of the collaboration model in the context of broader knowledge from public administration and network governance data, can contribute to the reflection process when planning interagency collaboration for vulnerable populations.

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CHAPTER 6

Collaboration Between Child and Adolescent Psychiatry and Child Welfare for Adolescent Girls with Multiple and Complex Needs: an Evaluation by Adolescents, (Step)Parents and Professionals*

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Abstract

Collaboration is put forward as a promising strategy to optimize care delivery for the most vulnerable populations.

The objective of this research was to explore how adolescents, (step)parents and professionals evaluate an intensive collaboration between a child welfare residential center and a tertiary child and adolescent psychiatric facility, aiming to optimize care delivery for adolescent girls with multiple and complex needs. This was done using in-depth interviews with nine adolescents and twelve (step)parents, along with focus groups with 44 professionals.

Several benefits were identified: 1. care delivery is better tailored to meet individual needs; 2. access to mental health services and therapy implementation and follow-up are ameliorated; 3. focus on integration into society as well as on psychiatric support; 4. capacity and efficiency of care delivery is enhanced. Potential pitfalls and points that warrant attention were also mentioned: 1. preserving agency of clients; 2. maintaining the identity of the collaborating partners and openness to professionals outside of the collaboration; 3. safeguarding continuity of care; 4. supporting individual professionals and teams.

Findings illustrate the potential of collaboration in working with adolescents with multiple and complex needs. They highlight the importance of keeping the needs of adolescents and families as a main focus, while also being attentive to professionals' needs.

Collaboration between Child and Adolescent Psychiatry and Child Welfare for Adolescent Girls with Multiple and Complex Needs: An Evaluation by Adolescents, (Step)Parents and Professionals

The literature confirms the anecdotal experience in social and health sectors that complex cases are increasing in frequency (Bass, Shields, & Behrman 2004; Webb et al., 2014). A growing number of persons experience “multiple and complex needs” (MCN), as a reflection of severe difficulties in different intertwined domains encompassing physical and mental health problems, family problems and social exclusion, educational issues, unemployment or justice involvement (Keene, 2001). Their needs are both “deep” (intense, severe) and “broad” (situated on different interacting domains) (Rankin & Regan, 2004).

Adolescent Girls with MCN are Especially Vulnerable

In this heterogeneous group of persons at the extreme of a spectrum of case complexity, gender and developmental age influence the consequences of MCN. A dimension, specific to the growing population of adolescents presenting MCN, is the developmental impact of their difficulties, putting personal development and integration into society at stake (Burnside, 2012). Also of particular importance in up-growing children and adolescents with difficult family situations is an “impaired protective system” that fails to meet their needs, and can aggravate a range of medical, mental, social and developmental problems (Child Welfare Information Gateway, 2006; Malvaso & Delfabbro, 2016). Girls with such complex needs are known to be even more vulnerable – regarding both psychosocial and physical health, and access to care – than their male counterparts (Handwerk et al., 2006; Hussey & Guo, 2002). Adolescent girls with MCN are likely to be involved with child welfare (CW), child and adolescent psychiatry (CAP), as well as the juvenile justice system. They are often sent from one facility to another, as no adequate support is available and their overwhelming and unmet demands undermine the confidence and aptitude of health and social care professionals (Burnside, 2012; Grisso, 2008; Pajer, 1998). (Over)consumption of health and social care, along with higher unemployment rates and risk of criminal involvement associated with some of the problems they present, yields a high societal cost (Burnside, 2012; Keene, 2001; Pajer, 1998).

Collaboration is Promising in Order to Optimize Care Delivery for those with MCN

No one organization or sector of care delivery has all the resources, skills, or reach to address both the personal needs of adolescents with MCN and their families and at the same time the social and economic factors that aggravate the complexity of these needs (Hornberger, S., Martin, T., & Collins, J., 2006). Several authors argue that it is critical to integrate services, particularly mental health, CW, juvenile justice and

substance abuse, to improve quality of care (Kodner & Spreeuwenberg, 2002; Anglin, 2004; Hornberger e.a., 2006) and that MCN can only be met through cross-sector collaboration among child-serving agencies (Chuang & Wells, 2010; Keene, 2001; O'Reilly et al., 2013). Cross-sector collaboration can be conceptualized as independent, yet interconnected sectors (e.g. health and social sectors) working together to better meet the needs of consumers and improve the quality and effectiveness of service provision when facing complex issues that they cannot tackle on their own (Bryson, Crosby, & Stone, 2015; Winters, Magalhaes, Kinsella, & Kothari, 2016).

Benefits of collaborative practice in child serving agencies are described (Cooper, Evans, & Pybis, 2016). However, collaboration between children's services is far from straightforward to implement, and the assumption that collaboration is inherently beneficial has been questioned (Horwath & Morrison, 2007; Hughes, 2006). Especially in cross-sector service provision, the different backgrounds such as health versus social work can complicate the establishment of common goals and a shared vision that anchor the collaborative efforts, due to differences in use of language, organizational cultures and procedures (Huxham & Vaugen, 2000; Winters et al., 2016).

Current research is seldom evaluative, doesn't offer a common language to describe collaboration nor provides consistent recommendations as to how to address challenges that agencies face when aiming to optimize care delivery for children and adolescents through collaboration. The pitfalls or challenges of collaboration do not receive enough attention and few studies seek to include service users as stakeholders (Horwath & Morisson, 2007; Winters et al., 2016).

Multi-Perspective Evaluation of Collaboration Initiatives is Necessary

The importance of evaluating the effects of specific interagency practices rather than just assuming their positive effects, is clearly pointed out (Wong & Sumsion, 2013). However, when evaluating services, service user perspective is not often included in studies about care delivery for adolescents (Cooper et al., 2016; Mayne & Howitt, 2015). Especially when considering publications about cross-sector services aiming to improve the care provided to consumers, an umbrella review about cross-sector care provision in health and social care by Winters and colleagues (2016) points out that the voice of the consumer is strikingly absent. This is an important missed opportunity, as investigating the parents' and adolescents' perspective on care delivery may give important insights into the need for and impact of these practices, highlighting aspects that are not captured in clinical outcomes alone, or in professionals' perspectives alone (Calheiros & Patrício, 2014; Ocken,

2004). While there is a research focus on collaboration in order to ameliorate mental health for vulnerable adolescents (Greene, Ford, Ward-Zimmerman, Honigfeld, & Pidano, 2016), to our knowledge no multi-perspective evaluation of the practical implementation of an intensive collaboration project for adolescents with MCN has been done to date.

This leads us to the central research question addressed in this study: What is the perspective of adolescents with MCN, their (step)parents and professionals on an innovative cross-sector collaboration project between CAP and CW? The account of adolescents with MCN, their (step)parents and professionals about what they identify as benefits and pitfalls in this cross-sector collaborative care, can enrich our knowledge about care delivery organization for this challenging population.

Methods

Design

This research project is part of an overarching Participatory Action Research (Bradbury & Reason, 2003) that aims to optimize services for adolescent girls with MCN. The impetus for this study came from the CW and CAP agencies starting an innovative collaboration project. In line with the Participatory Action Research principles, we collaborated closely with the clients and professionals, via frequent meetings with the different stakeholders (adolescents, relatives, professionals) and the assignment of a “steering group” and “expert group” with representation of adolescents, relatives and professionals, that guide and evaluate the research project. Goals, research questions, data collection and findings were discussed with all parties involved in each step of the project. Taking into account the preferences of adolescents, their (step)parents and professionals regarding data collection, we opted for individual in-depth interviews with adolescents, because we were seeking to understand the individual meaning of given phenomena and concepts from these participants, and wanted to eliminate the peer influences and anonymity issues. The perspectives of professionals were collected in focus groups, because we believed the group interaction in these multidisciplinary groups would add to richness of the data collected (King, 1994).

Setting

The collaboration project studied in this research is located in Belgium. CW and CAP do not typically collaborate very intensively in Belgium. This could be attributed amongst others to the fact that (Mental) Health and Welfare are regulated and financed by different governments in the Belgian federal system. The regional Welfare government allocated a specific budget to this collaboration project. Tables 1 and 2 provide

information about the collaboration project and the role of both partners in this project. This collaboration is specifically set up for adolescent girls with MCN. These girls have a combination of psychiatric problems and a family environment that does not provide safety and stability. A history of (physical, emotional or sexual) abuse or neglect is very common. Most of these girls have a combination of internalizing (mostly depression) and externalizing (mostly conduct disorder) difficulties. Further group level characteristics are: high-risk behavior (such as suicide attempts, self-harm, teen prostitution, substance abuse), physical problems and school dropout. In this project, all girls reside in the CW facility. A large majority of them is referred by juvenile court and each of them has had multiple out-of-home placements.

Table 1. Description of the collaboration program

Characteristics	Description in collaboration project
Outcomes: Goal and purpose of program	Treatment: intensive services for mental health and social needs, to provide a stable living environment and continuity of care.
Size: Population density	Two group-based, and two independent living programs and ambulatory aftercare program.
Population: Adolescents served	Adolescent girls with multiple and complex needs. Referrals in a majority from juvenile court, also child and adolescent psychiatry and social services.
Setting and location	Urban, freestanding home.
Program model: Approach or framework that organizes interventions	Innovative: Collaboration between child welfare and child and adolescent psychiatry. Holistic child welfare focus with family service orientation ^a . Approach in the facility guided by principles of New Authority ^b and Institutional Pedagogy ^c and some of the child and adolescent psychiatry interventions based on Dialectical Behavioral Therapy ^d
Practice elements: Activities within the program	Mental health services offered through very intensive collaboration between child welfare and child and adolescent psychiatry. Independent living skills, family involvement, educational

	programming, recreational programming, psychiatric diagnosis and treatment when appropriate. Trauma oriented program ^e
Staffing: Model, training	Shift staff, specific training (by child and adolescent psychiatrist)
System influences: Macro level forces that provide resources	Oversight from child welfare and mental health. Initially project funding
Restrictiveness: Standards set in the living environment to meet safety, developmental or therapeutic needs	This residential care facility is gated, not locked

Note: This reporting follows the standards described by Lee and Barth (2011) in Lee, B. R., & Barth, R. P. (2011). Defining Group Care Programs: An Index of Reporting Standards. *Child and Youth Care Forum*, 40(4), 253-266. <http://doi.org/10.1007/s10566-011-9143-3>

^aHetherington, R. (2002). *Learning from difference: Comparing child welfare systems*. Keynote Address at the Positive Systems of Child Welfare Conference, Waterloo, ON.

^bOmer, H. (2001). Helping parents deal with children's acute disciplinary problems without escalation: the principle of non-violent resistance. *Family Process* 40 (1), 53-66.

^cOury, F. and Vasquez, A. (1968). *Towards institutional pedagogy/Vers une pédagogie institutionnelle*. Paris: Maspéro.

^dLinehan, M.M. (2015). *DBT Skills Training Manual* (2nd ed.). New York: Guilford Press.

^eStruik, A. (2010) Sleeping dogs? Awake them! A stabilisation technique for chronically traumatized children. Slapende Honden? Wakker maken! Een stabilisatiemethode voor chronisch getraumatiseerde kinderen. *Pearson Benelux Clinical*.

Table 2. Input from child welfare and from child and adolescent psychiatry in the collaboration project

	Child welfare	Child and adolescent psychiatry
Joint input	<p>Joint <i>intake</i>: establishing goals and planning with adolescents (and relatives) who start the program</p> <p>Joint <i>team meetings</i>: decision making and evaluation for all cases: 2.5 hours, every 2 weeks</p> <p>24/7 <i>availability</i> of CW supervisors and child and adolescent psychiatrist: dialogue, advice, crisis assessment</p> <p>Communication with <i>external partners</i> (schools, adult services, ...)</p> <p><i>Stakeholder meetings</i> to evaluate the project together with other partners in youth care or related domains: every 6 months</p> <p>All <i>decisions in the care planning and implementation and regarding the collaboration itself</i>, are made together by CW and CAP, with joint responsibility but respecting each other's field of expertise.</p>	
Input from each partner	<ul style="list-style-type: none"> - <i>safe and stable daily living environment</i>, group care setting - <i>independent living skills</i> - <i>contextual working</i>, focus on relationship with relatives, building a social network - focusing on safety, reducing <i>high-risk behaviors</i> - focusing on <i>societal integration</i> (including administration, school work, ...) 	<p>For adolescents:</p> <ul style="list-style-type: none"> - <i>short consultations</i>: 2 hours every 2 weeks - <i>diagnostic testing</i> - <i>ambulatory therapy</i> (verbal and non-verbal, individual, group, family) - residential or semi-residential crisis or <i>treatment service</i> (including time-outs) - <i>psychopharmacological treatment and medical coordination</i>

		For staff: - participation in <i>management meetings</i> : 1.5 hours every month - advice or participation in <i>case evaluation meetings</i> - <i>super- and intervision</i> : 1.5 hours every two weeks - <i>training</i> on CAP specific topics: 3 hours every two months
Staff	24 persons investing full working days in the CW facility - administrators: 3 fte - team coordinators (social workers): 3 fte - psychologists: 2 fte - family social workers: 3 fte - social workers: 13 fte	8 persons investing part-time working days in the CW facility but providing 24/7 permanency - coordinating child and adolescent psychiatrist: on-site approximately 2 days a week, ensuring permanency - second child psychiatrist: part time, in the facility on indication, ensuring permanency - psychologists: 4 fte, in the facility on indication - dietician: 1 fte on indication, working in CAP - social worker: on indication, working in CAP

Note: fte stands for full time equivalent

Population

We used convenience sampling, and after discussing the research project on stakeholder and team meetings and with the adolescents and parents, we officially invited the potential participants verbally (adolescents and parents) or by email (professionals). We included 9 girls (mean age 16.8 years, mean duration of enrollment approximately 2 years) and 12 parents (9 biological parents and 3 stepparents; 4 couples and 4 single mothers) of 8 girls who were enrolled in different phases of the program. Additionally, we did 6 focus groups with 30 out of 32 potential professionals working in the residential facility or the CAP hospital and involved on a daily basis in the collaboration project, and an additional 14 out of 20 potential professionals who work in other agencies but play an important role in the care delivery for the girls enrolled. In these 44 participants, all disciplines involved in the project and in the global care delivery for these girls were represented. Reasons for not participating were time constraints or illness.

Data Collection

A literature review and exchanges with the different stakeholder groups assisted in the design of an interview guide for both the in-depth individual interviews and the focus groups.

The mean duration was 75 minutes for the interviews and 150 minutes for the focus groups. Individual interviews were conducted by the first author (child and adolescent psychiatry trainee), with another researcher (clinical psychologist) observing and taking field notes, and a third one joining for the external focus

groups. Focus groups were undertaken by the first author and another researcher (professor in anthropology) in the moderator respectively observer role (taking field notes). Individual interviews and focus groups were structured around a series of open-ended questions about how the collaboration project was perceived. An example of a question from the adolescent interviews is: *“Is there something they [professionals involved] would have to watch out for, in order to make the project valuable for the adolescents enrolled?”* An example of a question from the focus groups is: *“What is your perception of the effects of this collaboration project on the level of the organization?”*

Although the collaboration went through a development process with more difficulties in the first period (Van den Steene, van West, Peeraer, & Glazemakers, 2018), during these focus groups no specific power issues or contradictions were observed.

Interviews and focus groups were audiotaped and transcribed verbatim. When we had interviewed 9 adolescents respectively 12 parents, and based on interim analysis, we stopped recruitment as we judged that the interviews were rich in details of personal descriptions of their situations, also referred to as “thick description” (Malterud, 2012). There was considerable variation in the kinds of experiences described, and detailed contextual information was provided. Also, several participants expressed similar views independently (e.g., the benefit of more tailored care delivery was mentioned by nearly every participant). By conducting six focus groups, we had enrolled nearly everyone who is closely involved in the project and had rich data from different professional perspectives (different professional backgrounds and different roles in the collaboration project).

Data Analysis

An additional researcher (last author) joined the team for data analysis. We used NVivo-11 (QSR International, Doncaster) to assist with management of data.

Verification of findings (Creswell, 1998) was achieved by different strategies: discussion of the interview guide between researchers; one researcher taking field notes in the “observer” role in both the individual and focus groups interviews; debriefing after the interviews; negotiating themes and interpretations until agreement was achieved in data analysis; and allowing member checking by inviting each participant to provide any additional information or clarifications that they wished after reading a copy of their transcript.

We used systematic text condensation (Malterud, 2012) and followed the four steps described in this approach to data analysis: (1) every researcher read and re-read the transcripts to obtain an overall impression

and find preliminary themes. Identification of themes was conducted separately in a first phase, and researchers then met to discuss and agree on the final themes; (2) each researcher identified units of meaning characterizing diverse aspects of the perception of the collaboration project, and coded for these; (3) researchers summarized the contents of each of the code groups into a condensate; and (4) re-conceptualized the data, writing an analytic text and adding useful quotations. Re-reading the original transcript ensured goodness of fit with the final code groups and themes. Language equivalency in the translation from Dutch to English was assured through review by a researcher fluent in both languages.

Credibility was enhanced by prolonged engagement of researchers in the facility, by researcher, method and source triangulation, member checking; whereas an audit trail and negative case analysis enhanced dependability (Lincoln & Guba, 1985). The audit trail, detailing context and rationale for all research decisions also enhanced conformability.

Author Reflectivity

The professional background of the researchers was closer to the CAP setting, compared to CW, which could have shaped interpretations towards a “CAP” reference frame. However, as a part of the participatory action research, researchers got familiarized with the way of working and the organizational culture in the CW facility and the exchanges with all stakeholders allowed for continuous checking of interpretations.

Results

This results section gives an overview of the benefits and pitfalls identified during the interviews and focus groups. Table 3 shows the benefits, as identified by the different participants. Table 4 illustrates the pitfalls they mentioned. This section is built on analytical texts representing synthesized condensates and illustrated by quotes.

Benefits of the Collaboration from the Perspective of Adolescents, (Step)Parents and Professionals

Table 3. Benefits of the collaboration from the perspective of adolescents, parents and professionals

Adolescents	(Step)parents	Professionals
Care delivery can be better tailored to the individual needs (of girls with MCN) including continuity of care		
Broader/more possibilities Non-disruption of contacts with known professionals	Broader/more possibilities More specialized treatment options Increased placement stability	Broader/more possibilities More specialized treatment options Better coordination in each individual case Increased placement stability
Adolescents and parents have better access to mental health services, and implementation of (psychological or pharmacological) therapy is better		
Lowered threshold (presence on-site, limited waiting list, more information) More exchange between “therapy” and daily life	Lowered threshold for adolescents and parents and motivating adolescents to engage in therapy (stigma reduction, involving and informing relatives regarding therapy, no financial threshold, continuous motivation by better-informed social workers in the facility, limited waiting list, presence on-site)	Lowered threshold (stigma reduction, limited waiting list, presence on-site) Better coordination and follow-up of psychotherapy or medication (more knowledge about possibilities, more exchange and feedback between professionals)
Specific attention for daily living skills and integration into society		
Not only focusing on (psychiatric) difficulties, but also on integration into society (focusing on daily living skills, school, ...)	<i>This aspect was discussed by (step) parents with a focus on “tailored care” (care delivery can be better tailored to the individual needs (of girls with MCN) including continuity of care)</i>	Providing a more “regular living environment” (compared to psychiatric hospitalization) and combined expertise that can enhance daily living skills and integration into society (focusing on contacts with peers, leisure time activities school, administration, ...)
Enhancing service capacity and efficiency		
	Enhanced skills and expertise of professionals in the facility Support for the professionals	Enhanced skills and expertise of professionals in the facility Support for the professionals, who feel empowered Enhanced efficiency thanks to better information exchange (more useful referral, more adapted advice, less loss of information) and preventing the same intervention being done twice Potentially reducing costs Developing and strengthening of the care delivery networks

Individually tailored care, enhanced continuity of care. Tailoring services to meet the needs of adolescents with MCN is a major benefit of the collaboration project, with two main aspects being emphasized. First, collaboration adds to the variety of possible forms of support and treatment that can be offered; second, continuity of care, identified as a major necessity in this population, is enhanced.

The profound and widespread needs of the adolescent girls who are enrolled in the program can be addressed thanks to the combined resources of both facilities, by having more specialized expertise to assess or treat some of the issues they encounter and by allowing for more coordinated care delivery. Independent living skills (self-care, cooking and administration) can be learned, alongside with treatment aimed at trauma or certain medical issues. The girls explain how in their experience, other institutions, that are less engaged in interagency collaboration, struggle to offer this broad spectrum of care delivery possibilities.

I find this collaboration a very good idea. Because in the end, all children here, who have experienced some difficulties, they all have psychological issues. And not every facility has these resources. In a previous facility where I resided, they couldn't understand what was happening to me and they didn't know what to do (...). Here, with child psychiatry, I have learnt a lot about it, about myself. I've had several therapies and went to the child psychiatrist – I found that really helpful. (adolescent interview 6)

Parents also emphasize the need for the combined expertise of different sectors in order to meet the complexity of needs.

This collaboration enables a more tailored approach to care delivery, where clients' needs guide care delivery, as this exchange between a policy maker in youth care and a social worker illustrates.

- at the same time the support here, like with administration, cooking, everything. We can ensure these adolescents a complete care, a safe and stable place to live, school, medical attendance, ... and also psychiatric and psychological; thus, striving for that continuity of care and meeting the needs thanks to truly working together. (focus group 3)

The fragmentation that characterized the care delivery trajectory of these girls, who were typically referred from one facility or psychiatric hospital or juvenile justice institution to another, is halted, and continuity of care is achieved thanks to the joint responsibility taken by the different collaborating partners. This is mostly addressed by adolescents as a non-disruption of contact with professionals they come to know and trust, and by parents and professionals as increased placement stability. Indeed, the CAP and therapists (some of whom they already know due to CAP hospitalizations) stay involved, and therapies continue, even during hospitalizations or a (short) stay in a different residential setting (in a juvenile justice institution or another CW or CAP institution). This aspect of continued contact is very important for the adolescents.

That [continuing to see people you know and trust] is so important, I have been on time-out a few times. The social worker and the psychologist came to see me. They come and see how you are doing and you can also call them, that is very good. (girl interview 5)

Another aspect of the notion of continuity is that longer care trajectories are possible thanks to this collaboration. This enhanced placement stability is mainly highlighted by parents and professionals. They relate it to the fact that there is less need for referral to other agencies.

The professionals also notice this large increase in placement stability and relate the continuity of care to better outcomes with the adolescents.

Considering their past, when we look at how long some of the girls have been able to stay here, that's such an amelioration! ... For example, the girl with 34 institutions in 6 years' time, and now she has been here for almost two years! That's fantastic. Also, the other girls who have had complex trajectories with psychiatry, juvenile institutions, ... and now they've been with us for a while. That stability is so valuable. (...) (focus group 3)

Better access to and implementation of mental health services. Concerning mental health services, two main ideas emerged: first, this collaboration lowers the threshold for engaging in any form of CAP

assessment or treatment; second, collaborating can optimize implementation of several forms of therapy or treatment.

Adolescents and their parents have better access to mental health care (assessment, therapy, psycho-education) thanks to the collaboration. They report that the threshold to engage in any form of CAP support is lowered. The adolescents themselves explain this by the fact that they can have assessments or counseling on-site, do not have to be on a waiting list and have a better knowledge of the options available. However, parents and professionals add that the collaboration contributes greatly to reducing stigma toward mental health care, and eliminates the financial threshold for parents (it is not charged separately). They also emphasize that the social workers are now much better informed and have an important role in motivating the adolescents.

One of the adolescents explains the benefits of having the possibility to have assessments or treatment in the facility, rather than having to go to CAP.

When we have a long school day and then in the evening a consultation at CAP, it's like "forget about it, I am too tired for that, I don't go there". But if the therapists come here, then it goes all right. If you leave it up to us, that doesn't work, when we have to go there. (adolescent interview 2)

Shorter or absent waiting lists for counseling and other CAP support are very valuable in reducing the threshold.

Being able to go there quicker, that helps. Instead of making appointments, waiting until they check who is available and staying on a waiting list. Because the waiting list in CAP is horrible. (parent interview 1)

Professionals from CW explain that the threshold towards CAP is reduced, because therapies are an integral part of the residential care options and the psychiatrist is on site, at fixed moments in the week. The CAP offer has become "mainstream", as some describe it, and it is not an "extra", something that puts any of the adolescents in an exceptional position.

- Yes indeed. The adolescents don't feel like "I'm crazy, I have to go to psychiatry" – because that stigma is still alive, there is a big taboo. Here, it's more like, "there are several options here and how

can we, together with psychiatry, look at what might help you: medication or counseling or something else". (focus group 1)

Another aspect, mentioned by a professional, is that this low threshold contact with CAP offers the girls the opportunity to get into contact with "psychiatry", and may reduce the threshold on for asking help later in their life.

At a young age and in a safe way, they get to know options that otherwise they would not have known. So, I think that is another way this collaboration benefits their further life. They come into contact with a psychiatrist ... maybe they don't do therapies here, but they have had contact and the high threshold to accept further intensive help is reduced for some of these girls. (focus group 2)

Besides lowering the threshold for engaging in assessment or treatment, another benefit of this collaboration is that therapy implementation can be optimized for adolescents and their family. Adolescents explain how the close contact between the CAP therapeutic setting and the CW facility enables them to make a link between what they have learnt in therapy and their functioning in daily life in the facility. The social workers in the facility know the focus of their therapy or treatment and know how they progress, so they can feed back observations from daily life at the facility to the adolescents and therapists. Professionals underscore that the fact that CW and CAP collaborate closely, results in a better coordination and follow-up of psychotherapy or medication. Professionals from both agencies have a better knowledge of the options available and of important aspects to monitor when engaging in a treatment or therapy. Moreover, the frequent exchange and feedback between professionals allows a closer follow-up.

We did the group therapy about emotion regulation. We were together in that therapy and meanwhile we could learn to get along with each other, as with the emotions, here at the facility. So really this way you can do something with it in daily life. (adolescent interview 4)

Concerning the optimization of therapy, professionals explain amelioration of pharmacological treatment of these girls with MCN thanks to the collaboration project. The need, adherence and effects of medication can be very closely monitored, and youth and social workers are better informed regarding effects and potential side effects of medication. It is particularly useful to have professionals who see and know the girls on a daily basis and can monitor the therapy effects.

I really see the difference in relation to medication. When they've found the right product for them you see an amelioration in the emotions, behavior ... Before this project, adolescents got medication prescribed, they took it, sometimes only once in a while, and no one further looked at it or evaluated. Now we are constantly monitoring that aspect. (focus group 6)

The exchange between the social workers in the facility and the therapists from CAP is very valuable in all phases of a therapeutic process.

It's that spiral, that interaction that is so valuable. We motivate the girl, we can tell the psychologist from CAP what works for her, how she's best approached, they tell us how they get to know them and what we can monitor here related to the therapy, in the living situation, and we feed that back to them. I feel like we provide so much better care that way. (focus group 1)

Specific attention for daily living skills and integration into society. Another advantage of this collaboration project is that psychiatric assessment or treatment can be given, with at the same time particular attention to daily living skills and integration into society. In the day-to-day life in the facility, the adolescents are supported in self-efficacy, school, and administrative tasks, and social workers focus on the “normal” aspects of life, more than could be done in a psychiatric hospital setting. Both adolescents and professionals emphasize that it is exactly this combination of a safe and structured living environment with a focus on integration into society, with at the same time the possibility of specialized psychiatric assessment and treatment, that can meet the needs of adolescent girls with MCN.

For professionals, meeting the psychiatric needs of these girls, but also focusing on integration into society, is greatly facilitated by the collaboration, as this team leader in CW explains.

This [adolescent girls with MCN] is the population you need such a collaboration for. These are issues that no agency can manage alone, they overwhelm you. Before, the link with psychiatry didn't exist, and we didn't have the resources to face the issues these girls have, like the self-harm, dissociation, the need for medication, ... And psychiatry didn't offer long care trajectories and didn't focus on the daily living skills. We [CW] can address their "normal", "healthy" part and help them to function in society. So there really was a gap, but here, all resources come together. (focus group 4)

The girls also emphasize the advantages of this collaboration, regarding integration into society.

You can live here, at the facility, but you go to the hospital school in CAP. And then you can have your classes there, or occupational therapy and your other therapies at daytime, and you sleep here. So you have all the therapies, but you don't have to stay in the hospital and can continue learning to live more independently here, and you to continue your school if you can't go to the regular school. That's really good. (adolescent interview 4)

Enhancing service capacity and efficiency. Another major benefit of the collaboration, mainly reported by parents and professionals, is the fact that the competence(s) of individual professionals and capacity of the organizations are greatly enhanced. Professionals report that before working together, the needs of these adolescents made them feel incompetent at times, and caused a lot of tension in the teams, often ultimately leading to a referral to another facility. Professionals repeatedly describe that this collaboration project empowers them. A first way in which the collaboration project strengthens the professionals is by allowing them to master new skills and gain expertise thanks to broader experience and cross-sector training. This enables them to tackle situations that were difficult to handle in the CW setting before (severe self-harm, dissociation due to trauma, ...). A second way in which the collaboration project

enhances the professionals' capacity is by facilitating mutual support for professionals from both organizations, which allows them to stand stronger when working with this very vulnerable and challenging population (facing aggression, secondary traumatization, ...). The fact that responsibility is shared and professionals "stand together" for all cases and during the complete stay, really allows to work with these adolescents on a longer and more secure base, rather than passing on the buck. Cases that are more complex can now be handled, as described by the child psychiatrist.

Thanks to the fact that we share the burden, we can achieve a lot more. I lively recall a girl with psychotic symptoms. Had she been in another facility, she could never have stayed there. But because I saw the girl every week here, they [CW professionals] felt it was OK, she was monitored psychiatrically. We have given them tips on how to handle it here on a day-to-day basis. Together we came to the conclusion that it was best to keep her here. It is so valuable that this girl could stay in the stable environment here at the facility, and that it is not just CAP being used for a hospitalization during the CW stay. (focus group 3)

The reciprocal support that is part of the collaboration is essential.

Support is very important with these MCN, because they need so much care in different domains and it is exhausting. Those complex needs really are fundamental, as they can undermine teams and make them powerless. (focus group 3)

Several professionals describe how they feel empowered by the collaboration project.

With all the trainings and the joint meetings, we really feel like we can stand our ground, we are becoming the experts in some way, we feel stronger. (focus group 1)

Efficiency of service delivery is enhanced thanks to better information exchange and because a close collaboration between services prevents the same work being done twice. There is less loss of information, and

referrals and consultations are much more efficient because professionals both take responsibility for all cases, and because they know each other's reference frame and organizational culture.

By limiting the placement changes and the care delivery fragmentation, this intensive collaboration reduces the administrative and financial load of care delivery for these adolescents with MCN.

Bureaucratically, always switching institutions, that costs a lot of effort and money. Always the starting up, the files and reports ... (focus group 1)

Also, knowing the large costs that can be expected from a population of adolescents with MCN due to their bad prognosis, helping this population in an adequate way has the potential of significantly reducing costs for society.

Cost-reduction in the future too – yes, that also is one of the goals of this project. Because we see that these adolescents are the ones that cost a lot of money to society when they grow up and as adults. Hospital admissions, not being able to go to work, difficulties in taking care of their children, costs due to suicide attempts and stays in intensive care ... The consequences of these problems as adolescents are huge when they are adults, if we don't provide the right care. The collaboration is also preventive that way. (focus group 2)

Moreover, the collaboration forms and strengthens the broader care delivery networks. The CAP and CW institutions collaborating in an intensive manner strengthens the ties and ameliorates communication with other partners in the care delivery network, as illustrated by a youth care policy maker.

In the search for tailored care trajectories, but also above the case-level in policy of care networks, it is very valuable to have a small network of partners who collaborate very closely, and to integrate that in a larger network of care delivery agencies. This creates a strong bond between organizations that is necessary to ensure continuity of care and security by everyone. (...) This is a collaboration on several levels. It is not only multi-sectorial but also intra-sectorial, it is not only multidisciplinary, but also

interdisciplinary. The more integration between and within different sectors and disciplines, the more complex cases you can handle. (focus group 5)

From the viewpoint of the general practitioner, the collaboration project has also ameliorated the somatic care for the girls enrolled in the program.

In general, in facilities, you prescribe medication, but you don't have enough information about patients, and you don't know if they'll be taking it. Here, thanks to the expertise the social workers have built up, and the continuous dialogue with the CAP, we can avoid the problem that these young people take much medication, we can always check both the physical and psychological components and we know there will be follow-up for the medication. That gives us a feeling of security. (focus group 6)

Pitfalls from the Perspective of Adolescents, (Step)Parents and Professionals

Table 4. Pitfalls for the collaboration from the perspective of adolescents, parents and professionals

Adolescents	(Step)parents	Professionals
Agency and autonomy of adolescents should be respected in spite of the growing capacity and complexity of care delivery		
Adolescents should be informed of all possibilities in care delivery and be maximally included in planning their own care delivery, in spite of the growing complexity	Adolescents and parents should be informed and maximally participate in care delivery planning, in spite of the growing complexity	While therapy plays an important role in the care delivery, it cannot be made compulsory. The adolescents should be maximally involved in the therapy choices
While therapy plays an important role in the care delivery, it cannot be made compulsory. The adolescents should be maximally involved in the therapy choices		A deontological and legal frame for sharing information is needed
Despite far-reaching integration, the collaboration partners should keep their own identity and roles to a certain extent and be open for other care providers outside the collaboration		
Social workers should keep their (confidants) role in spite of the	Close collaboration between two or more partners should not restrict contacts with other care	The identity and expertise of both collaborating partners should be respected/kept

presence of psychologists	providers	
Close collaboration between two or more partners should not restrict contacts with other care providers		The collaborating partners should actively enlarge the collaboration network

All facets of continuity should be monitored, despite the complexity of starting up a collaboration

Continuity in contacts with known and trusted professionals is very important and is challenged by trainees, people leaving or joining the collaboration, ...		Placement stability is very important and, despite the organizational pressure to have a higher turnover, no duration limits should be put (additional to the age limits) on the duration of support
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The functioning of individual professionals and teams should be monitored and supported

Support for social workers and other professionals is necessary in order to prevent dropout	The workload (and pressure/expectations) brought about by the collaboration and the challenges of working with a very vulnerable population should be watched, and debriefing and counseling offered
	Team building activities can help to progress to a strong and united team, in spite of the organizational changes and challenges

Agency and autonomy of adolescents should be respected in spite of the growing capacity and complexity of care delivery. A major pitfall of the more complex care delivery system that comes along with collaboration between agencies, is diminishing the feeling of control that service users have over their own situation. It is very important to aim for a maximal participation, in spite of more partners being involved, more options available and more complex communication paths. Also, in spite of a more explicit focus on mental health assessment and care, brought about by the collaboration with CAP, the choice to engage in screening or therapy should still be discussed with each youth individually, without the assumption that each adolescent enrolled will (immediately) engage in assessment and/or therapy. Several of the adolescents illustrate the importance of having an input in decisions about therapy.

Another adolescent illustrates the importance of finding a balance between motivating them, and being too “pushy”.

There are many girls and I am one of them, who feel like “I don’t want a psychologist”. I don’t want to talk about my problems all the time. But then when they come after you the whole time: “it would help you, you should try and go to a psychologist at CAP, they can help you there” ... I think that can be inconvenient for some adolescents. I was like that, before, when I didn’t have therapy. I found it terrible that they spent their time saying, “you should go to the psychologist at CAP”. Now I’m quite glad I have my psychologist and so, but it had to be when I was ready, not them pushing me. (adolescent interview 8)

Particular attention must be paid to several aspects of information sharing. Information sharing between agencies has benefits in terms of quality and efficiency of care delivery. However, it also entails risks for the autonomy and privacy of adolescents whose personal information is now shared in a much larger network. Adolescents emphasize that all information sharing must be viewed critically and can only occur in the best interest of the youth. Professionals also call for a clear deontological and legal frame for information sharing.

Yes, everything is passed on, to the CAP and to the facility ... I don’t like that. You want some privacy at the doctor’s! If you go and consult for something delicate, you don’t want them to send out an email to everyone. (...) And here with the social workers, there’s a file “private information”, but that’s still accessible for all 8 social workers in my group. (adolescent interview 8)

A juvenile judge argues that information sharing is crucial when dealing with MCN.

I think that is crucial. If we don’t share the information, you can set up any kind of organization, it won’t work. You need to share the information in a network – I mean, I know that a lot of partners

argue that it is a medical secret or the trusting bond with the youth. That is true, but it is “outdated” and not applicable in these kinds of cases. (focus group 6)

Despite far-reaching integration, the collaboration partners should keep their identity and roles to a certain extent, and be open for other care providers outside the collaboration. Despite a call for maximal integration, it is a pitfall to lose the individual roles and expertise of the collaborating partners. Adolescents emphasize that social workers should keep their (confidants) role, and not refer adolescents instantly to the psychologists who joined the team thanks to the collaboration.

One of the adolescents illustrates how they want social workers to keep their original role, in spite of the new possibilities offered by the collaboration.

When I don't feel so well, and just want to have a chat with someone, I go to the social workers and I just want them to listen to me, to have a conversation about it. I don't want them to send me to the psychologist “go and talk to them”. (adolescent interview 1)

On the organizational level, professionals also emphasize that the expertise and focus of both collaborating partners should be safeguarded in spite of a far-reaching integration. For example, both the medical model and assessment and treatment options from the CAP setting, as well as the focus on a safe, structured and nurturing living context provided by CW are necessary. The “thinking alike” that grows while collaborating, should still be attentive to the original expertise and focus that make the complementarity of both settings.

A social worker illustrates the importance of keeping the expertise and functions of each collaborating partner.

We don't have to become a part of them, and they have to keep their expertise too. In the beginning we had to search for that balance, maybe we became too dependent and followed their vision too

much, because it was so helpful! But now each has different but equivalent expertise that's important. (focus group 1)

Also, despite the far-reaching integration between CW and CAP, they should be open to other care givers, outside the collaboration. Adolescents who want to engage in an alternative therapy or seek a second opinion regarding medical issues, must be able to do so, outside of the program designed by the collaboration. There must be an openness and even an active investment to develop care delivery networks adjusted to the needs of this specific population.

Some adolescents reported they felt like consulting professionals (doctors or therapists) external to the collaboration, was discouraged, and perceive this as a lost opportunity for their evolution.

Other professionals or services? Oh, but they're not open to that! Once I suggested something like that – maybe it was a bit difficult because it is something they don't have in this CAP hospital. And I asked for it and they said no, because you are supposed to go to there. (adolescent interview 6)

All facets of continuity should be watched, despite the complexity of starting up a collaboration. Adolescents and professionals point out different pitfalls related to providing continuity of care. Indeed, the difficulties associated with the starting phase of this collaboration project led to a turnover of professionals, which is perceived as a disruption in continuity of contacts with known professionals, in spite of a maintained placement stability.

You can have someone you trust already, so that you don't have to have someone new. Because that irritates most girls here, and me too, having to trust someone new. Because the last half year there were new people, different psychologists, and that is hard for me. (adolescent interview 7)

Professionals highlighted the importance of not putting time restrictions on the duration of stay of adolescents in the facility (other than the legal age limits). Despite the fact that this may lengthen the waiting list for enrolment in the collaboration program, adolescents must have the guarantee that they can stay in the facility as long as needed, in order ensure continuity of care.

We need that time with them. It's only after like 6 months or even 18 months that they come to trust you, because they've lived so much. If you then have to start preparing for them to leave, that's not continuity. (focus group 2)

The functioning of individual professionals and teams should be monitored and supported. Parents and professionals highlight the pitfall of overcharging professionals in the collaboration project. In spite of all benefits that professionals experience, this collaboration project also leads to increased demands put upon them. First, whereas before they would at times have one or a few cases with this level of complexity in the facility, now all girls enrolled in the project have significantly more complex needs. Professionals are confronted with more aggression, traumatic stories, and very difficult family situations. Second, the collaboration project brought about additional responsibilities and time-consuming tasks such as meetings and training. The same goes for the team functioning, as large organizational changes can lead to a turnover of team members and complicate the team functioning. Therefore, attention must be paid to the workload and emotional challenges faced by the professionals closely involved in the project. Major benefits are associated with debriefing as well as team building activities.

Parents show a lot of respect for the work that is done, but are worried about the initial higher turnover of social workers.

I really respect what they get done, even if you only have two like mine! (...) But still they should be thinking about what is going on, because a lot of them left, disappeared. If you see in the three years we've been here, how many different individual social workers she [daughter] has had? Maybe they get too much on their shoulders. (parent interview 5)

The social workers emphasize the additional demand the collaboration puts upon them. They have to invest time and energy to enhance their skills and expertise, and in order to optimize the exchange with the partners in the collaboration.

It's so very valuable, but it makes everything more intense, a lot more demands. The trainings, the meetings, coordinating with partners, ... the workload is enormous. (focus group 4)

Discussion

Drawing upon in-depth interviews with adolescents and (step)parents of girls with MCN, and focus groups with professionals, the aim of this study was to conduct a multiperspective evaluation of an innovative cross-sector collaboration between CW and CAP. Enriching the knowledge on cross-sector collaboration as a potential way of meeting the needs of those with MCN, is valuable for planning and implementation of further care delivery.

The main benefits of this collaboration are: care delivery is better tailored to meet the individual needs including continuity of care; access to mental health services and the implementation and follow-up of (pharmacological or psychological) therapy are ameliorated; there is a strong focus on integration into society; the collaboration enhances the expertise and resources of care delivery. Main pitfalls are: agency of clients must be preserved; identity and roles of the collaborating partners and openness to professionals outside of the collaboration must be maintained; facing the growing complexity, continuity of care must be a continuous focus; individual professionals and teams should be monitored and supported.

These findings can be related to the existing knowledge and offer some insights for clinical practice. First of all, our findings illustrate the statement of the literature on MCN, that highlights the importance of collaboration in order to meet the depth and breadth of needs experienced by those at the extreme of a spectrum of case complexity (Rosengard, Laing, Ridley, & Hunter, 2007). Specialized care as well as a safe and stable living environment, with the combined expertise of different professional backgrounds, can better be achieved when complementary agencies collaborate. Rather than dealing with different issues in a

compartmentalized way, collaboration between agencies allows for a holistic approach that is more efficient and convenient for families with multiple needs (Young & Gardner, 2002; Cooper et al., 2016). This was clearly endorsed by all participants in our study, and illustrated by the larger therapeutic possibilities available, and the fact that a focus on societal integration could be combined with attention and care for mental health.

Moreover, our findings also demonstrate that this collaboration addresses another characteristic of MCN. Those families who require support services the most, are often the least likely to access them (Centre for Community Child Health, 2010; McKay & Bannon, 2004). This is especially true for mental health services for young people in out-of-home care (Ford, Vostanis, Meltzer, Goodman, & Ord, 2007; Malvaso & Delfabbro, 2016). Collaborations between agencies can increase families' willingness to use services that will benefit them. More streamlined approaches within collaborative delivery are shown to be promising in order for clients to receive services in a more timely manner, and can ameliorate access to mental health services for adolescents in care (Chuang & Wells, 2010; Schmid, Goldbeck, Nuetzel, & Fegert, 2008). Indeed, these adolescents, who previously had difficulties in access to care and had very fragmented care delivery, now report a lowered threshold towards CAP. Not only the access to a more complete care delivery is enhanced, but also the placement stability. Adolescents mainly highlight the continuity in trusting relations with professionals, which can be enhanced by this project. Professionals put emphasis on the fact that this collaboration project enables the current CW center to ensure placement stability, because thanks to the shared responsibility, they have no need to refer the adolescents to another facility. Earlier research demonstrated that integrating CW and behavioral health services – joint training as well as working in the same larger agency – can result in fewer moves (Chuang & Wells, 2012; Cooper et al., 2016). Increased placement stability holds the potential to ameliorate behavioral health and well-being, educational achievement and adult criminal involvement (Daining & DePanfilis, 2007; DeGue & Widom, 2009; Rubin, O'Reilly, Luan, & Localio, 2007)

This is not only related to the package of treatment options that is larger when collaborating, but especially due to the integration of services that strengthens the individual professionals, organizations and networks. Professionals feel empowered, and strong care delivery networks are formed, thanks to better communication, information sharing and mutual support. This positive reaction of professionals to interagency collaboration in child serving agencies, and the benefits identified at the level of the professionals and the larger care delivery network, are in line with earlier research (Oliver, Mooney, & Statham, 2010).

When considering the pitfalls perceived by the service users and professionals in this study, most important is to have the service users' needs as a starting point, and to maximize participation. The literature confirms – especially for those with MCN – the importance of recognizing the failure of generalist services, and tailoring services to the individual needs (Horwath & Morisson, 2007; Winters et al., 2016). This can avoid the pitfalls regarding agency, role identity and openness to other professionals, and ensure continuity of care (Winters et al., 2016). Family-centered models, defined as programs in which families' needs and desires determine all aspects of service delivery and resource provision, and the concepts of needs-led youth care (Dunst, Trivette, & Hamby, 2007; Metselaar, van Yperen, van den Bergh, & Knorth, 2015), offer a valuable framework valuable in this respect.

This project made maximal use of the input of service users and illustrates how a multi perspective evaluation can lead to valuable information about services. Involving service users is crucial to the success of integrating child serving agencies (Winters et al., 2016). Aside from benefitting parents and children, the involvement of service users in collaborations and partnerships has also been theorized as adding to the effectiveness of the collaboration as a whole (Head, 2011). The involvement of service users brings additional, “local” knowledge that can be useful for targeting resources where they will be most effective. The involvement of parents and adolescents may further enhance the better identification of problems and can encourage services to remain focused on what parents and children need (El Ansari & Andersson, 2011; Gal & Duramy, 2015).

The functioning and well-being of the individual professionals and the team is another important issue. Parents and professionals alike highlighted the importance of installing sufficient support for the professionals involved. Indeed, earlier research suggests that interagency collaboration across childcare services may increase the workload, undermining the effectiveness of professionals (Oliver et al., 2010; Cooper et al., 2016). Being attentive to the needs of professionals indirectly benefits the adolescents by enhancing the quality of their work and preventing a high turnover of professionals. Working with these vulnerable adolescents puts extremely high demands on the professionals involved, as they deal with aggression incidents and are exposed to secondary traumatization daily. Moreover, the large organizational changes brought about by the start of the innovative collaboration project put even more demands on the professionals involved. Therefore, the functioning and well-being of the individual professional and the team must be closely

monitored, as reported also in an umbrella review on cross-sector collaboration between health and social care by Winters and colleagues (2016).

We are aware that caution should be exercised when clients are reporting high levels of satisfaction, since these may be the consequence of face-to-face interviews that can lead to more positive satisfaction ratings than if questionnaires are completed in relative anonymity (Godley, Fiedler, & Funk, 1998).

The findings and recommendations in this study cannot automatically be transferred to other settings and populations. This project could, however, inspire other professionals and researchers who work with vulnerable populations whose complex needs call upon expertise and resources from different sectors. Recommendations are made to comprehensively assess the needs of the target population, and to select complementary partners who take joint responsibility to address these needs. It would be interesting, in further research, to compare the perceptions concerning this collaboration project to other collaboration initiatives for vulnerable populations. This qualitative exploration could also be used as a basis for the development and use of quantitative tools and/or evaluations of collaboration projects for adolescents with MCN.

Conclusion

Adolescents with MCN, their (step)parents and professionals evaluated an innovative collaboration between CAP and CW. They identified benefits for service users (including a more complete approach that better met their needs) and for professionals (empowering individual professionals and strengthening care delivery networks). They also called for a continuous needs-centered approach in order to avoid possible pitfalls (such as limiting agency, being restrictive in the collaboration partners) and highlighted the importance of providing the necessary support for professionals and teams.

Lessons for practice are, that the presumed benefits for clients and for professionals of collaboration in order to meet MCN, seem to be perceived from different perspectives in the case of this cross-sector collaboration project between CAP and CW. However, several challenges and pitfalls are brought about by the increasing complexity of care delivery when more agencies are involved. Keeping a family-centered perspective and being attentive to the needs of the professionals involved, seem good strategies to limit these difficulties. Apart from these insights into collaboration projects for vulnerable populations, our research puts forward the importance of participation of clients in the design, implementation and evaluation of care delivery and the value of participatory action research as described herein.

Compliance with Ethical Standards

This study was approved by the ethics committee of the University of Antwerp/University Hospital of Antwerp (B300201525959). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

All participants were fully informed and gave their written informed consent prior to participation in the study.

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CHAPTER 7

Professionals' Views on the Development Process of a Structural Collaboration Between Child and Adolescent Psychiatry and Child Welfare: An Exploration Through the Lens of the Life Cycle Model*

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Abstract

This study, as a part of a participatory action research project, reports the development process of an innovative collaboration between child and adolescent psychiatry and child welfare, for adolescent girls with multiple and complex needs. The findings emerge from a qualitative descriptive analysis of four focus groups with 30 professionals closely involved in this project. They describe the evolution of the collaborative efforts and outcomes through time. Participants describe large investments and negative consequences of rapid organizational change in the beginning of the collaboration project, while benefits of the intensive collaboration only appeared later. A shared person-centered vision and enhanced professionals' confidence were pointed out as important contributors in the evolution of the collaboration.

Findings were compared to the literature and showed significant analogy with the Life Cycle Model (LCM) for Shared Service Centers, that describes the maturation of collaborations from a management perspective.

The findings of this study enrich the knowledge about the development process of collaborations in health and social care. In increasingly collaborative services, child and adolescent psychiatrists and policy makers should be aware that gains from a collaboration will possibly only be achieved in the longer term, and benefit from knowing which factors have an influence on the evolution of a collaboration project.

Professionals' Views on the Development Process of a Structural Collaboration Between Child and Adolescent Psychiatry and Child Welfare: An Exploration Through the Lens of the Life Cycle Model

For the promotion of health, and delivery of welfare services adapted to the needs of users, models of inter-organizational and interprofessional collaboration have been launched for decades, all over the world (World Health Organization, 1986; Rivard & Morrissey, 2003; Department of Health & NHS England, 2015). Collaborative projects have also been at the core of child mental health and social services policy, since overcoming the fragmentation in services for the growing and challenging population of young people with multiple and complex needs (MCN) can only be accomplished through collaboration among child-serving agencies (Keene, 2001; Rankin & Regan, 2004). Existing research identifies potential benefits of collaboration in child serving agencies, for patients, professionals and organizations (Hurlburt et al., 2004; Bai, Wells, & Hillemeier, 2009; Rowlandson & Smith, 2009; Oliver, Mooney, & Statham, 2010). Professionals in health and social services are increasingly being called to collaborate not only around individual patients but also at the practical and system levels (Fritsch, Schlesinger, Habeger, Sarvet, & Harrison, 2016). Increased investment in collaborative working is especially relevant for mental health services, given the changing role of child and adolescent psychiatry (CAP) (Fritsch et al., 2016).

However, whilst a useful and motivating concept, collaboration is challenging and is characterized by a complex development process (Oliver et al., 2010; Hughes, 2006; Horwath & Morrison, 2007; Smith & Mogro-Wilson, 2007). Earlier research suggests that the manner in which the development towards collaborative working is handled, paying attention to building trusted networks and nurturing relationships, is as important as any of the decisions about goals, governance or structures (Horwath & Morrison, 2007; Hamblin, Keep, & Ask, 2001). As Kodner and Spreeuwenberg (2002) state, more efficient care is merely a “hope” when engaging in collaborative projects. Hence, before making pronouncements on the strategy’s cost-effectiveness, a thorough calculation and monitoring of all costs is necessary, and collaboration projects must be reviewed systematically (Wong & Sumsion, 2013).

Some of the frameworks for collaboration (D’Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005) describe stages in the process from initiation through implementation. Kagan (1991) describes the development of collaborative relationships in three stages: the beginning stage, when the collaboration is forming and making plans; the growth stage, when plans are implemented in programs and policies; and the evaluation stage, when results are examined and decisions are made about whether or not to make changes. In

the related field of interprofessional education, a more recent publication by Khalili, Orchard, Laschinger and Farah (2013) describes similar stages in the development of interprofessional collaborative person-centered practice. Other authors concentrate on the planning of interagency development and describe sequential steps in this process (Horwath & Morrison, 2007; Smale, 1996). Hodges, Hernandez and Nesman (2003) present stages of collaboration in which agencies plan and deliver services for a particular population, and emphasize the need for a parallel development of interprofessional and family-professional ties.

However, the health and social literature seems to offer little guidance concerning the development process or the expected timeline of challenges and benefits when engaging in collaboration. Indeed, collaborative projects could benefit from knowledge on what progress should be expected during the process of the collaboration. Hence, our central research question is: What are CAP and Child Welfare (CW) professionals' perspectives on the development process of cross-sectoral care in the start-up of an intensive collaboration project? A secondary question is: What are the underlying factors that influence the development process of a collaboration project?

Methods

In this participatory action research (McTaggart, 1994) about care delivery for adolescent girls with MCN, the professionals participated in every step of the research project: setting goals and choosing methods, discussing intermediate findings and directing further research steps. In order to describe the development process of the cross-sectoral collaborative care project (CSCC), a collaboration project for adolescent girls with MCN, the perspective of involved professionals was explored in focus groups.

Setting

The innovative care delivery project studied in this research is located in Antwerp, Belgium, and started one and a half years prior to the focus groups. It offers residential and ambulatory care for girls aged 14–21 years, who have MCN. In this project, CAP and CW engage in an intensive, equivalent and bidirectional collaboration on all hierarchical levels (table 1). They take joint responsibility and work simultaneously to optimize care delivery for these vulnerable girls whose needs could not be met by CAP nor CW in isolation. The collaboration was initiated by the CW and CAP organization, faced with the challenges brought about by adolescents with MCN. It received regional funding from the Flemish Government. Basic agreements on the input of both partners were made at the beginning of the project, but the collaboration was regularly evaluated and roles and tasks changed according to the needs of the population served.

Table 1. Input of CW and CAP in the collaboration project

	Child welfare	Child and adolescent psychiatry
Joint input	<p>Joint <i>intake</i>: establishing goals and planning with adolescents (and relatives) who start the program</p> <p>Joint <i>team meetings</i>: decision making and evaluation for all cases: 2.5 hours, every 2 weeks</p> <p>24/7 <i>availability</i> of CW supervisors and child and adolescent psychiatrist: dialogue, advice, crisis assessment</p> <p>Communication with <i>external partners</i> (schools, adult services, ...)</p> <p><i>Stakeholder meetings</i> to evaluate the project together with other partners in youth care or related domains: every 6 months</p>	
Input from each partner	<ul style="list-style-type: none"> - <i>safe and stable daily living environment</i>, group care setting - <i>independent living skills</i> - <i>contextual working</i>, focus on relationship with relatives, building a social network - focusing on safety, reducing <i>high-risk behaviors</i> - focusing on <i>societal integration</i> (including administration, school work, ...) 	<p>For adolescents:</p> <ul style="list-style-type: none"> - <i>short consultations</i>: 2 hours every 2 weeks - <i>diagnostic testing</i> - ambulatory <i>therapy</i> (verbal and nonverbal, individual, group, family) - residential or semi-residential crisis or <i>treatment service</i> (including time-outs) - <i>psychopharmacological treatment and medical coordination</i> <p>For staff:</p> <ul style="list-style-type: none"> - participation in <i>management meetings</i>: 1.5 hours every month - advice or participation in <i>case evaluation meetings</i> - <i>super- and intervision</i>: 1.5 hours every two weeks - <i>training</i> on CAP specific topics: 3 hours every two months
Staff	<p>24 persons investing full working days in the CW facility</p> <ul style="list-style-type: none"> - administrators: 3 fte - team coordinators (social workers): 3 fte - psychologists: 2 fte - family social workers: 3 fte - social workers: 13 fte 	<p>8 persons investing part- time working days in the CW facility but providing 24/7 permanency</p> <ul style="list-style-type: none"> - coordinating child and adolescent psychiatrist: on-site approximately 2 days a week, ensuring permanency - second child psychiatrist: part time, in the facility on indication, ensuring permanency - psychologists: 4 fte, in the facility on indication - dietician: on indication, working in CAP - social worker: on indication, working in CAP

Note: fte stands for full time equivalent

Data Collection and Sample

In January and February 2016, we conducted four focus groups at the CW center, with a total of 30 professionals involved in the collaboration project. A literature review on MCN and collaboration assisted in the design of an interview guide. Examples of the starting questions were: *How did the collaboration project develop? Did you notice changes when you compare the current situation to the beginning? What was*

underlying to those changes? Two researchers conducted the focus groups (moderator and observer taking field notes), a third one joined them for data analysis. Each focus group lasted for about 150 minutes, was audiotaped, transcribed verbatim and anonymized. After four focus groups, the data were rich in details of professionals' descriptions of the development of the collaboration project, referred to as "thick description" (Malterud, 2012).

In order to achieve an interprofessional in-depth description of the CSCC, we used a purposeful sampling strategy. Potential participants were professionals from CW and CAP closely engaged in the CSCC. Thirty-two persons were approached verbally, of whom 30 gave their written consent for voluntary participation in the focus groups (94% participation rate). The distribution of professions over the focus groups was representative for the collaboration project. The two persons who did not participate were a child and adolescent psychiatrist and a CW administrator, and their reason for not participating was time constraints. Table 2 illustrates the distribution of participants.

Table 2. Composition of the focus groups

Focus group number	Focus group 1	Focus group 2	Focus group 3	Focus group 4
Group	CW	CW	CAP	CW
Number of participants	8	8	8	6
Professions	CW administrator (n=2) Psychologist (n=1) Social worker (n=5)	CW administrator (n=1) Psychologist (n=1) Team coordinator (n=2) Social worker (n=3) Family social worker (n=1)	CAP (n=2) Psychologist (n=4) Social worker (n=1) Dietician (n=1)	Team coordinator (n=1) Social worker (n=3) Family social worker (n=2)

This table illustrates the composition of the 4 focus groups and for each focus group details the number of professionals and their background.

Data Analysis

Data analysis was performed using the procedure for systematic text condensation, as described by Malterud (2012). In this approach of qualitative analysis, four sequential steps are performed: 1. the three researchers read the transcripts multiple times in order to obtain an overall impression, and each of them identified preliminary themes. Discussion between the three researchers led to agreement on the final themes

(e.g. “development process at an organizational level” or “factor driving the development”); 2. each researcher identified units of meaning that characterize diverse aspects of the development process of the collaboration and coded for these, whereas parts of the transcript not relevant to the research question, were removed from the analysis; 3. after discussion between the researchers, the content of each of the code groups was summarized into a condensate; and 4. data was re-conceptualized, and an analytic text with useful quotations was written. Re-reading the original transcript ensured goodness of fit with the final code groups and themes. These texts and quotations were translated from Dutch to English. Review by a researcher fluent in both languages assured language equivalency. NVivo 11 assisted with coding and management of data.

Credibility was enhanced by prolonged engagement of researchers in the facility, by researcher, method and source triangulation, member checking; whereas an audit trail and negative case analysis enhanced dependability (Lincoln & Guba, 1985). The audit trail, detailing context and rationale for all research decisions also enhanced conformability. For example, verification of findings was increased (Creswell & Poth, 2017) by discussion of the focus group interview guide between researchers; observator taking field notes during the focus groups; debriefing after the focus groups; discussion and negotiation of themes and interpretations until agreement was achieved; member checking by providing the opportunity to check the transcripts, and by feeding themes and interpretations back to participants in order to ensure that participants' own perspectives are represented. Researcher triangulation by means of in-depth discussion between researchers occurred right after the focus groups and after coding.

Author reflectivity

Main researchers were a clinical psychologist, a PhD student in CAP training, and an anthropologist. The educational background of the first author is closer to the CAP setting than to CW. However, as a part of the participatory action design, a close contact with the CW-setting has taken place since the start of the collaboration project. Participants knew the researchers and the research project, without researchers being involved in the daily practice of the CSCC.

Results

Our findings outline the development process of the collaboration and are structured by describing the changes on the professional, team and organization levels. Professionals also described what they considered to be the underlying factors driving the maturation of this collaboration. This section is built on analytical texts representing synthesized condensates and illustrated by quotes.

Description of the Development Process of the Collaboration

Individual professional level. For the professionals, core elements of the change process were a change in attitudes and the process of getting to know the population and the professionals in the other agency. Through the first months, an attitude change towards more acceptance of the psychiatric needs and enhanced belief of the value and feasibility of helping this population in a CW setting occurred. At the start of the project, CW staff members were not familiar with psychiatric problems and considered them as “not fitting in CW”. These girls were indeed announced as presenting – besides the contextual issues that CW was used to focus upon – a comprehensive traumatic history, concerning personality development, behavioral problems, self-harm and suicide attempts. This initial attitude was illustrated as:

“That’s not for us, she’s a girl for psychiatry”, we’d use to say. (social worker, focus group 1)

Despite the intent to take joint responsibility in a collaboration project, there was initially much doubt regarding the feasibility of care delivery to this population within a CW-setting. At the time of the focus groups, professionals were convinced of the benefit for the girls to stay in CW, despite psychiatric problems:

Now, we have a different feeling compared to the start – having a team that, for example, exudes something like “that’s a tough case here, that’s one for psychiatry” – if that’s the attitude in a team, the girls feel that immediately. That attitude doesn’t exist here, or much less. There you see the change in attitudes towards these young people, and they feel that, too (psychologist, focus group 3)

The changing attitudes due to the evolution of the collaboration project also lead to a de-stigmatization of psychiatry.

Accessibility and visibility make the difference. When we previously spoke of psychiatry – we didn’t speak of psychiatry, it was “therapy” we said – then it was always like “I’m not crazy huh, I just have problems”. Now, in fact, that is no longer what they say. Sometimes the girls say “I’m not enthusiastic”, but they don’t see it as an additional label. That is also because child psychiatry is present in our center. (family social worker, focus group 4)

A second process that professionals describe at the individual level, is getting to know each other. At the start of the project, CW and CAP professionals were not familiar with each other's vision and procedures. Getting to know each other's setting and goals supported the aforementioned change in attitudes and ameliorated the collaboration. The process of getting to know each other and engaging in formal and informal communication facilitated joint working and developing common routines.

It was the perception of the professionals that as the investments in the collaboration were so large and all routine was lost due to the large organizational change, the care delivery and client-centeredness was diminished.

In that first period, we had to invest so much time and energy into making that collaboration work! Making appointments, discussing everything, adapting to all changes – we spent so much more time enabling that collaboration than actually seeing the girls together or having them in therapy sessions. (child and adolescent psychiatrist, focus group 3)

Team level. In the initial months of the implementation of the collaboration, several professionals left, apparently due to large organizational changes and the challenges set by the new population. The current team is constituted of very motivated people who actively choose to work with these adolescents with MCN. Clarity about “who are we?” (identity) and “what do we do?” (approach) further helped the development of a team spirit. It has, however, also been indicated that “taking care of the team” is still of great importance:

Every single professional working here wants to work with these girls. I think that is very bonding. I now feel that we are more like one team, while not so very long ago it was a very different situation. I think we as a team really need attention – because I think we can still evolve. (CW administrator, focus group 1)

The team dynamics appear to be an important catalyst of the collaboration project. Truly being one team, crossing CW and CAP boundaries, strengthens and supports professionals in the face of the severity of problems presented by these adolescent girls.

The togetherness, feeling that you are not alone – that we form one team with CAP and not two separate services – because we have a totally different outlook and approach, but we really are one true team – we all feel that now. (CW administrator, focus group 2)

Organizational level. At the level of the organization, after a period of changing procedures and roles, accompanied by a loss of efficiency, an evolution towards effective communication, clear joint routines and role definition, and a balance between the two complementary ways of working is described.

When I see how it evolved, how the approach has changed – how the crisis situations you are constantly confronted with here, are handled now – this initial anxiety of “how are we going to tackle that?” compared to what is achieved now – incredible what we now can attain here. (CW administrator, focus group 1)

A lot of effort was put into developing an approach that meets the needs of these girls with MCN, and which both partners in the collaboration can endorse. Only after several months and with considerable effort, joint procedures became clearer, certain routines were streamlined and the care delivery has shifted from an “ad hoc” approach to a more proactive action.

In the beginning, you desperately seek answers to “oh my god, how do we do this?” Back then, we went to the team meeting the same day to find some solutions, but now we start to really have a proactive approach, also as a team – how to handle crises and certain behavior – we know how to address our population, we have the procedures. (social worker, focus group 2)

At the start of the collaboration project professionals’ roles were not sufficiently clear, but with time the various tasks and responsibilities were better defined.

In the beginning, it was not really clear who was going to have which role and task. Because we already had psychologists here, I thought – “there are psychologists and therapists coming from CAP?”

Why?" ... – but the role of the psychiatrist was immediately clear: advice and team meetings and consultations and medication monitoring ... But now, we have indeed progressed, now that that is clearer, the collaboration certainly has benefits. (family social worker, focus group 4)

Communication has been hugely invested in from the very start of the project. At the time of the focus groups still, much time and energy was spent on dialogue, exchange and coordination. Initially a common language and communication pathways had to be developed. According to these professionals, collaboration is most effective when both formal and informal communication is used and face-to-face consultation as well as mail and telephone communication takes place. A lot of communication efforts were invested in conditions that enable the therapy and strengthen the collaboration.

Everything surrounding it, to enable that contact between you and the girls and to maintain, to feed and to let further grow this collaboration, you need to spend an incredible amount of time. (child and adolescent psychiatrist, focus group 3)

At the time of the focus groups, there is such a far-reaching integration that a new professional identity, specific to the CSCC project, is being formed.

So, you're creating your own culture, and that culture, I think you can also see that in what we are currently proclaiming. (social worker, focus group 1)

Factors Driving the Positive Evolution of this Collaboration. In these focus groups, shared vision and value base seem to anchor the collaborative efforts. The professionals express their motivation to make a difference in these complex cases and relate this to the collaboration.

These are young people who have been in many institutions – because of their problematic behavior they didn't belong in psychiatry; and they cannot stay in a regular institution because of the problematic behavior and the psychiatric behavior. So where could they get proper help? Nowhere!

Then it's nice to know that some of the girls who previously got stuck, can now be helped. (social worker, focus group 1)

From the start of the collaboration project, there was a clear and common goal, guided by the urgent needs in service delivery for adolescents with MCN. The commitment and focus on a common goal increases the willingness of all partners:

We are no longer looking at each other and waiting – previously everyone had their own agenda – now it's just one shared goal and you also know each other much better, and I think that it makes it more of a “team”; that makes continuity possible. (child and adolescent psychiatrist, focus group 3)

Participants describe a person-centered attitude as the core of the shared vision.

Our girls are the core of this collaboration. And that's what connects us. (CW administrator, focus group 1)

The target population is central in this whole CSCC project and is described as a “unifying factor” between the professionals. Therefore, they are not only the focus of the collaborative efforts, but the solidarity a person-centered approach entails is also a facilitating factor for common efforts.

Participants describe how the collaboration project strengthens them by making them feel supported by the collaboration partners when facing the challenges of working with adolescents with MCN, and by enhancing their knowledge and skills. Empowerment, with a focus on enabling professionals to gain confidence, appears as guiding in the positive evolution of the CSCC project.

A key element in the empowerment process is the training by the child and adolescent psychiatrist in the CW setting, which enhances knowledge and expertise among care providers. This cross-sector training contributes to understanding the background of certain problems and provides guidelines for addressing them, making the professionals more confident. The need to have a framework to understand behavior, is also related to the gravity of problems presented by these adolescent girls with MCN.

You have to be able to find a reason for their behavior, I guess. These girls are very cool ladies, but their behavior ... You get scolded, there is suicidal behavior, yes, it is really hard work, if you don't have a basis of what is this, why is this happening, and I think you could not manage it. While now, thanks to working together with the child and adolescent psychiatrist, you have more background and you know more about, say, self-harm ... (team coordinator, focus group 2)

The child psychiatrist also describes these trainings as empowering for the CW professionals:

The goal is to give the team there training on CAP issues, so they are actually strong enough to handle, to grasp and to understand them. So, there's a lot of training, but in those weekly meetings we also give a lot of advice. (child and adolescent psychiatrist, focus group 3)

The working relationship was also strengthened by the joint meetings and training. Having a shared reference frame lowers the threshold to inform each other, facilitates the development of a shared care delivery plan and increases the possibilities for mutual support.

You see that during joint meetings or after trainings, we speak the same language. It increases the trust we have in each other. And its makes it easier to call each other and ask "hey, what do you think?" (social worker, focus group 2)

Besides the training, the relational aspects of the CSCC project also have a positive effect on the (self-) confidence of the professionals, and in this way, are also empowering. Thanks to the partnership, the professionals feel supported when confronting problems.

Collaboration also allows for growth. I think we sometimes dare to keep a girl in our facility rather than to send her away, because there is confidence, we get support, we are not alone. I think it really makes a difference if you have to evaluate those cases on your own, without psychiatry, or when it is a psychiatrist who actually doesn't know the setting, the team and the case, who judges it – that's not

the case here – As we gain confidence, we trust CAP and are therefore more confident in ourselves, because we trust them. (team coordinator, focus group 4)

In addition, not only CAP and CW, but also the rest of the network feels this empowerment and is influenced by it. Thanks to the good basic care and continuity offered, and because CAP is available for advice for partners too, schools, juvenile justice institutions and youth court are also strengthened.

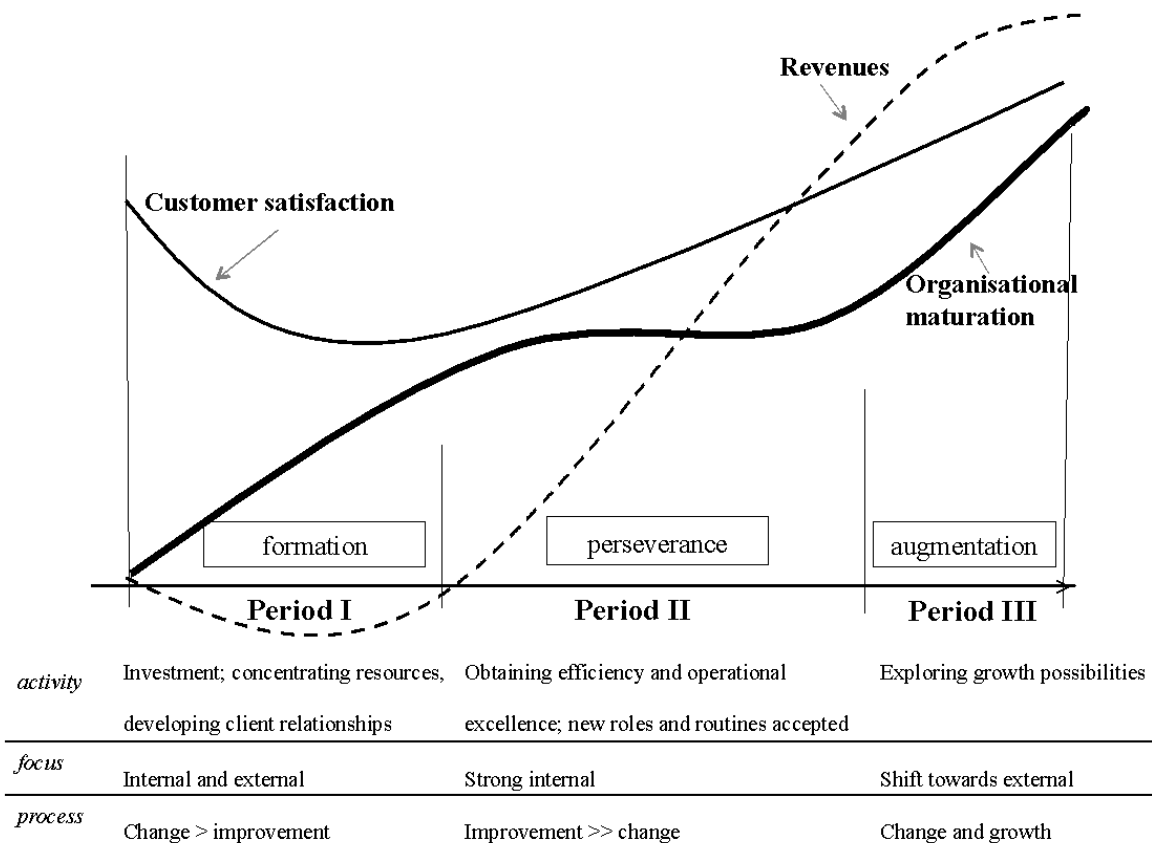
You find yourself pushing back the juvenile court into their position, almost saying please, for once, take your responsibility and do not fear that psychiatric part. And there we also have a really vital role to get everyone to act normal again, facing young people who make everyone back away. (CW administrator, focus group 1)

Discussion

Collaborating is an integral part of the role of a CAP, both on the case and systems level (Fritsch et al., 2016). Professionals' perspective on the development of CSCC, an intensive collaboration between CAP and CW in care delivery for adolescent girls with MCN, was explored in this research project. As the development path of the CSCC became clear after data-analysis, we found it especially striking that after a first phase, characterized by the consequences of rapid organizational change, a second phase was perceived as yielding the benefits of collaboration. After data analysis, a theoretical framework to assist in understanding these findings was sought. We did not find information about the development process of a collaboration in the health and social literature and therefore referred to the management literature.

The Life Cycle Model (LCM) describes the development process of a shared service centre (SSC) organization (Struik & Brugman, 2008). The first curve in the LCM (Figure 1), depicting sequential evolution of a SSC into a "mature" organization, is particularly relevant in understanding the process of developing collaborative projects, as its steepness is an indicator for the intensity of change perceived by customers and clients (Figure 1). The second curve shows the evolution of customer satisfaction, whereas the third one depicts revenues. The collaborative development process occurs in three periods in the LCM (Figure 1).

Figure 1. Life Cycle Model for Shared Service Centers



The Life Cycle Model for Shared Service Centres, after Struik and Brugman (2008), illustrates the progress of a collaboration project. The x-axis depicts the three consecutive periods of the development process of a collaboration. Three curves describe different aspects of the progression of a Shared Service Centre: the thick, full line shows the organizational maturation, the thin, full line shows customer satisfaction, whereas the thin, interrupted line describes the revenues produced by the Shared Service Centre.

The first period, “formation of a SSC”, revolves around concentrating resources and developing the customer relationship. This is reflected in a combined internal and external focus, as the collaborating professionals focus on their own and the partner organization. The maturation curve is steep in this first period, indicating important changes, as the whole organizational culture shifts. During these large organizational changes, service delivery is perceived as declining, as reflected by the customer satisfaction curve. In this initial period, very large personnel and financial investments must be made, but the financial revenue balance should not be expected to be positive. Most collaborations go through difficult times during this phase and many organizations would consider withdrawing from the collaboration as the efforts don’t seem to weigh up against the benefits.

The second period, “perseverance”, is aimed at obtaining efficiency and operational excellence. Protocols and organization functioning are further developed; new roles are accepted and routine created. This means a strong internal focus resulting in more improvement than change. It is in this second period, where the revenue curve is steeper, that efficiency and revenues should appear, and user satisfaction increases.

In the third period, “augmentation”, the focus once again starts to shift externally towards looking at further growth possibilities.

To our knowledge, the LCM has not yet been used to describe the development of collaboration projects in mental health and social services. We describe our findings using the lens of the LCM. When comparing the emerging themes, we found that the perspectives of participating professionals are coherent with the periods described in the LCM.

First of all, although a common goal was clear from the start, the first period of the collaboration was characterized by the need for large personnel and financial investments and the feeling of chaos and uncertainty. On the individual level, professionals had to handle a radical change in their work habits, population served, and communication procedures. They had to invest in new expertise and skills, but also in the relationships with new partners. The team composition changed several times, and tensions were described. Complementary skills and communication pathways had to be developed, and important financial investments were made. Difficulties existed where “two different worlds” met, at the level of organization-specific procedures and language. In this first period, the perception of professionals was that there was a lot of uncertainty, for themselves and for youth served. In summary, this fits well in the first period of the LCM, where the change is very rapidly occurring and felt by all concerned, corresponding to a steep maturation curve.

When reporting about the current situation, professionals describe a different picture. On the individual level, a change in attitudes has occurred and professionals have come to know each other’s setting. They feel empowered and supported by each other. The team is now composed of people who explicitly chose this population and work arrangement. On the organizational level, a shared vision and global plan of action has been developed. Some issues are still incompletely resolved. For example, some redundant communication still occurs due to a lack of agreed-upon procedures and protocols.

The situation at the time of the focus groups corresponds to the end of the second and beginning of the third period in the LCM, where collaboration has been established and different routines are set. The

maturational curve is less steep, reflecting there is less change and more amelioration. The yield curve is now positive, reflected in the better care delivery described by the professionals. Looking out for further growth possibilities in terms of parent support and networking could be the first glimpse of the third period, while unresolved communication and procedure issues are remnants of the first period.

The LCM does not describe underlying factors that influence the maturation of the collaboration project. However, in our findings, such themes appeared. Important driving factors in the development of the collaborative project were: 1. a common person-centered vision; 2. the empowerment felt by professionals on different levels, thanks to this collaboration. Freeth (2001) also identified a continued need to collaborate and empowerment to do so, as favorable conditions for maintaining collaboration by describing a collaboration project between a medical and a nursing school in the UK. Our finding that a common vision is driving the development of collaboration, could be related to Freeth's description of "continued need", as a prerequisite for sustaining collaborative efforts. Likewise, our participants pointed out empowerment as the underlying positive evolution of the collaboration project. Our findings are also in line with the literature pointing out that successful interagency collaboration requires value clarification and the development of a shared philosophy and goals (Hunter, 2004; Drabble, 2007) and that, conversely, having different understandings of children's problems and having different goals is identified as a major barrier to good collaborative care for children and youth (Cooper, Evans, & Pybis, 2016). The literature confirms the importance of a person-centered perspective (Gondek et al., 2009) and its role in staff working. In an integrated structure, focusing on improving patient care helps to overcome professional boundaries (Kodner & Spreeuwenberg, 2002; Armitage, Suter, Oelke & Adair, 2009).

The concept of empowerment has been used in a variety of ways, and different conceptual approaches exist (Gibson, 1991; Kuokkanen & Leino-Kilpi, 2000). From the organizational and management point of view, empowerment is most often described as a process, and is correlated with staff wellbeing and commitment to their work (Chandler, 1991), as well as increased productiveness (Kuokkanen & Leino-Kilpi, 2000). According to our participants, the new organization and the training and experiences seem indeed to lead to more efficiency at the organizational level, and a sense of confidence in daily practice.

Also, cross-training of staff has been described as an important strategy for building relationships between staff at different agencies, and helping staff to understand how other organizations operate and ultimately reduce service fragmentation (Drabble, 2007; Salmon, 2004). In this project, effort is put in providing

ongoing education on relevant themes in a very concrete way, through training and by discussing cases from different perspectives in team meetings. Professionals state that this helped them to have enough background to understand certain behaviors and to enhance skills in coping with crisis situations.

Our findings have theoretical, as well as practical relevance. On the theoretical level, it is interesting to see that a model originating in the management literature, can give valuable information to describe the evolution of a collaboration project in social and mental health sectors. Our findings add a dimension to this model, describing not only the sequential phases, but also the factors that appear to have driven the positive evolution. Further research, ideally combining qualitative (interviews or focus groups and observations) with quantitative data (e.g. questionnaires about the perception of collaboration, a measure of “efficacy”, ...), will determine if the framework needs adjustment for the health or social care contexts and could investigate the time line of the phases described in the LCM, in a collaboration between child serving agencies.

On the practical level, knowing what developmental course to expect when starting a collaboration project is very useful for policy makers and clinicians working in an increasingly collaborative care delivery system. The LCM describes that a difficult start, when the consequences of large organizational change ask for large investments that may not seem to yield enough benefits, is to be expected. Knowing this, can assist in the planning and allocation of resources, and can motivate professionals to persist in the collaborative efforts, in spite of the challenges they meet.

A strength of this study was, that we described the collaboration process in the service delivery to adolescent girls with MCN as seen from the perspective of an interprofessional team closely involved in the project. This study also has a high participation rate (94%) and a representative distribution of the professions involved in care delivery. A limitation is the fact that we only gathered perceptions of professionals, rather than combining them with observations of the collaboration. It would be interesting to consider the perspective of the professionals who left the CSCC project in an early stage, or to question those who do not participate in the collaboration project, but do take part in the delivery of care to these girls with MCN. It would be valuable that future research includes the view of the adolescent girls and other professionals working with these girls (e.g. schools, juvenile court).

Concluding Comments

Perspectives of professionals involved in an innovative collaboration project for adolescent girls with MCN on the process of this organizational change, were explored through focus groups. The evolution of

benefits and investments that follow the pattern described in the LCM for SCC was described. This is useful knowledge for those starting a collaborative project and could motivate them to maintain their efforts even when a first period is characterized by the impact of large investment and change. Developing a shared person-centered vision as well as empowerment, are important aspects in the development process towards more satisfaction and efficiency in the collaborative care.

On a theoretical level, it is interesting to notice that a collaboration project between child serving agencies appears to follow the predictions of a model from the management literature. On a practical level, knowing that large investments in collaboration projects may not pay off immediately, could inform policy makers planning collaborations including CAP, and could motivate those engaged in such collaboration projects to maintain their efforts.

Ethical Standards

All human studies have been approved by the ethics committee of the University of Antwerp/University hospital of Antwerp and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments. All persons gave their informed consent prior to their inclusion in the study.

Declaration of Interest

The authors declare that they have no conflict of interest.

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PART 2

PART 2

Part 2 of this thesis builds on some of the interrogations that arose while conducting the participatory action research (PAR) at Van Celst, described in part 1. Indeed, during the iterative PAR process that involved stakeholders from different sectors, the – research and practice – need for an agreed-upon definition of multiple and complex needs (MCN) in children and adolescents was highlighted. Chapter 8 builds on the knowledge constructed during the PAR, reports on a Delphi study and an international survey regarding the definition of the concept of MCN, and addresses the following research objective:

- To systematically build a consensus definition of MCN in Flanders and assess the international perspective on this definition based on information obtained from an international panel.

CHAPTER 8

Towards a Definition of Multiple and Complex Needs in Children and Adolescents: Delphi Study in Flanders and International Survey*

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Towards a cross-sector definition of multiple and complex needs: Delphi study in Flanders.

Abstract

Multiple and complex needs (MCN) in children and youth jeopardize their development and pose significant challenges to the different professionals they meet. However, there is no agreed-upon definition of this vulnerable population.

The aim is to develop a definition of “MCN in children and adolescents” that is meaningful for all professionals involved in care delivery for this population.

A cross-sector, multidisciplinary and geographically spread panel of 47 experts representing mental health, youth care, juvenile justice and education in Flanders participated in an online Delphi study. Qualitative analysis of answers in the first round yielded 4 definition possibilities that participants then ranked in the second round. In the last round, participants rated their agreement with the highest ranked definition. An additional survey asked 25 international experts to rate and comment their agreement with the final definition. The final definition was: Children and adolescents with profound and interacting needs in the context of issues on several life domains (family context, functioning and integration in society) as well as psychiatric problems. The extent of their needs exceeds the capacity (expertise and resources) of existing services and sequential interventions lead to discontinuous care delivery. As such, existing services do not adequately meet the needs of these adolescents and their families. Cross-sector, integrated and assertive care delivery is necessary for safeguarding the wellbeing, development and societal integration of these young people. Response rates to the three Delphi rounds were 76.6%, 89.1% and 91.3%. The definition was widely endorsed among Flemish (93.2% agreement) and international experts (88% agreement).

A definition of MCN in children and adolescents was constructed using the Delphi method and further evaluated for international relevance in an additional survey. Such an agreed-upon definition can be valuable for optimizing care delivery and conducting research.

Towards a Definition of Multiple and Complex Needs in Children and Adolescents: Delphi Study in Flanders and International Survey

A growing number of children and adolescents experience “multiple and complex needs” (MCN), as a reflection of severe difficulties in different life domains (Keene, 2001; Rosengard, Laing, Ridley, & Hunter, 2007). This includes intertwined physical and mental health problems, social exclusion, educational issues and for some of them justice involvement (Keene, 2001; Rosengard et al., 2007). The developmental impact of these problems puts their well-being and optimal integration into society at stake (Stalker et al., 2003). This situation may lead to important societal costs due to extensive use of the health and social care and justice systems, as well as the potential compromise for academic and work outcomes (Burnside, 2012; Grisso, 2008; Leve & Chamberlain, 2004; Rosengard et al., 2007).

Experiencing these “multiple” and “complex” needs leads children and adolescents to engage in frequent contacts with professionals throughout different sectors of social and health care and justice (Burnside, 2012; Thoburn, 2009; Zachik, Naylor, & Klaehn, 2010). Very often, this group experiences difficulties in getting adequate support, as no single agency or sector has all the resources, mandate, or reach to address both the personal needs of these vulnerable young people and their families and at the same time the social and economic factors that aggravate the complexity of these needs (Rosengard et al., 2009; Walker, 2003). As a consequence of insufficient resources and capacities as well as poor integration and individualization of services (Fay Mitchell, 2012; Keene, 2001), these adolescents currently have long and fragmented care delivery trajectories, suffering the consequences of insufficiently coordinated referrals and sequential or parallel interventions by different services (Katz & Spooner, 2006).

The lack of a common working definition of MCN hampers systematic understanding of the concept and greatly complicates efficient multi-agency care delivery for these children and adolescents (Burnside, 2012; Horwath & Morrison, 2007; Rosengard et al., 2007). Indeed, a plethora of terms are used to designate these “multiple” and “complex” problems in different health and social disciplines, most often unspecified and interchangeably (Rosengard et al., 2007). There is a tendency towards a narrow definitional lens, focusing on the problems presented by the adolescents from one professional perspective only, rather than seeing the interactional nature and context of the variables that cause cumulative harm. Another pitfall is to focus on the actual presenting problem on each occasion rather than to have a holistic perspective and response. These difficulties regarding care delivery contribute to what is referred to as “complex” cases (Burnside, 2012;

Rosengard et al., 2007). There is a widely recognized and growing need for an expert-endorsed definition of MCN in children and adolescents, both within and between the professional fields involved in the care for this population (Burnside, 2012; Stalker et al., 2003).

This study aims to systematically construct an agreed-upon definition of MCN in children and adolescents utilizing the expertise of a multidisciplinary, cross-sector and geographically spread sample of Flemish professionals. An additional survey evaluates international agreement with the resulting definition. Such an agreed-upon definition can contribute to optimizing care delivery for children and adolescents with MCN and their families.

Method Setup

The study reported in this paper is presented in two parts:

Part 1: In a three-round online Delphi survey (Shelton, Haynes, & Creggan, 2017), a consensus-based definition of MCN in children and adolescents was systematically constructed and assessed for agreement.

Part 2: An additional survey evaluated the international level of agreement on construct validity for the final definition of the Delphi study in Part 1.

Part 1: Delphi Study

Participants. To achieve an agreed-upon definition of MCN in children and adolescents and given the fact that this population meets a wide variety of professionals in different fields, a cross-sector and multidisciplinary expert panel was recruited for this Delphi study, following sampling guidelines (Shelton et al., 2017). The purposive sampling (Trevelyan & Robinson, 2015) was done via an initial email invitation sent to 53 experts. Experts were selected based on their expertise in and experience with complex issues in children and adolescents and were working in the following fields: youth mental health services, youth care, welfare, juvenile justice, services for disabled persons, and education counseling. Forty-seven (89%) of the invited experts agreed to participate. Geographical spread was ensured as experts from every province in the Dutch speaking part of Belgium (Flanders) were included in the sample.

Table 1 details some of the sample characteristics.

Table 1. participants

	N participants	N responders round 1	N responders round 2	N responders round 3
Youth mental health				
Policy	3	2	3	3
CAP (hospital) psychiatrists	8	3	7	7
CAP (hospital) psychologists	3	3	3	3
Mental health center child and adolescent psychiatrists	2	2	2	2
Mental health center psychotherapist	1	1	0	0
Youth care				
Policy	5	4	5	5
(General) youth care	9	7	8	9
Youth care for (presumed) Child abuse	3	3	3	3
Welfare				
Welfare centers for families	1	1	1	1
General Welfare	5	2	1	3
Juvenile justice				
Juvenile judges	2	2	1	2
Social workers in juvenile justice	2	2	2	2
Professionals from juvenile justice institutions	2	2	2	1
Services for persons with disabilities				
	2	1	2	2
Education counseling				
	1	1	1	1
Total	47	36	41	42

This table illustrates the composition of the expert panel in the Delphi study. For each sector of care, the number of participants and the number of respondents per round are detailed.

Data collection. In each round, all participants received a unique link to an online questionnaire in Qualtrics (Provo, Utah, version 3.8.0). Deadline for responding was set 3-4 weeks after the questionnaire was distributed and non-responders were sent reminder emails and contacted by phone. After each round, all

participants received personalized feedback on their own answers and the panel's answers in the previous round.

Round 1. Following the recommendations for classical Delphi studies (Brady, 2015; Trevelyan & Robinson, 2015) the first round consisted of an open question. The question was: how would you, based on your vision and expertise, describe the population of children and adolescents with multiple and complex needs?

Round 2. In the second round, participants were asked to rank the four definition options that were formulated, based on the analysis of round 1. In an additional open question, participants could write down additions or changes they would make to the definition they ranked highest.

Round 3. In the third round, participants were asked to score their agreement with the definition that resulted from the second round, on a 6-point Likert scale.

Ethics. This research project was approved by the ethics committee of the University of Antwerp/University hospital Antwerp. All potential participants received written information and had the opportunity to address further questions to the research team. All participants gave their informed consent prior to participation.

Data analysis. Qualtrics (Provo, Utah) and Excel (Microsoft) assisted in data analysis.

Round 1. The answers to the first round open question were analyzed following the sequence described for systematic text condensation (Malterud, 2012). Three researchers followed the steps described in this approach of qualitative analysis:

1. Reading the transcripts multiple times gave an overall impression and helped each of them to identify preliminary themes. Final themes were agreed upon after discussion between the three researchers.
2. Each researcher identified text units, so called units of meaning that characterize aspects to incorporate in the definition of MCN and coded for these.
3. Researchers summarized the content of each code group into a condensate.
4. Four definition possibilities were synthesized as an analytic text after reconceptualization of the data. Re-reading the original answers to the first-round question ensured goodness of fit with the final themes and code groups (Malterud, 2012).

Round 2. By weighing each position in the ranking order (attributing 4 points to the highest rank, 3 points to the second position, 2 points to the last but one and 1 point to the last position), the definition participants indicated as most fitting (the one with most points), was identified.

Round 3. A priori, agreement was defined as a score of 4, 5 or 6 on a 6-point Likert scale (ranging from strongly disagree to strongly agree) evaluating the rate of agreement. Cut-off for consensus was defined at 75%, in line with the literature (Diamond et al., 2014). Moreover, the comments of all participants were reviewed, and following the pre-set cut-off, an addition or correction to the definition would be presented to the entire panel, if mentioned by at least 10% of the participants.

Part 2: International Survey

Participants. In a subsequent survey, an international perspective was sought on the definition that was constructed in the Delphi study. Twenty-five experts (response rate 33%) originating from 11 different countries (United Kingdom, France, Netherlands, Austria, Spain, Switzerland, United States, Canada, Australia, India and Ecuador) rated and commented their individual agreement with the definition. Experts in MCN were sourced from their scientific publications and via professional societies. They represented different domains of expertise: child and adolescent psychiatry (36%), child psychology (28%), social work (20%), forensic psychiatry (8%), children's nursing (4%), public policy (4%). Moreover, all participants in the survey had a longstanding experience ($M=25.72$ years of professional experience in participating sample) with specific academic and practical expertise MCN (56% professor or associate professor, 16% director/manager in youth care, 16% counselor/therapist, 8% researcher).

Data collection. Participants were asked to rate their agreement with the definition constructed in the Flemish Delphi study on a 6-point Likert scale (ranging from strongly disagree to strongly agree) and were given the opportunity to comment on the definition.

Data analysis. In analogy with the Delphi study, score of 4, 5 or 6 on the Likert scale were quantified as agreement.

Results

Part 1: Delphi study

Participation. Response rates were as follows: 73.5% for the first round, 85.4% for the second round, and 91.7% for the third round. In each round, each of the professional fields and every Flemish province were represented. Table 1 illustrates the number of participant responses in each round.

Construction of the definition. The main themes in the answers to the open question in round 1 were identified using systematic text condensation (Malterud, 2012) and related to:

1. the issues pertaining to the children and adolescents themselves (the degree and the different affected life domains),
2. the role and efficacy of care delivery, and
3. the service needs of this population.

After sorting the so-called “meaning units” (text fragment containing relevant information) in the process of getting from themes to codes, definition possibilities were built in the condensation and synthesis steps of the process of systematic text condensation (Malterud, 2012). Whereas these main themes suggested by all participants were very similar, differences emerged with regard to two aspects: 1. the extent to which they viewed “family context” problems as a separate and essential aspect of MCN and 2. the (casual) role that is attributed to (inadequate) services with regard to complexity. Inserting the two possibilities for each of these two aspects of the definition, 4 different definition options were built.

The results from the analysis of round 1 are summarized in Table 2.

Table 2. Analysis of the answers to the first round open question

Themes	Subthemes	Code examples	Definition aspects for which different opinions exist
Issues; domains affected	Severity; interrelation	“interrelation of problems”; “family problems”; “psychiatric problems”	Family problems as a separate issue vs. no specific emphasis on family problems
Care delivery problems	Fragmentation in care delivery; incapacity of existing care delivery to cope	“negative impact of uncoordinated care”; “services are overwhelmed”	Causal role of failing care delivery vs. inadequate care delivery not mentioned as contributing to complexity
Care delivery needs	Integrated services; assertive approach	“assertive care”; “integrated care delivery by different sectors”	

This table illustrates the construction of four definition options, based on the answers to the open question in the first round of the Delphi study.

In the second round, participants ranked the four definition possibilities. The definition that was selected, received 20% more points (based on the ranking by participants) compared to the definition with the second highest amount of points.

Definition and consensus Delphi study. The final definition of multiple and complex needs in children and adolescents was:

Children and adolescents with profound and interacting needs in the context of issues on several life domains (family context, functioning and integration in society) as well as psychiatric problems. The extent of their needs exceeds the capacity (expertise and resources) of existing services, and sequential interventions lead to discontinuous care delivery. As such, existing services do not adequately meet the needs of these adolescents and their families. Cross-sector, integrated and assertive care delivery is necessary for safeguarding the wellbeing, development and societal integration of these young people.

There was a high consensus rate for this final definition, as 93.2% of the participants agreed with it. Approximately 35% of the participants made an additional comment in round 2, regarding the highest-ranking definition. However, each of these ideas was mentioned by less than 10% of the experts, and consequently the definition was kept as formulated in the second round.

Participants suggested: 1. that physical problems/biological/medical domain should be emphasized specifically in the definition (n=4); 2. that certain aspects (“school problems” (n=1), “at risk for unemployment” (n=1), “parents with psychiatric illness” (n=1), “parents in a (temporary) difficult psychosocial situation” (n=1), “behavior” (n=1)), should be mentioned separately in the definition; 3. to add “, ...” between brackets after “societal integration” to show the list is not limited, and to replace “safeguarding” with “stimulating” (n=1); 4. to complete the last sentence (regarding services) with: “as to prevent discontinuity” (n=1), “starting from a shared vision with adolescents and parents” (n=1), “high intensity of treatment needed” (n=1), “multidisciplinary” (n=1), and 5. that the definition is complete and/or should not be longer (n= 4).

Part 2: International Survey

Participation. Twenty-five international experts (response rate 33%) rated their agreement with the definition that was developed during the Delphi study. Eighty-eight per cent of these international experts agreed with the definition and gave scores 4 and above on a 6-point Likert scale (M=4.6, SD=1.2; Mdn=5). Sixty per cent of the international experts made an additional comment. It was mainly suggested: 1. that the definition should include the aspect of problems of the child/adolescent as well as the shortcomings of

services. This was viewed by some as very positive, as they highlighted how a mismatch between services and needs or failing services are part of the cumulative harm (n=4). Others indicated they would not include this in the definition (n=4); 2. that the term “psychiatric problems” should be replaced by “mental health” (n=3), or that too much emphasis was placed on the psychiatric aspect in the definition (n=2); 3. that the definition should specify some aspects: “detail psychiatric problems: behavior, attachment, ...” (n=1), “frequent history of trauma” (n=1), “family problems” (n=1), “high-risk or criminal behavior” (n=2), “financial problems” (n=1), “difficulties to access services due to remoteness” (n=1), “school problems” (n=2), “work problems” (n=1); 4. that it should specify “existing services working alone” rather than “existing services” (n=1); 5. that “profound” should be replaced by “severe” (n=1), and 6. that the definition is too long and/or too complex (n=2).

Discussion

Current research doesn't offer a common definition of MCN in children and adolescents to the variety of professionals working with this population. This compromises understanding of service delivery, and risks patient outcomes and research validity. In a three-round Delphi study, a definition of MCN in children and adolescents was systematically constructed, based on the contributions of a multidisciplinary and cross-sector panel of experts in child and adolescents serving agencies in Flanders. The definition constructed in the Delphi study was widely endorsed, as reflected by the high consensus rate amongst Flemish experts (93.2%) and the fact that a large proportion of international experts (88%) also expressed their agreement.

The hope is that such an agreed-upon definition could help the development and implementation of services that more effectively respond to the needs of children and adolescents with MCN and their families. Having a common definition could optimize communication, coordination and exchange between professionals on the case level, and inform policy makers on priorities in developing (collaborative) programs and allocating resources. A common language is important for research, in order to collect and use epidemiological data or to evaluate programs effectively.

A potential limitation of this Delphi study is the limited generalizability across diverse settings. The fact that only Flemish experts were included in the Delphi study may have resulted in local factors (such as specificities of the youth care or mental health organization) influencing the final definition. The inclusion of experts from every province ensured the relevance of our findings for the whole of Flanders. Such an approach has its use in order to inform and adapt local care delivery programs but may not yield a definition that is useful to professionals working in different settings. However, the fact that international experts in the field,

who have academic as well as practice experience, agreed with the definition at least to some extent, suggests that it could be useful in a wider context.

A strength of this study is the fact that the Delphi study had high response rates and was conducted with a heterogeneous and geographically spread sample of qualified experts throughout the relevant fields for vulnerable children and adolescents. The survey with highly experienced international experts not only provided an international perspective regarding agreement rates, but also raised interesting topics for reflection.

Definition Compared to the Literature

The definition of MCN in children and adolescents that was constructed in this Delphi study is largely in line with the concepts scattered in social and health literature describing MCN. Elements of the definition that are similar to the literature are: 1. the importance of the dimensions of severity (“depth”) as well as interrelatedness (“breadth”) of issues in determining the complexity, 2. the role of services in complexity, and the need for services to collaborate (Rankin & Regan, 2004; Rosengard et al., 2007). However, the physical conditions that are often mentioned in the literature about vulnerable children and adolescents with multiple needs, were not included as an element of the definition in this Delphi study.

The needs of children and adolescents with MCN are characterized by the participating experts as being profound as well as interacting on several life domains. The fact that complexity in needs revolves around severity as well as interrelatedness of issues, is described in terms of “depth” (severity) and “breadth” (affecting several domains) in earlier reports (Rankin & Regan, 2004). The degree of severity of one issue can create a considerable challenge for the service system, but the fact that a multitude of issues exists, is even more daunting, as it is the interaction of risks that produces the most harmful effects (Burnside, 2012; McLaughlin et al., 2010). Considering the breadth of issues, it is important to look beyond a narrow definitional vision limited to each sector’s specific expertise, and to have sufficient attention for aspects relating to functioning and participating in society and ordinary life (Rosengard et al., 2007; Schmied, Brownhill, & Walsh, 2006). In line with this idea is the recommendation to use a definition for MCN that is non-categorical in that it doesn’t assign the responsibility to one single sector or discipline but rather acknowledges the fact that needs may arise from a number of different conditions and that focuses on the interrelatedness of issues (Schmied et al., 2006).

Besides pointing out the difficulties of these young people and their relatives, the definition developed in this study also highlights the mismatch between the needs of these families and the fragmented care delivery they may experience. The perspective that the needs of these populations at the extreme of a spectrum of case complexity overwhelm the resources, mandate or possibilities of individual professionals or agencies, is also endorsed in the literature (Burnside, 2012; Keen, 2001). Even when individual services are providing high quality care, the varied, specialized and changing needs of children and adolescents with MCN, ask for cross-sector resources and expertise, with a focus on continuity of care.

Some authors define a population of adolescents as high-risk due to the fact that their individual characteristics (e.g. behavioral issues) conflict with system characteristics such as high caseloads and reactive casework. That conflict results in care delivery that does not meet the needs of these complex cases, and professionals who are overwhelmed and feeling helpless (Smyth & Eaton-Erickson, 2009). Others take this idea one step further and take the shortcomings of care delivery, rather than the individual problems, as a starting point and argue that complexity arises due to the failure of services to meet needs adequately (Rich, 2009). In that prospect, the person's needs are not necessarily complex, but it is the challenge in coordinating all different services that people with MCN need across the various sectors, that creates complexity (Richard & Smallwood, 2011). As such, complexity is by some authors considered to originate in the eye of the beholder, referring to the fact that skills and resources of professionals affect how "complex" a child's issues and circumstances are considered to be (Rich, 2009).

The definition constructed in this Delphi study highlights the importance of an integrated care delivery approach, and as such is in line with literature recommendations pointing out the importance of intensive interagency and cross-sector collaboration including shared goals, accountability strategies and outcome evaluation. Indeed, adequately meeting the needs of this population requires all professionals to work collaboratively and join resources to achieve common goals: ensuring a safe and caring environment with consistent structure and routine, emotional containment and support, and planned specialized responses to behaviors and emotions (Rich, 2009). Several authors point out that limited communication and coordination of services across sectors is not sufficient to ensure that the needs of adolescents with MCN are adequately addressed. They argue the critical importance of integrated care; particularly mental health, justice and child welfare, as a means of improving measurable outcomes for the most vulnerable children (Hornberger, Martin & Collins, 2006). The idea that more complex cases require stepping up on the collaboration spectrum is widely

endorsed in the broader literature on interagency collaboration (Cooper, Evans & Pybis, 2016; Seaburn et al., 1996).

A divergence when comparing the definition in this Delphi study with the available literature, is the fact that physical problems or risks were not explicated in the definition constructed by the expert panel in this study. However, numerous accounts in the literature highlight how in vulnerable populations of children and adolescents, physical and psychosocial difficulties are strongly related and reinforce each other (Nelson et al., 2012). Possibly, these experts do not view the physical problems as a condition sine qua non (absolutely necessary) in order to classify a case as MCN. Alternatively, this could be related to the fact that most of the expert panel did not work in a medical setting. Either way, considering the frequency of physical problems in vulnerable adolescents (Nelson et al., 2011), it seems important to be attentive to them when evaluating children and adolescents with MCN.

Reflection on Experts' Comments

None of the suggested changes or additions that experts made after the second Delphi round exceeded the a priori threshold to be presented to all participants.

Regarding the survey, following the suggestions of the international experts could lead us to a further adaptation of the definition:

- replacing psychiatric problems by mental health issues, due to the fact that psychiatric problems are too narrow as a term or too definitive of psychiatric pathology, and can have different significance in different countries.
- adding "individual" services, in order not to put emphasis on the fact that current services fail, but rather on the potential of collaborating.

Other issues were more contested. While some international participants stressed the importance of having both the child issues and the failure of services or the failure to access services in the definition, others indicated they would not include any information on services or their capacity to cope in a definition. As described above, this disparity also exists in the literature.

In our opinion, while no generalization nor determination of a causal link is possible, fragmented care delivery and many referrals could be important in the cumulative harm experienced by these children and adolescents and warrants attention when evaluating their needs and planning services.

Clinical Significance

In Flanders, where this definition was constructed on the basis of the inputs of a variety of experts in the care for children and adolescents with MCN, these results could guide definitive understandings of MCN, practice and policy. In the evaluation of the needs of children and adolescents with MCN, the different aspects mentioned by these clinical experts should all (at once) be taken into account: mental health, integration and participation in society, family and broader social context. This calls upon a multidisciplinary problem evaluation. There should also be attention for the accessibility of services and the aim should be to provide a holistic support addressing the different needs and focusing on continuity of care.

Different ideas for broader practice and research can be derived from the resulting definition of MCN in children and adolescents. For practitioners evaluating families and planning services for individual cases, it seems important to keep in mind that both the severity of issues and the fact that they occur on different life domains are important contributors to complexity, and consequently both aspects should be evaluated and addressed. In evaluation of services, an open and collaborative professional attitude seems especially important for this vulnerable population.

Finding a common language and exchanging information on individual cases, as well as broader expertise between professionals, can make significant changes for individual cases and can be valuable for professionals too. On the policy level, investing in cross-sector coordination and optimizing service accessibility and responsiveness to MCN would make an important contribution to care delivery for children and adolescents with MCN.

Future research utilizing an international Delphi study would be valuable to construct an international consensus on a definition of MCN. The perspectives of children and adolescents with MCN and their families would be immensely valuable to future MCN definition research.

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GENERAL DISCUSSION

Case Illustration

A. remained in the Van Celst collaboration project for three years.

The initial period of A.'s participation in the project was characterized by frequent suicide attempts, serious self-harm, aggressive behavior toward social workers, and absconding. After more than six months, these problems and the consecutive CAP crisis interventions or time-outs became less frequent. More difficult periods (often co-occurring with re-starting school or with changes in family composition) remained. However, a general tendency toward less frequent and less severe crisis situations prevailed. Some therapeutic advances were made regarding emotion regulation, coping strategies, and relationship stability. With some of the social workers, a trusting relationship grew over time and A. learned to better express her emotions and intentions toward professionals and other adolescents. The communication between A. and her mother also showed a general amelioration. With the help of an educational orientation counselor, different schooling options were discussed (studying part-time, having time-out possibilities, etc.), but it nevertheless remained difficult for A. to engage in school for longer periods. Independent living skills were stimulated and A. made the transition toward a more "independent living" module of the Van Celst project. Around her 18th birthday, A. began ambulatory therapy in adult psychiatry while still residing in Van Celst. Her child psychiatrist and social workers from Van Celst stayed in contact with the adult psychiatry services when she made the transition to adult residential services.

The professionals indicated that their initial apprehension toward caring for a person with this intensity of psychiatric needs in a welfare setting, faded little by little as their confidence in their own expertise and trust in their collaboration partner grew. The research process assisted in this awareness and reflection:

The research gives words to our experience, illustrates and pins down what we feel and "know" in daily practice. What the complexity of cases really means, the unicity of each girl and context, their strengths and possibilities, it confirms our ideas and empowers us to see that ... The focus groups invited for true and critical reflection and dialogue on the collaboration model, and that process strengthened the common commitment. We learned about the literature and constructed answers to relevant questions together. (social worker)

The fact that so many girls and relatives were committed and participated actively in the research project, give me hope. They made this research possible, they brought the project to a higher level. Instead of bitterness and despair and distrust, they showed vulnerability and took action and were strengthened. (administrator CW)

In the case described, despite the remaining difficulties and the inherent variability of the problem presentation, some achievements can be discerned due to an intensive collaboration that had A.'s needs as its primary focus. For this girl, with her specific needs as a guide, the problems in psychiatric, somatic, social, and educational domains were simultaneously addressed in an individualized and longitudinal care program. The CW and CAP professionals took joint responsibility and could turn to each other for advice and support when facing difficult episodes during A.'s stay, without the need to disrupt her care trajectory.

Introduction

This participatory action research (PAR) thesis originated from the practice interrogations that arose when starting and developing the Van Celst project, a collaboration between child and adolescent psychiatry (CAP) and child welfare (CW), designed to help adolescent girls with multiple and complex needs (MCN). These practice objectives primarily concerned the description of this vulnerable target population's characteristics and needs, as well as the identification of the collaboration model's characteristics, development process, benefits, and pitfalls. A secondary aim, building on questions that arose during the initial research phases, was to build a consensus definition of MCN.

From a research perspective, the PAR project aimed to address the lacunae mentioned in the literature regarding the conceptualization of MCN and (cross-sector) collaborative services to address these needs.

An important overarching aim was to include the clients' and professionals' perspectives, thus combining the expertise from the participating adolescents, relatives, professionals, and the research team.

The hope was to stimulate reflection that would allow for the optimization of services and research for the most vulnerable populations.

Main Findings and Recommendations

Tailored Care and Continuity

Tailored care. In child serving agencies, services are sometimes more focused on the supply side than on the actual demands of clients (Roose & De Bie, 2003). This complicates services for complex cases for which adjusted care delivery that is guided by thorough knowledge of needs – at the case and population levels – is essential. A deep and multi-perspective understanding of target population characteristics and service needs is a crucial step toward adjusted services for complex cases (Chapter 2). A better understanding of the characteristics of the target population can facilitate communication between different sectors that serve that population. An important objective in this project was to describe the characteristics and needs of the target population at Van Celst (Chapter 2) and to provide an understanding of MCN at a broader, cross-professional level using a Delphi study (Chapter 8).

Need for continuity. One of the most characteristic issues of the target population studied in this project is fragmentation in care delivery. Discontinuous trajectories are described by all stakeholders as an important vulnerability of the population at Van Celst (Chapter 2). The parents and professionals specifically mention the discontinuity as a problem that contributes to personal issues of the adolescents and their families directly, and also indirectly by hampering adequate care delivery (Chapters 2 and 4). In the files, this fragmentation and the associated placement instability were clearly reported (Chapter 2). The harmful discontinuity described in the qualitative data of the Van Celst project was related to two important service requirements of persons with complex needs (Chapters 3, 4 and 6). On the one hand, there is a need for combined expertise and for the possibility to address multiple problems at the same time. The incapacity to offer such holistic care leads to clients being referred from one facility to another when one of their issues necessitates the expertise of another care provider. On the other hand, service needs are intensive and difficult

to handle. A lack of resources and support in services facing very complex cases, also leads to frequent referrals when existing services cannot cope in isolation.

The concept of continuity of care is crucial in services for persons with MCN (Rosengard et al., 2007). To date, comprehensive reviews of the quantitative (Reid, Haggerty, & McKendry, 2002) and qualitative (Waibel, Henao, Aller, Vargas, & Vasquez, 2012) literature have conceptualized continuity of care as consisting of three broad dimensions: *relational*, *informational*, and *management* continuity. The first dimension, relational continuity in care delivery, concerns the contacts a client has with the provider and the interpersonal skills of that provider. The second dimension, informational continuity of care, relates to the quality of the information flow in services, i.e., how data concerning a patient are exchanged between professionals. The third dimension, management continuity, is connected to how different services are coordinated. Waibel et al. (2012) suggest that the different types of continuity of care are best conceptualized as interdependent. For example, having consistent staff (relational continuity) reduces communication barriers and increases accumulated knowledge (informational continuity), which improves treatment plans and supports mutual understanding (management continuity). Tobon, Reid, and Brown (2015) studied continuity of care in the sphere of children's and adolescents' mental health. They found the same three dimensions of continuity to be important here. In addition, unique to this healthcare context, they mentioned *coordination across sectors* and *transitions* as risks to continuity.

In the findings presented in this thesis, different stakeholders all pointed out the importance of continuity of care and gave examples in relation to these three dimensions of care continuity (Chapters 2, 3, 4 and 6). Adolescents mostly reported relational (dis)continuity and stressed the importance of this aspect with regard to their wellbeing (e.g., when having to tell their story to each new professional they come to meet). It is important to note that the risk of this relational discontinuity is not restricted to placement instability, but also exists when the adolescent stays in the same facility for a longer period (e.g., when the function of personal social worker is switched to another staff member, or in contact with social work students who stay only three months at the facility). (Step)parents also mentioned the concept of relational continuity regarding the difficulty of trusting new professionals in each new residential setting for their child. Informational discontinuity was mentioned by both professionals and parents who noticed the loss of data in the transfers between different sectors and placements. Some of the (step)parents referred to this same issue when they stated that they were shocked to find that their assumption – that a shared file would follow their child

through placements – was proven wrong. The management (dis)continuity concept was mentioned by all stakeholders, but was especially discussed in the focus groups with professionals external to the Van Celst project, who noticed that a lack of a common and coordinated plan across services resulted in discontinuity, frustration, and suboptimal services.

In line with the literature findings mentioned before, both the coordination between sectors and the transitions between different care providers are threatening the continuity of care. For many of the girls enrolled in Van Celst, there is a need for exchange of information and a common plan between partners in CAP, youth care, juvenile justice, and education sectors. The fragmented responsibility, and differences in organizational culture and secrecy policy, complicate cross-sector collaboration and result in episodic and parallel interventions rather than continuity in care. The situation becomes even more complicated when the adolescents approach the age of majority, with transition to adult services for mental health, justice, social, housing, and financial support.

It is not surprising that the concept of continuity of care received such strong emphasis in the Van Celst project. Within the context of Van Celst's target population characteristics, several professionals claimed the need for continuity in care delivery to be one of the prominent vulnerabilities of that population and related it to the concept of attachment relations (Chapter 2). This vulnerability with respect to attachment issues can be related to a difficult early age (caregiving) context (Oriol, Sala-Roca, & Filella, 2014). Among other factors, residential care itself can complicate the construction of safe attachment relations (MacLean, 2003). Attachment difficulties can also be connected with other difficulties these adolescents experience. Earlier research confirms that the vast majority of adolescents facing early or chronic mental health problems have an insecure attachment style (ambivalent 73.6% and avoidant 90.5%) (Macbeth, Gumley, Schwannauer, & Fisher, 2010).

Organization of services. The organization of services impacts the continuity of care they can provide. The intensive collaboration in the Van Celst project (Chapters 5 and 6) aimed to prevent fragmented care delivery in the trajectories of adolescents with MCN in two ways. First, it brought together the expertise from different sectors, reducing the need for referral to face the multiple problems. Second, it augmented the capacity of care delivery services by optimizing skills, mutual support and joint responsibility between the agencies. Both strategies were aimed to enhance continuity in care delivery trajectories and provide adequate care.

Regarding relational continuity of care, the disruptions of contact with care providers are minimized in the Van Celst project. Relational continuity can be enhanced in this manner because the therapist follows the adolescent they are working with to whichever setting she stays in. This can be achieved due to the fact that the CAP psychologists are not part of the staff of the facility. Also, the different way time-outs are used – not as a rejection or an end-point but as a part of the trajectory – allows relational continuity to be enhanced, e.g., by having social workers/family social workers visit the adolescent and family, continuing the work done in the facility during time-out periods. Informational continuity is enhanced thanks to team meetings, where all cases are discussed and all information obtained from different sources (through testing, observations, etc.) is united. The fact that CAP is in contact with the general practitioner and with other medical specialists provides additional continuity of care. With respect to the management coordination of care, the organizational structure greatly enhances care coordination, as the expertise from different sectors, such as CAP, CW, and other partners, is united in one joint care delivery trajectory. This is made possible by joint planning of the care delivery trajectory and by taking joint responsibility for its implementation. Also, communication between professionals from different backgrounds is greatly enhanced by joint intake and meetings. When professionals know each other and each other's plans, this can limit disruptions to care or double work. For example, therapy needs and self-help skills can be addressed at the same time. Important underlying factors are the joint focus on the target population's needs and the empowerment of professionals. As professionals feel less overwhelmed, there are less referrals (management continuity) and less disruption to relations (relational continuity). The joint focus on the adolescents' needs guides the coordination and the communication aiming to lessen information loss. However, continuity can also be threatened by factors related to collaboration – e.g., in the starting phase, due to large organizational changes, some professionals left the collaboration project (Chapter 6). Although this did not cause placement instability, it certainly disrupted relationships.

At Van Celst, there also was a need to focus on attachment related issues in the practice approach. Attachment is described in the literature as an important concept in the organization of services (Bucci, Roberts, Danquah, & Berry, 2015). The attachment system is important in determining how patients will seek help and how they will react to staff (Barber et al., 2006). The literature provides some information regarding the organization of services with respect to attachment. Several of the principles explained are relevant to the Van Celst setting. A review by Bucci et al. (2015) describes how attachment theory can be the basis for designing mental health services. They highlight the importance of focusing on providing a secure base, by

developing meaningful relationships with staff. In this context, Berry and Drake (2010) recommend that staff should be encouraged to engage in one-on-one activities with service users. This is also clearly put forward in the data from this project, especially by adolescents and parents who highlighted the benefits they experienced from non-formal activities with their personal social workers (Chapter 6). In earlier research, developing this type of relationships is shown to aid the recovery in a mental health care setting, regardless of the type of therapy offered (Horvath, Del Re, Flückiger, & Symonds, 2011). The papers included in the review link the assurance of the continuity of care to factors that enhance the stability of teams (Schuengel & van IJzendoorn, 2001). The recommendations include creating a positive work atmosphere with good support mechanisms and adequate remuneration for professionals. The findings in this thesis, regarding the maximization of continuity thanks to the beneficial effects of mutual support by both collaborating partners, are in line with these literature findings (Chapter 6). Other papers focus specifically on the need for staff support in an attachment informed setting, because this approach tests internal resources (Seager, 2013). Seager (2013) and Berry and Drake (2010) suggest that case-loads should be watched so that staff members are not assigned too many patients with high levels of attachment needs at the same time. This would be hard to accomplish in the Van Celst project as it specifically targets adolescents with MCN.

Collaboration

Collaboration in order to address complex needs. The central assumption of the Van Celst project is that complex needs in adolescent girls can better be addressed by uniting capacity and expertise from a tertiary CAP center and a CW facility in a very intensive collaboration (Chapter 5). Expertise from different sectors is necessary to address MCN (Keene, 2001). However, placement instability can further aggravate attachment issues and lead to further trauma (Zegers, Schuengel, van IJzendoorn, & Janssens, 2006). By enhancing the ability of services to welcome these girls back to the same stable living environment, in spite of crisis episodes and extreme behavior, the hope is to break this cycle in Van Celst (Chapters 2 and 6).

In the Van Celst project, collaboration was set up for all adolescents in the facility – including the ones who had chosen not (yet) to engage in any CAP therapies – and for their entire care trajectory, from intake to finalization. This differs significantly from collaboration projects in which there is an episodic, case-related interaction between different agencies. As an example, the CAP described the advantage of being present at the first contact between the adolescent and the facility, introducing the CAP offer right from the start. The CW staff highlighted the benefits of having a CAP who knows every girl in the facility, with regard to exchanging

expertise and providing purposeful training. Knowing each other's organizational culture and taking joint responsibility in planning care trajectories in a longitudinal way was perceived to enhance quality of the care provided (Chapters 5 and 6).

Aside from the broad (all cases) and longitudinal (whole trajectories) dimensions of the interaction between CAP and CW, a complete horizontal and vertical integration adds to the intensity of collaboration. All professionals, at all levels of the collaboration, engaged in exchanges with each other, instead of the collaboration being only at the policy level or on the work floor. For example, the social workers have direct formal and informal contact with the child psychiatrist, and psychologists, (family) social workers, child psychiatrist and policy makers have joint meetings. This is perceived to facilitate the joint planning and implementation of services (Chapter 5 and 6)

Yet another aspect of the collaboration's intensity was the fact that there was not only factual partnership and joint work but also mutual support. Professionals from both agencies reported in the focus groups that, thanks to the collaboration, they felt they were not alone in facing the challenges of working with these girls with MCN and could count on each other for advice, debriefing, and resources. The support encompassed both an increase in expertise, and the assurance that joint responsibility is taken for these challenging cases. This was due to the fact that expertise was shared for all cases in a longitudinal manner, and to the fact that the training, adjusted to the very specificities of the target population, could be organized based on intense case knowledge (Chapters 3 and 4). The low threshold for contacting each other and the many opportunities for informal communication seemed to contribute further to the perceived support. The empowerment and growing expertise allowed them to provide better care for the adolescents and to do so in a manner that did not overwhelm or destabilize them (Chapter 6).

As such, intensity of collaboration was reported as characteristic for this project and important for the ability to offer services that can meet the needs of the population of adolescent girls with MCN and their relatives, as well as for strengthening the professionals to allow for the provision of longitudinal care to this challenging population.

In the literature, MCN cases are described to require the extremity of what is often depicted as a collaboration continuum (Cooper et al., 2016; Collins, Hewson, Munger, & Wade, 2010; Katz & Spooner, 2006; Seaburn, Lorenz, Gunn, Mauksch, & Gawinski, 1996). The dimensions characterizing this end of the collaboration spectrum are described by Seaburn et al. (1996) as frequent and meaningful contacts (*depth of*

collaboration) and involvement of more stakeholders (*breadth* of collaboration). Besides the “magnitude” of collaboration, several authors argue that a patient- or family-centered vision should guide service provision when dealing with MCN (Kodner & Spreeuwenberg, 2002; Walter & Petr, 2000).

Collaboration is challenging. As mentioned in this thesis (Chapters 6 and 7) and the literature (Cooper et al., 2016), collaboration has the potential to benefit both service users and organizations; however, such benefits are not automatic or easy to realize. Collaboration is very challenging for professionals and organizations, especially when they have different backgrounds (Bryson, Crosby, & Stone, 2006). Collaboration can be undermined by the complexity that arises at the organizational level or from the characteristics of the team or network itself.

Awareness of the possible impact of organizational change (Chapters 6 and 7) and the need for a continuous reflective and needs-led attitude (Chapter 2) were important findings from the PAR described in this thesis. Indeed, when studying the development process of this collaboration project, a first phase in which investments were larger than yields, was clearly depicted (Chapter 6). When discussing the fundamental characteristics of this collaboration project and when discussing factors that contributed to its favorable development, a joint focus on the target population needs, as well as mutual support for professionals, were put forward (Chapters 6 and 7).

Public management literature offers recommendations for cross-sector collaborations that can be valuable in the collaboration between health and social sectors (Bryson, Crosby, & Stone, 2015). Amongst others, the need for a clear collaborative advantage is put forward. Both collaborators, by working together, must gain something that they could not achieve alone. In the case of the Van Celst collaboration project, the collaboration with CW offered to CAP a context-oriented and longitudinal normalizing approach (school, daily living skills). For CW, the CAP input offered support for dealing with psychiatric issues and crisis situations (suicide attempts, self-harm). As such, there was a clear advantage of joining the resources and expertise to meet the needs of adolescents with MCN that neither CAP nor CW could meet in isolation. Further considering our findings, this collaborative advantage seems more likely to occur when the collaborating partners have complementary skills and expertise. Also, this idea is in line with the notion that collaboration and the way it is organized, should be entirely tailored to needs of a population. For populations with less complex needs, there may be no collaborative advantage.

Another important factor for the success of cross-sector collaborations is attention to the process and, in particular, the “people factors” at the individual and organization level. Therefore, the socio-emotional dimension of collaboration can neither be overlooked nor reduced to a set of “obstacles” (e.g., rivalry, tribalism) to be resolved by integrated structures and processes. Instead, the challenge for integrated work is to equip the professionals to recognize and deal with group dynamics in whatever form they assume in each individual (Hood, 2014). Horwath & Morrison (2007) stress that the manner in which the process of moving toward more collaborative work is handled, is just as important as any of the decisions made about the goals, governance, or structures. Failure to dedicate enough attention to the process of collaboration, aside from outcomes, puts the service users at risk (Horwath & Morrison, 2007). Child abuse inquiries have pointed out the dangers that exist for at-risk children during periods in which the focus is on organizational change (Reder & Duncan, 1999). This is especially problematic when the changes are not planned for the long term with client needs central; or when the changes are imposed from “above” rather than through a collaboration prompted by a common desire or need to address an issue together (Horwath & Morrison, 2007). Indeed, research on failed collaborations identifies the neglect of people issues as a principal cause of failure (Hamlin et al., 2001). This suggests that paying attention to nurturing relationships and building trusted networks becomes imperative (Hudson et al., 2003). Moreover, the literature stresses the importance of involving clients in the organization of services. Involving service users in collaborative efforts lifts the collaboration to the next level (Hodges, 2003). From a public health management perspective, Bryson et al. (2015) also advise that the expected process of the collaboration is taken into account. Their advice is to take a design approach to cross-sector collaboration – starting with the goal in mind and designing the process, structure, and interactions. This must be done in way that the outcomes and accountabilities are met while building ongoing learning into the design. The same points – having shared goals and continuous monitoring with attention given to the collaboration process and not merely to the outcomes – are also emphasized by Winters et al. (2016) in an umbrella review on cross-sector collaboration in the health and social care sectors. Thus, in order to ensure good quality of care and safety, the needs of and outcomes for the target population must be the initial focus and remain the focus even during periods of rapid organizational change.

Well-targeted and structural collaboration between services and sectors is an essential strategy to enable care delivery to address such complex needs. Aiming to provide tailored care by combining resources in

collaborative projects fits in a more global evolution of service and research priorities from evidence-based medicine to personalized medicine (Ng & Weisz, 2016).

Participation

Involving service users and professionals. At Van Celst, in addition to the need for specialist interventions spanning different domains from a longitudinal perspective, there was also the need for adjusted, personalized care delivery. This included a wish for agency and input in the care trajectory (Chapter 3, 4). The adolescents and parents referred to the need for answers that fit their personal situations, which they have not found in regular services. They also explicitly state the importance of being heard and of having influence, both in terms of acknowledgement and with respect to their own expertise and insight for their situation (Chapters 2, 3 and 4). Professionals discussed these same issues in terms of the necessity of a needs-led approach. The emphasis on “normalization” also expressed the willingness to let persons take control of their own situations. Relatives may feel sidelined in the treatment process and consequently distressed. They wish to be respected and involved in recovery (Katsikitis, 2017). This can only be achieved when offer-guided services make room for needs-guided participatory services that involve adolescents and their relatives. Moreover, the participation of clients strengthens the collaborative care itself. In the Van Celst project, the feedback from adolescents and their parents shaped the practical development of the project. Hearing results and discussing these aspects strengthened the motivation of the stakeholders in the project (Chapter 6).

As an example of increasing the attention toward needs-led care, an increased focus on patient-centered services means that there is now a legal duty in several countries to involve the service users in research design and conduct (Staniszewska, 2009). This is believed to benefit research by producing better quality studies that, in turn, achieve more effective service redesign and service quality improvement (Staniszewska, 2009).

The service users’ involvement is especially relevant for higher order collaborations and thus for complex cases (Hogan & Murphy, 2002; Huxham & Vaugen, 2000). Understanding the users’ experiences and expectations is crucial to identify a mandate and to develop responsive services (Brett et al., 2014). This “partnership” is sometimes seen more as a means to promote interprofessional work rather than as a way of placing the service users at the center of agencies’ attention, as the primary stakeholders for collaboration. Morrison & Lewis (2005) highlight that the degree to which the Child Protection Committees had further

engaged with service users in terms of determining the mandate and service development strongly influenced the outcomes for the families involved.

There are many benefits to be gained from integrating service users and relatives in all mental health service change management aspects, and this is likely to work best when they are equal participants and are involved from the beginning (Brett et al., 2014). Benefits can include empowering the service users, adding authenticity to the data, actively contributing to the change direction, and sharing learning between the professionals and service users (Hutchinson & Lovell, 2013; Brett et al., 2014). It can give a voice to people whose views may otherwise be marginalized (Koch & Kralik, 2002) and is thus very powerful in cases where the intention is to offer them better services. In the PAR described in this thesis, service users were involved in adjusting and evaluating the collaboration (Chapter 6).

Avoiding tokenistic participation. The partnership with service users should extend beyond tokenistic participation in both research and practice (Cooke & Kothari, 2001; Katsikitis et al., 2017). Consumers and care givers are experts by experience, and are willing and have the skills to guide changes in their own care delivery process and in mental health services (Jones et al., 2016). Katsikitis et al. (2017) bring awareness to the need for consumer and carer partnerships to extend beyond superficial involvement, and their findings call for a paradigm shift in the mental health sphere. Professionals should routinely involve service users and their relatives in processes to make services relevant and consumer involvement meaningful (Hitchen, Williamson, & Watkins, 2015). The principles behind this inclusion are: clarity about the reasons for involvement, honesty about the potential for change, and training of the front-line staff regarding participant involvement. Extra time and support, sensitivity, and clear communication are required. Ensuring organizational commitment and agreeing on how the outcomes are fed back to the service users is also important (Roose & De Bie, 2003).

In research, it is a caveat to call projects participative when, in fact, they are either entirely designed by academic researchers or only through user participation in a limited phase (giving consent for the research), or by a selective group of stakeholders. Such practices make participation “tokenistic” and empowerment cannot be achieved through apparent participation (Katsikitis, 2017).

With regard to participation in the Van Celst research project, there was a fundamental aim for reciprocity, for giving back and supporting both professionals and service users. Professionals and service users were involved in every step of the PAR (Chapter 1). Reciprocity is discussed in the literature as protection against tokenistic participation (Wilmsen, 2006). An important way in which PAR can lead to empowerment is

through the reciprocity in the relationships between researchers and participants. Wilmsen (2006) describes, that reciprocity implies relationships that are characterized by open communication, trust, mutual respect, and an exchange between the researchers and those investigated. Empowerment can also be reached with research that is not explicitly participative, but participation without reciprocity would lead to extractive research (Elliott, Heesterbeek, Lukensmeyer, & Slocum, 2006). Projects that are most successful at empowering participants are those with the most highly developed relationships of reciprocity (Wilmsen, 2006). In this sense, participation is also a means to counter the research practices in which researchers only “extract” knowledge from the examined groups for the benefit of academic or general interest, while the situation of the community involved does not change (Elliott et al., 2006).

Consequently, reciprocity and continuous negotiation are necessary to ensure the PAR benefits. To nurture this interdependence, and to prevent the interests of professional researchers from leading to extraction, open communication is required and the situated interests of all parties involved need to be identified early on in the research process.

Responsibility. Another concept that came forward, is the notion that when service user participation is discussed, there should also be a reflection about responsibility. In the findings of this thesis, the (step)parents were the stakeholders who most explicitly talked about responsibility (Chapter 2). (Step)parents pointed out that their daughters needed to take on more responsibility in their care delivery trajectory. On another level, they also found it very valuable that the adolescents were stimulated to participate in the vegetable garden of the facility. (Step)parents suggested that projects should be started, such as creating a small shop, through which the adolescents would be able to make some money to finance excursions for the whole group. The professionals also mentioned responsibility as something to be attentive to when trying to accommodate the needs of this target population – e.g., organizing the consultations in the facility instead of the CAP hospital lowers the threshold for the adolescents, but the concern was that this greatly diminishes the responsibility of the adolescents. Indeed, they do not have to organize themselves to get to the CAP hospital.

In the literature, there is also a conceptual change toward having patient autonomy as a guiding ideal/principal rather than as an evident right (Struijs & Jongsma, 2013). This goes along with changing the expectations from practice as services should now pay more attention to supporting patients in making their own choices. It is interesting to view patient responsibility as a construct that is an outcome which can be achieved as a result of a successful treatment relationship (Chapter 2). When patients have increasing input in

the implementation and design of services at the case and organization levels, there also exists a duty for them to play an active role in their own care trajectory. At the same time, participatory processes can help patients to take on more responsibility. Indeed, participation, through its empowering effects, can motivate persons and give them the tools necessary to take on responsibility. This fits in with a movement toward less hierarchic service models.

From these different concepts and interpretations, the most compatible with the findings of this thesis is the concept of viewing patient responsibility as a construct that creates interaction between the caregiver and the service user. A participatory approach can give a voice to the patients and take them toward a path of action and reflection. Participatory research gives them a voice and a role in their own trajectory and in the development of services.

Role of the PAR Researcher

Three functions of the PAR researcher are described in the literature (Roose & De Bie, 2003). The first one is an advisory function, bringing the research subjects into contact with relevant data. In the advisory role, the researcher has a bridging function between the stakeholders and the data (inside or outside of the direct field of research) that could be relevant to them. An example of this in the Van Celst project was the introduction to the literature on the development process of a cross-sector collaboration stemming from the management literature (Chapter 7). The second function is a training function, where the researcher aims to improve learning processes and to make alternative action feasible by asking questions about the ways of working. The training function is related to assisting the development of practice, facilitating alternative action, and improving learning processes. For example, information sessions regarding the questionnaires were organized at the facility, for professionals (Chapter 1). The experiences and the learning curve for the collaboration itself were also discussed with all stakeholders (Chapter 7). The third function is the research function, examining practical actions on the basis of existing theory and new theory development (Roose & De Bie, 2003). This function aims to construct a new theory subsequent to the actions in the PAR. For example, in the Van Celst project, some findings on the collaboration process were added to the knowledge base on cross-sector collaborative care (Chapters 5 and 7).

When considered in the light of studying complex situations, it is interesting to suggest a fourth function of the researcher in PAR: “facilitator of reflection”. Researchers have the meta-position that allows them to stimulate self-reflection as well as reflection at the cases or organization level. This allows them to

address different aspects of complexity (Hood, 2012, 2014). It is possible for a university researcher to not only play a role in addressing the causal complexity responsible for change in the actual events, but also in addressing the social complexity that shapes the behavior of the studied social system in PAR. In this way, a researcher would not only help integrate the various pieces of expertise, experience, and knowledge available in the process of addressing the primary needs that began PAR, but could also help with managing the social processes entailed in doing so.

This role could be viewed in the context of critical thinking that is advocated by Freire (1973) and recognized as an important process in PAR in the field of health (education). It is hypothesized that critical thinking is part of the educational process of the participatory approach toward empowerment and action (Wallerstein, 1992). The (academic) research partner can facilitate this process and thus contribute to what Kemmis and McTaggart describe as reflective enquiry (Kemmis & McTaggart, 2005).

In the Van Celst project, for example, an important contribution of the researchers was their adoption of a meta-perspective and the assistance they provided to the collaboration network as a network, guiding it to reflect on its own processes of understanding and communication. Indeed, the “fourth role” is directed at facilitating the reflective process and dialogue between participants. Especially during team meetings, the impression was that the researcher had a privileged position to stimulate debate and self-reflection subsequent to presenting literature comparisons, or after initiating discussion about a certain aspect of the data or part of the research project.

Implications for research and practice

Changes brought about by the PAR process

In line with the aim of PAR, this project added to ecologically valid knowledge and facilitated several favorable changes in practice (Chapter 1). Those changes, as the result of an iterative reflection process in which all stakeholders engaged, were situated in practice at the case, group and organization level. Favorable changes concerning the research planning also occurred. The following are examples of those (intermediate) social changes thanks to the PAR. In practice, case level adjustment of diagnostic, therapeutic and care delivery planning was positively influenced by the introduction of clinically relevant and user friendly questionnaires, in a setting (CW) in which previously no questionnaires were used. Data on the target population needs led to individual adjustments in care delivery planning (e.g. considering the thresholds towards therapy, or the

different views on continuity of care). At the group level, the detailed description of needs reflected significant differences with the initial perception of the target population. More specifically, the finding of frequent and intensive traumatization as an important characteristic of this target population led to a more trauma-focused approach (e.g. less training in therapeutic approaches directed at personality disorders, in favor of trainings on trauma-sensitive approaches). Also, the target population data on somatic disorders contributed to the development of a more appropriate medication management (e.g. using specific medication files, keeping medication with the social workers and not in the adolescents' room) and better coordination with the general practitioner. At the organization level, the use of questionnaires in the CW center was initiated in this PAR, and led to more openness and interest in using such tools in practice. Also at the organization level, the PAR led to knowledge exchange and dissemination in the broader policy and scientific field. Indeed, reflections on the findings discussed at congresses or during the policy seminar that was organized, were fed back to professionals in the organization. As a more overarching consequence, professionals felt empowered and acknowledged when reflecting on the target population, the collaboration model, and the changes in practice.

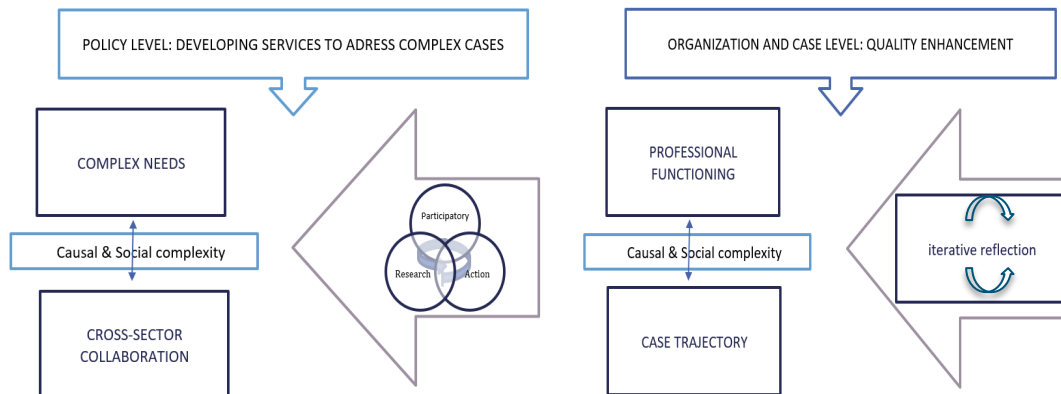
The research project itself was also positively influenced by the iterative reflection process that included all stakeholders in study objectives and design. Methodologically, the addition of two focus groups with external professionals was a result of reflections of professionals. This added to the knowledge about the network of external partners, including their perception and needs. It led to efforts to ameliorate certain collaborations with external partners, and to maximize benefits for other partners. Regarding the interpretation in research and practice of certain concepts, there was also a result from the PAR process. The iterative process involving different stakeholders pointed out how differently adolescents, relatives and professionals evoke the concept of continuity of care. This, in turn, entailed practical consequences at the case level (e.g. regarding the switch of individual social workers), but is also interesting knowledge for research purposes (e.g. when interpreting studies that point out the importance of continuity in care delivery).

Broader Implications

This section reflects on and discusses some broader implications of the findings of this thesis for the practice of care delivery and research in the field. In short, the argument is in favor of the use of PAR when developing and optimizing (novel) services for persons with complex needs. It also describes how quality improvement techniques, such as the plan–do–study–act method (Taylor, McNicholas, Nicolay, Darzi, Bell &

Reed, 2014), that are increasingly used in health care, have principles similar to those of PAR. Implementation of these principles is valuable for ameliorating services at the (complex) organization and case level (Figure 1).

Figure 1. Iterative action and reflection



This figure illustrates how iterative reflection and action can be valuable to address social and causal complexity at the policy and organization/case level. Causal complexity, concerning cause and effect in complex systems, traditionally belongs to the field of the complexity theory within social sciences. Social complexity refers to the process of knowledge construction in the care delivery process. It is the way in which causality feeds into relationships, processes of assessment, intervention, and perceptions of risk (Hood, 2012).

PAR is valuable for developing, studying, and optimizing services for complex cases.

Based on both the findings in this thesis and the literature, the use of PAR is promoted for the development, study, and amelioration of child and youth services for complex cases. PAR, as an iterative reflective process that starts with practice needs and brings together expertise from multiple sources, is valuable for policy decisions when dealing with complexity. It is argued that the basic approach in PAR (starting from practice needs, engaging in a reflexive iterative process that unites different perspectives) has the potential to evaluate and positively impact both the causal and social complexity of MCN and, as such, to aid in the development of the services needed to address them (Figure 1, left hand side).

The needs of persons with MCN, as well as the strategies used to address them, are characterized by complexity. There are the profound and multiple interrelated problems of the client and the difficulties faced by collaborating professionals (Brown & White, 2006). Cross-sector collaboration, presented as the solution for

meeting complex needs, is challenging (Bryson et al., 2015; Hood, 2014). It can be undermined by complexity that arises at the organizational level or from the characteristics of the team or network itself.

Complexity is often used in a metaphorical meaning referring to the difficulty of resolving multiple and interrelated problems, or what have been called “wicked problems” that defy technical solutions (Devaney & Spratt, 2009). In the field of children’s services, there has been some interest in adapting theories of complex systems to explain the challenges of frontline settings such as child safeguarding, in which events can move in volatile and unexpected ways (Nybell, 2001; Stevens & Cox, 2008). In these contexts, complexity theory is mostly used as a conceptual framework

The complex realist approach set out by Hood (2012) offers an understanding of the complexity encountered in social work by describing its two dimensions – *causal* and *social*. In line with Hood’s (2012) framework, it is a combination of causal and social complexity that best describes the difficulties related to MCN and the services created to address them (as described in the findings presented in this paper and in the literature). The additional understanding offered by the complexity theory is obtained through viewing the difficulties that these types of cases can present in relation to causality, prediction, and change. After all, services are not only in the business of assessing what is going on in a system, they are also expected to change things for the better by dealing with unexpected events or acting on new information (Hood, 2012, 2014).

In spite of offering valuable conceptual clarity, the discourse associated with complexity theory can convey a false impression that complexity means a set of impersonal forces whose “dynamics” govern cause and effect (Hood, 2014). Yet, complexity in the context of care delivery is far from impersonal. On the contrary, it is experienced and managed by families and professionals on a daily basis. It involves different perspectives in perceptions and understanding (Hood, 2014).

Therefore, PAR is proposed as a suitable approach to study and support the development of care delivery for MCN. PAR can address both causal and social complexity due to its characteristics, including:

1. a participative collaborative approach in which knowledge and experience from all perspectives are exchanged, providing empowerment and support;
2. a focus on action and social change in real life processes, by enhancing personal and group level reflection;
3. a research focus on knowledge generation that stimulates learning and bridges the science–practice gap.

PAR, as a means of studying and supporting MCN, can explore the interplay between causal complexity – related to how a certain input generates a particular outcome in a social system – and social complexity – the process of knowledge generation that, considering cognition and relations, mediates access to events in such social systems (Hood, 2012). PAR is effective for identifying the difficulties, needs, and preferences of the target population as well as the professionals. It can do so in a manner that respects the service users' wishes for agency and participation, combines the unique perspectives of all stakeholders, bridges these with research data, and is part of an interactive process that can deepen knowledge and support action.

Complexity leads to dynamics that change on a case-by-case basis, requiring a kind of reflexive adaptability that goes beyond protocols and guidelines. In other words, the network needs to be helped as a network to reflect on its own processes of understanding and communication (Reder & Duncan, 2003). PAR enables practitioners to gain a better understanding of causal mechanisms than they could obtain on their own, or provides the collective resources that can help nudge outcomes in the right direction. Hood (2014) argues PAR is as much about the reflexivity of the network as that of the individual practitioner, aiming to move collaboration beyond routine communication and information sharing. If networks are to become more than the sum of their parts, then they need the ability to evaluate and adapt their own collective endeavors.

Both regarding the target populations' issues and concerning the collaborative efforts, PAR can ally the literature research data with the practice experience of practitioners. This can benefit professionals and clients by offering new knowledge or guidelines and can, in turn, add to the knowledge base regarding complex cases.

In the Van Celst project, PAR identified practice needs in a comprehensive manner, paying attention to their multilayer character and mutual influence. Causal complexity – e.g., in determining the input of both partners – as well as social complexity – e.g., regarding support and empowerment of professionals – in these needs were taken into account. PAR also assisted in developing the collaborative network. By its action-oriented and responsive nature, it could stimulate change in order to optimize the care delivery for MCN. PAR was used to study how events or actions related to causal complexity affect the collaborative network. It also allowed the investigation of the relationships, assessment processes, and perceptions of risk that constitute social complexity.

The need for innovative ways of designing and implementing care delivery for vulnerable populations, in ways that are embedded in practice, strengthening the researcher–practitioner collaboration is beautifully described by J. Weisz and colleagues (Weisz, Chu, & Polo, 2004). They point out how important it is in the mental health

and youth care fields not to limit research to traditional methods in analogy with (psycho)pharmacological trials, but rather to focus on practice needs and aim for implementation of research findings. These goals are in line with the aim of implementation science, striving to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015; Williams & Beidas, 2019). PAR, starting from practice needs and accompanying the implementation process seems a very valuable research approach to realize such goals.

Principles similar to PAR are valuable in quality enhancement methods

For practical implementation at the case and organization levels, the PAR assumptions and methods are found to be very similar to methods designed to improve quality in health care such as plan–do–study–act methods (Taylor et al., 2014). Such plan–do–study–act cycles provide a structure for iterative testing of changes to improve quality of systems (see Figure 1, right hand side).

In the same line of thought, Simonsen and colleagues argue for the use of more participatory approaches to complement quality evaluation and to stimulate program accreditation (Simonsen, Hertzum, & Scheuer, 2018). They demonstrate how accreditation, which focuses on processes and standards, needs to be supplemented and balanced with participatory approaches that allow for local experimentation and implementation of high-quality outcomes.

Indeed, an iterative reflection process that involves different sources of expertise, benefits the service users and professionals at the case and organization levels. Starting from practice needs and bringing together expertise from multiple sources, and systematic joint reflection, are valuable for dealing with complexity in practice at the case level.

Complexity leads to dynamics that will change on a case-by-case basis, requiring reflexive adaptability moving beyond protocols. Therefore, social systems need support to reflect on themselves and the networks they are a part of (Reder & Duncan, 2003).

This need for reflection in professional teams is put forward in mentalizing approaches, an important principle that such care delivery ameliorating approaches share with PAR. These approaches, such as the AMBIT approach, also balance the respect for classical evidence with respect for local expertise and ecological validity (Bevington, 2019). Moreover, they highlight the value of an iterative process of care delivery

optimization and have attention for knowledge dissemination in the community, by promoting a (wiki-based) “open source approach to therapy” (Bevington, 2019).

PAR and co-production

Co-production is defined by Bovaird (2007) as the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions.

This concept is interesting to reflect about in relation to PAR. Some similarities and differences can be found.

Most frequently, in PAR, a professional researcher engages in a research process with practice stakeholders. In analogy, in co-production processes this dyad professional – service user also exists. Both also believe in the potential benefit of associating perspectives or efforts of a professional and community partner (Boviard, 2017). Both are more or less directed at democracy stimulation through collective responsibility and decision-making. They co-production requires a relocation of power towards service users (Realpe & Wallace, 2010). Both (can) have a transformative intent. Indeed, so-called transformative co-production uses cyclic ‘plan, act, observe, reflect, refine’ iterations informed by user attitudes and experience, an approach that has much in common with action research cycles (Pestoff, 2006).

On other aspects, co-production and PAR differ. Whereas PAR is a research method and has knowledge generation as one of its main aims, in co-production, knowledge generation is not always a goal. The initiation/stimulus for the project comes from practice needs in PAR, but in co-production, the process is not necessarily initiated by the community (Boviard, 2017).

Another important difference is that it is not a strict requirement that community and professionals have direct interaction in co-production, as long as they work on the same goal at the same time (Pestoff, 2006). In PAR, the iterative process involving the more or less stable group of researchers and stakeholders engage in together is crucial. On a broader level, empowerment process on the level of the individual (and not the population) seems to be more central to PAR than to co-production. In the setting of mental health services, the participation in a PAR process may be considered to some extent ‘therapeutic’ on the level of the individual, as was the case in the Van Celst project.

Strengths, Opportunities, and Limitations

Different opportunities in this project allowed us to develop new insights and to formulate recommendations that may incite reflection in care delivery organization more broadly through:

- the fact that the collaborating partners chose to have a research project added from the start; and
- the joint efforts from all stakeholders, both professional and non-professional, to increase knowledge and ameliorate practice (without requiring incentives).

This allowed for rich content creation and for the study and amelioration of the change process in practice.

Part of the reflective attitude that is an important part of PAR relates to acknowledging the limitations of the research conducted. Although it was attempted to include and involve as many parties as possible in the research project, some professional and non-professional stakeholders were not included. For instance, the needs and preferences of siblings, as well as the (step)parents, could have been explored. Also, despite the fact that the research project began very early on in the development of the collaboration project, the researchers were not present during the preliminary meetings in which the concept of the collaboration was discussed. It would have been interesting for them to have been involved in the planning and decision-making phases of the project as well.

In line with the research approach that was applied, which does not aim toward a generalization of findings, caution should be used when applying the project findings to other populations or settings. However, the goal of offering reflection that can inspire and prompt dialogue about other target populations and care delivery organizations can, nevertheless, be met. The numerous occasions on which the findings were disseminated to a wider audience have contributed to the implementation of this aim.

In this section, we suggest where transferability of findings of the qualitative chapters towards other settings is, or is not, likely.

For Chapter 3, regarding the needs from care delivery, transferability to some extent is likely to other populations of vulnerable adolescents with cross-sector needs and difficulties in matching with available care delivery, e. E.g. adolescent girls involved in teen prostitution. Findings may be transferable to some extent to boys with a profile of multiple and complex needs, but care must be taken as some gender related vulnerabilities make the needs profile of boys and girls different.

For Chapter 4, the needs from care delivery as depicted by the (step)parents of adolescents at van Celst are likely to be transferable to other settings with parents of children in care delivery in CW or in the hospital. The specificities of the problems of the adolescents may well complicate transferability, e.g. the relationship with staff is likely to be different in a general hospital.

For Chapter 5, findings regarding the principles of this collaboration model are likely to be of use for the design of other collaboration projects for vulnerable populations. However, less complex needs may require less intensive collaboration. Furthermore, the role and extent of involvement of external partners is specific to the health and social care organization in Flanders.

In Chapter 6 we discuss benefits and attention points for the collaboration project. These may be relevant for other CW- CAP collaborations for children and adolescents who need cross- sector expertise.

Chapter 7 relates to the development process of the collaboration, and findings are likely to be transferable to other shared service centers or newly started structural collaboration models with shared goals and responsibility between partners in health and social care.

This study could offer a deeper insight into different aspects of a specific vulnerable target population and of an innovative collaboration model. Moreover, the expertise of different sectors was brought together in the creation of a consensus definition of MCN. The participatory iterative process allowed for an in-depth analysis of both the target population and the collaboration model, combining information from very different perspectives. A high degree of participation of different stakeholders was achieved and the positive feedback about the practical relevance and use of the project was rewarding.

Recommendations for Further Research

1. Registration and description of target populations. It is pointed out that, when dealing with complex issues in particular, registering and describing the characteristics of target populations and of interventions is very useful. This serves iterative reflection that can ameliorate services in an organization, but can also be useful to a wider audience of professionals, by enriching the knowledge base on complex needs and the services used to address them. Such registration should not only include episodic characteristics, but should also take into account the longitudinal trajectories through different sectors and services. Collaboration with university partners can be helpful in order to organize the data registration in a way that minimally

interferes with practice. With this PAR, we achieved a change that in our opinion is important and should be further stimulated by future projects: stimulating settings that work with vulnerable young people to register as much relevant information as possible. Currently, needs, problems, treatments and care trajectories in CW and CAP are barely documented.

2. Importance of collaboration intensity when addressing MCN. In order to be able to meet the needs of MCN, the organization of services and the support of professionals are both very important. A tailored offer for both the service users and the enhancement of service capacities can be achieved through an intensive collaboration of two partners with complementary expertise in a network of external partners. Formal and informal communication, including all levels and functions in collaborating organizations, is important in order to achieve a synergistic effect.

3. Including service users in an international Delphi study. Studying the concept of complexity can ameliorate communication between a variety of professionals working on complex cases. It would be interesting for future research to conduct a Delphi study concerning MCN as a concept and regarding the service needs of persons with MCN. Including the service users and their relatives would prove to be very valuable in this respect. Of course, it is also important to keep in mind the large heterogeneity of populations with complex needs and the great differences in the existing services created to address them.

4. Documenting the PAR process itself. Documenting how the PAR process itself is perceived and how this could be ameliorated, would serve to better describe the effects of this research approach and to optimize its implementation. Although the benefits of PAR are extensively documented in the literature, very few projects have directly asked the participants about their experiences with PAR.

Conclusion

The first part of this thesis aimed to explore, through PAR, the needs and characteristics of a target population of adolescent girls with MCN and to study the innovative collaboration project Van Celst, joining CAP and CW. Building on questions that arose in that first section of the thesis, its second part was concerned with systematically developing a consensus definition of MCN using a Delphi study conducted in Flanders and with exploring international perspectives on this definition through an additional survey.

The depth and breadth of the needs and the difficult care delivery trajectories, along with the specificity of the needs of these adolescents and their relatives, call upon innovative care delivery. Collaboration is put forward as promising for meeting the needs of MCN, but is not straightforward to

implement. Several important aspects that were identified in the Van Celst project may serve in other contexts – its client-centered approach that empowers professionals and coordinates the input from an intensively collaborative core with external partners. This approach can offer a more tailored and continuous care delivery for adolescents and their families, while also enhancing the capability and capacity of professionals and the wider professional network.

In general, it was possible to reach a consensus definition of MCN that could be used in future research and practice. Taken together, a plea for more participative and needs-led approaches in both research and practice arises. Collaborative approaches that are tailored to the need profiles and vulnerabilities of specific populations appear to be very valuable, especially when they focus on participation and empowerment of both clients and professionals.

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SUMMARY

Chapter 1 provides an overview of the main characteristics of participatory action research (PAR) and the arguments for its use in (youth) mental health services. It also illustrates the use of this research approach in the Van Celst collaboration project. In the PAR approach, researchers, practitioners, and the community engage in the research process together. The research itself is prompted and guided by practice needs. PAR uses joint expertise to enrich knowledge, facilitate social change, and empower stakeholders from different backgrounds. In health and social care, this research approach can contribute to enriching propositional and practical knowledge about health and disease, facilitate positive social change in services, and empower stakeholders such as patients or clients, their relatives, and professionals. In this way, it can also contribute significantly to the integration of research and practice in a variety of projects in the field of mental health care. However, it comes with specific challenges and ethical considerations. In the Van Celst project, for example, the experiences were mainly positive as stakeholders were empowered and rich data was obtained. However, practical challenges were encountered.

Chapter 2 highlights the main characteristics of the target population enrolled in the Van Celst collaboration project. It is based on in-depth file analysis and on the questionnaires and data obtained from focus groups and in-depth interviews. The resulting profile of vulnerabilities is heterogeneous. It shows psychiatric issues, somatic problems, frequent medication use, a difficult familial context, schooling problems, and contacts with professionals in different social and health care sectors. The issues are profound (e.g., very high trauma scores, SDQ total scores, number of girls with probation orders, interruption of schooling, etc.) and the problems exist in different domains at the same time. The care delivery history of these girls is complicated and is characterized by discontinuity and multiple incidents. From an organizational point of view, complex needs are indicative of a higher level of vulnerability, characterized by multiple problems that overlap organizational and disciplinary boundaries, which should be addressed by coordinating expertise from a number of agencies and professions. They overwhelm the expertise and resources of individual professionals, organizations, and sectors. None of them has the resources, skills, or mandate necessary to accommodate the severity and multiplicity of needs in isolation. Such a description of the target population has an essential role in the PAR process. The file study and questionnaires used for the Van Celst project, along with the broader literature frame, enhanced understanding of several aspects of the target population. The feedback from professionals, adolescents, and parents pointed out areas that needed further research in order to have a comprehensive description of the characteristics and needs of the girls participating in the project. This guided

the adaptations in clinical practice (e.g., more trauma-focused training and clinical approach), but it also gave acknowledgement to the adolescents, their parents, and professionals.

Chapter 3 presents an account of the service needs of adolescent girls with multiple and complex needs (MCN) from the perspectives of their (step)parents, the professionals involved, and themselves. Data were obtained via focus groups and in-depth interviews. Adolescent girls with MCN are especially vulnerable and suffer harm due to the fragmentation of services. Yet, their service needs are not comprehensively covered in the literature, especially not from their own or their relatives' perspectives. The main service needs identified in the Van Celst target population were: 1) adolescent–professional relationship, 2) agency, 3) holistic and adjusted care delivery, 4) efficient coordination of services, 5) focus on the individual, and 6) continuity of care. These findings enrich the knowledge about the service needs of adolescents with MCN and are found to be in line with the framework of needs-led child and youth care: continuous focus on the clients' needs, participation in the care process, and professionals who display needs-led attitudes and skills. Better knowledge of the needs of the adolescent girls with MCN could ameliorate service provision for this vulnerable population.

Chapter 4 reports on the service needs of the (step)parents of the adolescent girls with MCN, based on the findings obtained from in-depth interviews. The perspectives of parents whose children are in residential care, have received only minor attention in the literature, despite evidence pointing out the value of parental involvement in the delivery of care for their child. Parents wish: 1) to have a true partnership with the professionals (involvement), 2) to feel respected by the professionals (respect), 3) to have the information and mandate necessary for decision-making (agency), and 4) to receive consideration and (emotional) support in addition to advice on how to handle the challenges their families face (support). Their plea draws attention to an aspect of the “parent–caregiver partnership” dimension in family-centered residential care that deserves more emphasis. The PAR approach makes it possible to involve parents not only at the case level but also in the development of a collaborative project.

Chapter 5 describes the characteristics and principles of the collaboration model used in the Van Celst project, drawing on data from professional focus groups. This paper explores the guiding principles of the Van Celst collaboration project between child and adolescent psychiatry (CAP) and child welfare (CW), which aims to help the adolescents with MCN. Cross-sector collaboration is promising for dealing with complex problems that defeat the expertise of professionals or organizations working separately. Cross-sector collaboration can

adjust and personalize care delivery, as a broader range of skills, resources, and expertise becomes available. Collaboration also promotes continuity in care. This is achieved thanks to the enhanced coping of professionals and through common engagement for a target population. Professionals gain more knowledge due to exchanges with colleagues from different backgrounds, and they feel supported knowing they can share the care for such complex cases with other experts. The main guiding principles that were identified are: 1) needs-led focus, 2) intensity of collaboration, 3) balance between integration (merging) and differentiation (specialization), 4) two collaborating partners integrated in a larger network. These ideas could inform reflections about collaboration projects addressing complex needs.

Chapter 6 presents the reported benefits and pitfalls of the Van Celst collaboration project from the perspectives of the adolescents, their (step)parents, and professionals. Several benefits of this form of collaboration between CAP and CW were identified: 1) adjustment of care delivery to meet individual needs, 2) easy access to mental health services, and enhanced possibility for therapy implementation and follow-up, 3) focus on integration into society and, at the same time, on psychiatric support, 4) positive influence on capacity of services at the level of the professional, the organization, and the larger network of services. Certain pitfalls were also mentioned: 1) preserving the agency of clients, 2) maintaining the identity of collaborating partners and openness to professionals outside the collaboration, 3) safeguarding the continuity of care, and 4) supporting the individual professionals and teams. These findings illustrate the potentials of collaboration when working with adolescents with MCN. They highlight the importance of keeping the needs of adolescents and families as a main focus, while also being attentive to the needs of the professionals.

Chapter 7 analyses the development process of collaboration and relates it to the Life Cycle Model. This study, as a PAR project, reports the development process of an innovative collaboration between child and adolescent psychiatry and child welfare for adolescent girls with MCN, that is based on an analysis of focus groups with professionals. It describes the evolution of collaborative efforts and outcomes through time. The participants of this collaboration describe large investments and negative consequences of rapid organizational change at the beginning of the project. The benefits of the intensive collaboration only appeared in the later stages of the collaboration. A shared person-centered vision and enhanced professional confidence were pointed out as important contributors for the evolution of the collaboration. The findings were compared to the existing literature and showed a significant analogy to the life cycle model for shared service centers, that describes the maturation of collaborations from a management perspective. These findings enrich the

knowledge about the development process of collaboration in the fields of health and social care. In increasingly collaborative services, child and adolescent psychiatrists and policy makers should be aware that gains from collaboration may possibly only be achieved in the long-term, and they may benefit from knowing which factors have an influence on the evolution of a collaboration project.

Chapter 8 presents a Delphi study that aims to build a consensus definition of MCN. It also reports the results of an additional survey that explored international perspectives based on the Flemish definition of MCN. It aimed to develop a definition of MCN in children and adolescents that is meaningful for all professionals involved in care delivery for this population. A cross-sector, multidisciplinary, and geographically spread panel of 47 experts, representing mental health, youth care, juvenile justice, and education spheres in Flanders, Belgium, participated in this online Delphi study. Qualitative analysis of answers in the first round, yielded four definition possibilities, that the participants then ranked in the second round. During the last round, the participants rated their agreement with the highest ranked definition. An additional survey asked 25 international experts to rate and comment on their agreement with the final definition. The third and final definition was: "Children and adolescents with profound and interacting needs in the context of issues on several life domains (family context, functioning, and integration in society) as well as psychiatric problems. The extent of their needs exceeds the capacity (resources) and expertise of existing services and sequential interventions lead to discontinuous care delivery". As such, existing services do not adequately meet the needs of these adolescents and their families. Cross-sector, integrated, and assertive care delivery is necessary for safeguarding the well-being, development, and societal integration of these young people. The response rates to the three Delphi rounds were 76.6%, 89.1%, and 91.3%, respectively. The definition was widely endorsed among both Flemish (93.2% agreement) and international experts (88% agreement).

The general discussion draws upon the entire thesis. It includes a reflection on and a discussion of the implications of the findings to practice and it presents suggestions for future research in this area. It stresses the utility of an iterative reflective process, starting from practice needs and bringing together multiple-source expertise, when dealing with complexity in research and practice. The PAR principles are argued to have the potential to evaluate and positively impact both causal and social complexity of MCN and, as such, to aid in the development of the services needed to address them. With respect to practical implementation at the case and organization levels, the PAR assumptions and methods are found to be very similar to the principles of quality

enhancement. Indeed, building on different sources of expertise in an iterative reflection process, benefits both the service users and professionals at the case and organization levels.

ADDEMDUM Chapters and corresponding publications or presentations

Chapter 1	The Value of Participatory Action Research for Clients, Professionals, and Researchers in Mental Health Care	Accepted for publication in <i>Tijdschrift voor Psychiatrie</i> : Participatief actieonderzoek: toepassing in (kinder- en jeugd)psychiatrisch onderzoek en illustratie aan de hand van een participatieve studie omtrent een cross-sectoraal samenwerkingsverband. Oral presentation UKJA Seminary April 24 th 2017.
Chapter 2	Target Population: Personal and Care Delivery Characteristics	Based on publication by Van den Steene, H., Glazemakers, I., & Van West, D. (2016). Adolescent girls in residential care: biopsychosocial characteristics. <i>JSM health education & primary health care</i> , 1(2), 1-13. Oral presentation study day “De meerwaarde van cross-sectorale samenwerking in de trajecten van Van Celst” June 6 th 2018. Also part of research report “De meerwaarde van cross-sectorale samenwerking in de trajecten van Van Celst” (Participatief actieonderzoek over een innovatief samenwerkingsverband tussen kinder- en jeugdpsychiatrie en bijzondere jeugdzorg)”, to be consulted via: https://www.uantwerpen.be/images/uantwerpen/contai ner2704/files/Rapport%20Van%20Celst.pdf
Chapter 3	A Multi-Perspective Exploration of the Service Needs of Adolescent Girls With Multiple and Complex Needs	Published as Van den Steene, H., Van West, D., & Glazemakers, I. (2018). A multi-perspective exploration of the service needs of adolescent girls with multiple and complex needs. <i>Children and Youth Services Review</i> , 90, 28-37.
Chapter 4	Needs and Preferences of Parents of Adolescents With Multiple and Complex Needs in Residential Care	Published as Van den Steene, H., van West, D., & Glazemakers, I. (2018). Needs and preferences of parents of adolescents with multiple and complex needs in residential care. <i>Child & Family Social Work</i> , 23(4), 693-700.
Chapter 5	A Model of Intensive Cross-Sector Collaboration Between Child and Adolescent Psychiatry and Child Welfare: Guiding Principles from the Professionals’ Viewpoint	Under review at <i>Social work in Health care</i> . Poster presentation ESCAP Genève July 11 th 2017.
Chapter 6	Collaboration Between Child and Adolescent Psychiatry and Child Welfare for Adolescent Girls With Multiple and Complex Needs: an Evaluation by Adolescents, (Step)Parents and Professionals	Published as Van den Steene, H., van West, D., & Glazemakers, I. (2018). Collaboration between Child and Adolescent Psychiatry and Child Welfare for Adolescent Girls with Multiple and Complex Needs: An Evaluation by Adolescents, (Step) Parents, and Professionals. <i>Residential Treatment for Children & Youth</i> , 1-28. Oral presentation ESCAP Genève July 11 th 2017.

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Chapter 8 Towards a Definition of Multiple and Complex Needs in Children and Adolescents: Delphi study in Flanders and International Survey

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