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**A multi-perspective exploration of the service needs of adolescent girls with multiple and complex needs**

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## Abstract

The increasing population of adolescents with multiple and complex needs (MCN), 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 MCN are especially vulnerable and suffer from fragmentation of services. 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 MCN could ameliorate service provision for this vulnerable population.

Our aim is a multi-perspective description of the needs of adolescent girls with MCN, 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 child and adolescent psychiatry hospital, aiming to optimize care delivery for adolescent girls with MCN.

Combining all perspectives, we found that the main service needs were: 1) *focus on youth-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 MCN and are found to be in line with the framework of needs-led child and youth care: 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 parents and professionals in research, care delivery planning and implementation.

**Keywords:** multiple and complex needs, adolescents, needs – led youth care, multiple stakeholders' perspectives, participation

## 1. Introduction

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 are also in contact with professionals from 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. 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, Carpenter, Phillips, Connors, MacDonald, Eyres, Noyes, Chaplin, & Place, 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 safe environments and opportunities to address areas of difficulty for many of the most vulnerable children and adolescents in youth care. 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, resolving 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, van den Bergh, & Knorth, 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 engaging them and involving them in treatment decision making, and in planning and assessing services (Koren & Paulson, 1997; Nix, Bierman & McMahon 2009; Metselaar e.a., 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 neither clinical outcomes alone, nor 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 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 parents and professionals in the context of a participatory action research.

## **2. Methods**

### **2.1 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 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 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 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).

## 2.2 Setting

The adolescents who were interviewed in this study reside in a residential child welfare (CW) facility located in Belgium. An innovative collaboration program 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,...). In order to meet the needs of these adolescents, an intensive collaboration with a tertiary child and adolescent psychiatry (CAP) service was set up. 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.
Size	17 girls in residential program, 6 ambulatory. Ages 14–20. 2 group-based, and 2 independent living programs.
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.
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 <sup>a</sup> and Institutional Pedagogy <sup>b</sup> , whereas Empowerment theory is guiding the overarching organization <sup>c</sup> . Some of the child and adolescent psychiatry interventions are inspired by Dialectical behavioral therapy <sup>d</sup> .
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.

### 2.3 Population

After discussing the participatory research project during multiple meetings and providing written information, we did interviews with adolescents and parents, and focus groups with professionals. We used convenience sampling and included 9 adolescents and 12 parents (9 biological parents and 3 stepparents) 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 involved 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 were included. 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, changing jobs, illness).

### 2.4 Data collection

Data for this study were gathered through interviews with a mean duration of 1 hour and 15 minutes, 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. Interviews and focus groups were structured around a series of open-ended questions about needs towards services. A literature search and discussions with professionals, adolescents and 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 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 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).

## **2.5 Data analysis**

Three researchers performed the data collection, and a fourth researcher (last author) joined them for data 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 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. 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.

### 2.6 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.

### 3. Results

In this section, the six themes representing 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, 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.

Table 2. Main themes

Needs (themes)	main concepts
<b>Focus on youth-professional relationship</b>	<i>attention and quality time, trustworthy and genuine professionals, feeling respected, bonding activities, focus on attachment, trust</i>
<b>Enabling youth to</b>	<i>control and power with regard to decisions, information, developing a shared plan of</i>

<b>have agency</b>	<i>action, empowering, adapting the degree of decision making depending on the case</i>
<b>Holistic and adjusted delivery</b>	<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 is necessary.</i>
<b>Efficient coordination</b>	<i>Coordination and collaboration between services, briefing of information, planned and coordinated care, efficient and transparent communication, cross-sector coordination</i>
<b>Focus on the individual</b>	<i>care about the individual, respect their individuality, adapt to the individual needs, needs instead of agencies offer guide care delivery</i>
<b>Continuity of care</b>	<i>relational aspect of continuity, placement stability, collaboration between services supports continuity in care delivery</i>

### 3.1 Focus on youth-professional relationship

#### Adolescents

When discussing the service needs of these girls with MCN, 'youth-professional - relationship', referring to the relationship between adolescents and professionals, is a prominent theme for adolescents, 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 girl 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 wellbeing 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. First of all they ask professionals to respect the limits they set, such as the physical delimitation of their room.

*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 girl 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)*

## **Parents**

Parents also attribute a lot of importance to the relationship between the youth and their 'individual residential care worker' who 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 youth 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 and as they are at 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)*

### **3.2 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 make their choices and 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)*

## Parents

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

*- In our opinion the juvenile judge and the facility should be more strict, 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 implicated 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 child and adolescent psychiatrist illustrates 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)

### 3.3 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 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)*

#### 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 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 learn them how to cope with their psychiatric vulnerability. Learn them to accept it and to integrate into society, rather than hiding behind the problems. They should learn 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 offered intensive psychiatric care also. 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)*

### **3.4 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)*

## Parents

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 also want to know what their reference frame is, 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 parents, and all different professionals who are involved. She says that such a 'common story' is necessary to centralize all information. Another couple of 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)*

### **3.5 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)*

#### **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. 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)*

### 3.6 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 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 worker, 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 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

to 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)*

### Parents

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 enhance.

*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)*

#### 4. Discussion and concluding remarks

The aim of this study was to explore the perception of adolescents, parents, and professionals regarding the needs of adolescent girls with MCN. Interviews and focus groups yielded the following themes: 1) *focus on youth-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 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.

##### 4.1 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 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, 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 parents emphasize the aspect of placement stability and professionals mention both aspects.

#### **4.2 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 on 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 their right to be involved in decisions that affect them seriously, 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 youth. 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 caretaker's 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 parents that professionals would focus on their *individual needs* and be interested in them as a person. Adolescents, 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).

#### **4.3 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 and 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 youths, 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 e.a. 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 abstinence, ...). 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 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 parents and siblings need to be assessed and attended as well. The methodology used does not allow for 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 parents in the exploration of their needs and the evaluation of services.

**Declarations of interest**

The authors declare no conflicts of interest

**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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**Highlights**

- Adolescents, their parents and professionals describe mostly similar needs
- Needs of adolescents with multiple and complex needs fit in needs – led youth care
- Service-users need to participate in service planning and research

ACCEPTED MANUSCRIPT