



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



Helena Van den Steene^{a,b,*}, Dirk van West^{a,b,c}, Inge Glazemakers^{a,b}

^a Collaborative Antwerp Psychiatric Research Institute Youth, University of Antwerp, Universiteitsplein 1, Antwerp 2610, Belgium

^b University Centre of Child & Adolescent Psychiatry (ZNA-UKJA), Lindendreef 1, Antwerp 2020, Belgium

^c Faculty of Psychology and Educational Sciences, Department of Clinical and Lifespan Psychology (KLEP), Free University Brussels (VUB), Pleinlaan 1, Brussels, 1060, Belgium

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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.

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,

* Corresponding author at: Collaborative Antwerp Psychiatric Research Institute Youth, Faculty of Medicine and Health Sciences, University of Antwerp, Campus Drie Eiken - Gebouw R, Universiteitsplein 1, Antwerp B-2610, Belgium.

E-mail addresses: Helena.vandensteene@zna.be (H. Van den Steene), dirk.vanwest@zna.be (D. van West), Inge.glazemakers@uantwerpen.be (I. Glazemakers).

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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 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, 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, Yperen, 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, 2010; Axford et al., 2009; 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 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 neither clinical outcomes alone, nor professionals' perspectives alone (Cooper, Evans, & Pybis, 2016; van 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 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.

2.3. Population

After discussing the participatory action 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 interviews with two parents 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

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