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The handle http://hdl.handle.net/1887/28630 holds various files of this Leiden University dissertation.

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**Title**: Ethnic minority youth in youth mental health care : utilization and dropout
**Issue Date**: 2014-09-10

# CHAPTER 1
# Introduction

This thesis focuses on three subjects: the accessibility of Youth Mental Health Care (YMHC), the diagnoses given in YMHC, and the premature termination (dropout) of therapy in YMHC. Differences between ethnic groups is the main focus in each of these subjects.

The prevalence of emotional and behavioral disorders (based on meeting symptom criteria) during childhood and adolescence is estimated to be between ten and twenty percent, which is comparable across countries (Lavigne et al., 1996; Rescorla et al., 2007; Rescorla et al., 2011; Rutter & Stevenson, 2008), and over different ethnic groups (Bengi-Arslan, Verhulst, van der Ende, & Erol, 1997; G. W. J. M. Stevens & Vollebergh, 2008; Zwirs et al., 2007). A smaller percentage of youths (i.e., about 7%) is limited in their functioning to such a degree that treatment is indicated (Rutter & Stevenson, 2008). In most western societies, only an estimated 2.5 percent finds its way to youth mental health care (YMHC) (Boon, de Haan, & de Boer, 2010; Meltzer, Gatward, Goodman, & Ford, 2000; Sytema et al., 2006; Zachrisson, Rödje, & Mykletun, 2006), indicating an overall underutilization of YMHC. For ethnic minority youth, this underutilization is considered to be even higher (Boon, De Haan, De Boer, & Klasen, 2014; V. C. Copeland, 2006; Garland et al., 2000; Goodman, Patel, & Leon, 2008; Ivert, Merlo, Svensson, & Levander, 2013; Kodjo & Auinger, 2004; Zwirs, Burger, Schulpen, & Buitelaar, 2006b). Untreated youth psychiatric disorders are likely to lead to detrimental outcomes later in life, i.e. these children are at increased risk to grow up as adults relying on mental health services, which has negative consequences for themselves, their surroundings and society (Domburgh, 2009; Dulmus & Wodarski, 1996; Gosden, Kramp, Gabrielsen, & Sestoft, 2003; Kazdin & Wassell, 1998; Sytema et al., 2006). Early treatment is not only effective for current disorders, it also has the potential to reduce the risk for disorders later in development (W. E. Copeland et al., 2013; Durlak & Wells, 1997; M.W.; Lipsey & Wilson, 1993; Webster-Stratton, Reid, & Hammond, 2004). Therefore it is clinically relevant to gain knowledge on the causes of underutilization of mental health care services. Both ethnic background and socioeconomic status are seen as important variables in relation to ethnic differences in mental health care utilization (Garland et al., 2005; Zimmerman, 2005). These variables are often correlated, i.e., ethnic minorities likely have a lower SES than majorities (Chen, Martin, & Matthews, 2006; Saxena, Eliahoo, & Majeed, 2002; Urbanus-Van Laar, 2006). It thus is not surprising that ethnic inequalities in health care are, at least to some extent, socioeconomic in nature (Stronks & Kunst, 2009). It is however difficult to find out to what extent each variable contributes to the underutilization, which is relevant because it will determine how mental health services can address the problem of

underutilization. The first aim of this thesis is therefore to describe the utilization of YMHC in the Netherlands. And whether there are differences in service consumption between ethnic groups, between children and adolescents, between males and females, and whether socioeconomic factors play a role in this utilization. It is further important that the disorders of children and adolescents who consult mental health services  minority youths are concerned, thus impeding effective treatment (Begeer, El Bouk, Boussaid, Meerum Terwogt, & Koot, 2009; Crone, Bekkema, Wiefferink, & Reijneveld, 2010; Kreps, 2006; Martin, 1993; Reijneveld, Harland, Brugman, Verhulst, & Verloove-Vanhorick, 2005; Van Ryn & Fu, 2003; Zwirs, Burger, Buitelaar, & Schulpen, 2006a). In line with these results it is interesting to analyze whether there are differences between ethnic groups and their received diagnoses in YMHC practice. The second aim of this thesis is thus to describe ethnic differences in the received diagnoses among YMHC patients.

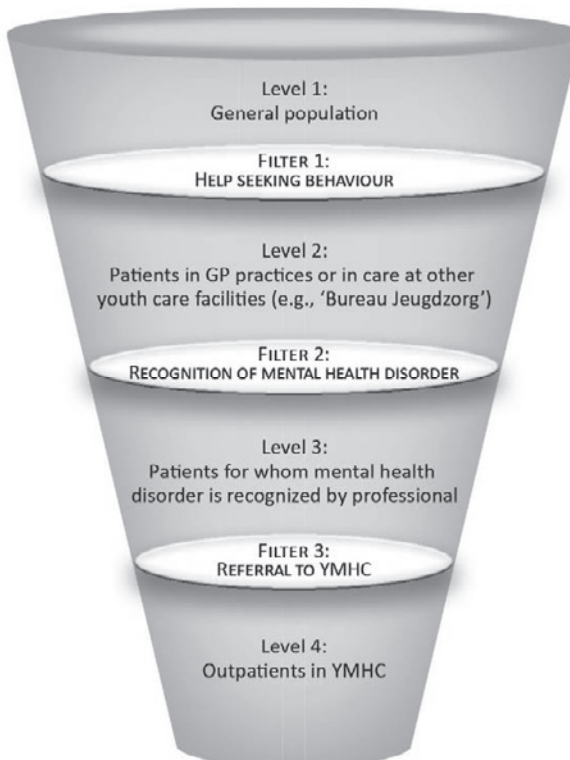
Another important factor contributing to the issue of possible non-effective treatment is the premature termination of treatment. Of all children and adolescents receiving treatment a quarter to up to three quarters terminate psychotherapy prematurely (Baruch, Vrouva, & Fearon, 2009; Lai, Pang, Wong, Lum, & Lo, 1998; Luk et al., 2001; Midgley & Navridi, 2006). As efficacy has been proven for many interventions (Weisz, Jensen-Doss, & Hawley, 2006), completing therapy definitely increases the likelihood of reducing disfunctioning due to psychiatric problems. When children prematurely terminate or drop out of psychiatric treatment, their disorders might persist or even worsen later in life (Dulmus & Wodarski, 1996; Reis & Brown, 1999). In order to prevent these negative consequences of treatment dropout, it is important to gain knowledge of its determinants. The third aim is therefore to describe the variables that relate to dropout and to analyze ethnic differences in dropout of therapy in YMHC.

**The pathway to Youth Mental Health Care**

As mentioned before, prevalence rates and patterns of disorders in child and adolescent populations are broadly similar across ethnic groups. One may thus expect that ethnic minority groups receive mental health care services at about equal rates as the majority group, which is not the case as we have seen. Underutilization of YMHC can at least partly be attributed to factors in the pathway that leads to these services. An important theoretical approach in understanding this pathway is the ‘filter model’ (Goldberg & Huxley, 1980), which was adapted

by Verhulst and Koot (1992) and Zwaanswijk and colleagues (2003, 2005a, 2007) for children and adolescents. The filter model discriminates between several levels (the *first level* being the total general population, and the *fourth level* being the patients in outpatient mental health care), each separated by a so-called filter (see figure 1). According to the model, a number of filters have to be passed before treatment in a mental health institution occurs (Colijn, 2001; De Jong, 2010b; De Jong & Van den Berg, 1996; Goldberg & Huxley, 1980; Verhulst & Koot, 1992). Although the focus in this thesis will be on the *fourth level* (i.e., outpatients in YMHC), the filters that precede this level will be described here to gain understanding of the mechanisms that lead to treatment in YMHC.

***Figure 1: Filter Model for the pathway to YMHC***



In the *first filter* the perception and the recognition of psychiatric problems by individuals and their parents, relatives, friends, or teachers, determine the eventual decision to consult a professional. De Swaan (1979) introduced the term 'proto-professionalization' to describe the extent to which individuals have the capacity to obtain, process, and understand basic health information, and have knowledge about the services needed to make appropriate health decisions. Where children are concerned parents have an important role in the help-seeking process, as do other relatives and teachers (Zwaanswijk, 2005). During adolescence parents continue to play a role in initiating the help-seeking process, although the process is characterized by increasing autonomy and the adolescent's own problem recognition. Next, the problems have to be presented to the GP or the youth care worker (i.e., from 'Bureau Jeugdzorg'). And subsequently in the *second filter* the problems have to be recognized by these professionals as being psychiatric problems. GPs and youth care workers may or may not detect and identify cases that are presented to them, and may or may not decide to treat these cases in general practice. In the *third filter* part of these cases will be referred for diagnostic examination or treatment in YMHC.

The process of 'selective filtering' is likely to explain to some extent why ethnic minority youth tend to make less use of mental health care than majority youth, despite similar prevalence rates (Colijn, 2001). According to Colijn (2001), De Jong and Van den Berg (1996), and De Jong (2010b) the filters have differential effects for different subgroups within the population, and are therefore more easily passed by some ethnic groups than by others. For instance, some ethnic minority groups are less familiar with mental health problems and with the possibilities of professional care than majorities, and the *first filter* might therefore be more easily passed by ethnic majority groups (Colijn, 2001). In addition, ethnic minority groups also tend to seek help with traditional or alternative healers, and according to some authors they should be added to the filter model when describing the pathway to YMHC for ethnic minority youth (Bhui & Bhugra, 2002). Healers may refer patients to the GP when they suspect (mental) health problems that they cannot cure themselves.

Next, GP's or other primary care or educational workers in the *second filter* might recognize mental health problems more easily among children of a majority background than among children of a ethnic minority background, which is likely to affect decisions on referral to mental health care services. For instance, there may be differences in verbal and non-verbal

presentation, in cultural definitions of important Western concepts like self and insight, the transcultural normality or deviance of ideas like hearing voices, in the believe that mental health care will work, in the knowledge of and trust in psychiatric treatment, and so on (Colijn, 2001; De Jong, 2010a). After children and adolescents are referred (*third filter*) to YMHC by the primary care workers, professionals working there have to decide which emotional and behavioral problems are present (i.e., the diagnostic process), and whether these patients are correctly referred.

As mentioned before, in this thesis the focus will lay on the *fourth level* (i.e., outpatients in YMHC). We will analyze which children and adolescents arrive at this level and which diagnoses these patients receive. The processes in the three preceding filters thus determine who will arrive at this fourth level. The described process of selective filtering indicates that ethnicity is an important factor influencing transition through the three different filters. It is unclear however, whether ethnicity influences the pathway to YMHC equally among age and gender groups. As mentioned before, ethnic majority youth underutilize YMHC as well, although little is known about the exact distribution of the utilization over age and gender groups. Hence it is important to focus not only on the ethnic background but also on the age and gender of patients. This thesis thus intends to study utilization of YMHC by ethnic, gender and age group. Because ethnic background and socioeconomic status are correlated, several authors state that SES actually explains the differences on the utilization of mental health care between ethnic groups (Cooper, 2002; Stronks & Kunst, 2009). However, Garland and colleagues (2005), Wu and colleagues (2001), and Kamperman and colleagues (2007) analyzed the ethnic disparities in use of YMHC while controlling for socioeconomic position, and found that ethnic disparities in the utilization of mental health services still remained. Although these are important studies, they focused on the situation in the United States (Garland et al., 2005; Wu et al., 2001) or on adults in The Netherlands (Kamperman et al., 2007). In the United States the insurance status of the patients always interferes with the SES and the possibility to receive (mental) health care. In most European countries however, the whole population has health insurance and insurance status is much less a confounding factor. It is therefore important to investigate the association between ethnic background, SES and youth mental health service use in European countries. Insights gained may determine how European youth mental health services can address the problem of underutilization.

Once children and adolescents have been referred to YMHC, decisions are made on the diagnosis and the treatment that is needed. Diagnostic accuracy is important because it predicts better therapy engagement, a decreased likelihood of therapy dropout, and better treatment outcomes (Jensen-Doss & Weisz, 2008). As stated before, psychiatric disorders are under-diagnosed in ethnic minority youth in particular, which, among other factors, can be attributed to the influence of ethnic stereotyping (Begeer et al., 2009; Kreps, 2006; Reijneveld et al., 2005). A number of studies have shown that clinicians assign different meanings to the same behaviour depending on race, class, or other demographic characteristics of the individual involved (Snowden, 2004; Van Ryn & Fu, 2003). For instance, in one study with a group of children that scored within the clinical range of an emotional and behavioural problem self-rating questionnaire, mental health care professionals recognized psychiatric problems among 9,4% of the ethnic minority children and among 21,4% of the native Dutch children (Reijneveld et al., 2005). Also, paediatricians more often diagnosed autism when judging clinical vignettes of European majority cases (Dutch) compared to vignettes including non-European minority cases (Moroccan of Turkish) (Begeer et al., 2009). Underdiagnosis is more likely to occur when diagnoses are made in an unstructured clinical interview by a single diagnostician, which is the assessment method most often used in the practice of YMHC (Cashel, 2002; Zayas, Cabassa, Perez, & Howard, 2005). It is therefore important to gain knowledge on differences between ethnic groups in the received diagnoses in the practice of YMHC, which will be illustrated in the present thesis.

**Treatment adherence in Youth Mental Health Care**

Compared to children receiving treatment, children with untreated behavioral problems or premature terminators are more likely to leave school without a qualification, engage in delinquent activities, abuse drugs and alcohol and become unemployed (Alonso, Chatterji, & He, 2013; Lochman & Salekin, 2003; Moffitt, Caspi, Harrington, & Milne, 2002). Also, untreated early-onset anxiety disorders often continue into adulthood (Dadds et al., 1999), and academic underachievement and substance dependence are likely to follow (Woodward & Fergusson, 2001). In addition, the pathway to YMHC is a difficult one, as we have described in the former paragraph. Evidence-based therapy is known to increase the likelihood that psychiatric problems get resolved and functioning is improved (Weisz et al., 2006). And it undesirable that therapy,

once it is started after the difficulties in accessibility, is prematurely terminated. It is thus important to gain knowledge of the dropout determinants in order to be able to prevent it.

Dropout predictors can be divided in three major groups: child factors (e.g., ethnic background, problem severity, age, gender), family factors (e.g., socioeconomic status, family composition, living situation), and therapy or therapist factors (e.g., therapeutic relationship, perceived relevance of treatment, waiting time) (Armbruster & Kazdin, 1994; Kazdin, Holland, & Crowley, 1997a). Studying child and family factors may lead to the identification of patients being at risk for dropout. Extra attention to these patients may prevent dropping out. Therapy factors are factors that can be changed during the course of therapy. For instance, the therapist is able to influence the therapeutic relationship during treatment. All three groups of predictors need different interventions in order to prevent dropout. A mere identification of the child and family factors without conceptualizations of the underlying process of premature termination (i.e., therapy and therapist factors) is unlikely to improve the understanding of dropout (Armbruster & Kazdin, 1994).

A theoretical model to understand underlying processes of dropout was introduced by Kazdin and colleagues; the barriers-to-treatment-participation model (Kazdin et al., 1997a; Kazdin, Holland, Crowley, & Breton, 1997b). This model proposes that families experience multiple barriers associated with participating in treatment, which increase the risk for dropping out. The absence of barriers may serve as a protective factor, i.e., for families with a high risk for dropping out, the presence of only a few barriers might attenuate the risk (Kazdin et al., 1997b). Many studies on dropout in child and adolescent psychotherapy have shown inconsistent results. It is therefore hard to discern the characteristics of child and adolescent patients that dropout of treatment and the conditions under which dropout occurs. In order to structuralize the findings of various dropout studies, a review or meta-analysis should be done. The last review was conducted in 1994 (Armbruster & Kazdin, 1994). In this thesis we will update the findings on dropout studies in child and adolescent therapy by conducting a meta-analytic review of the studies published later than 1994. Considering that ethnic minority youth are treated less often for their mental health problems than ethnic majority youth, analyzing the levels of dropout among ethnic minorities, as well as ethnic-specific dropout determinants carries substantial importance. This has become feasible since several dropout studies specifically focused on ethnic minority children, or described the ethnic background of their

respondent group. Therefore, a review specifically focusing on the ethnic minority status aspect in dropout studies will also be included in this thesis.

The earlier described interplay between ethnic background and socioeconomic variables also accounts for the predictors regarding dropout. Indeed both factors were found to be predictive for dropout (Kazdin & Wassell, 1998; Kendall & Sugarman, 1997; Peters, Calam, & Harrington, 2005; Warnick, Gonzalez, Weersing, Scahill, & Woolston, 2012), while the relationship between both is not clear. Nor is it clear for which specific ethnic or socioeconomic groups the risk for dropping out is elevated. This thesis will try to extend the knowledge on dropout in psychotherapy with ethnic majority and minority children and on the interfering relationship of ethnic background and SES variables. Until now, most studies did not specifically make a distinction by age, i.e., some studies only had children as their respondent group while other studies only included adolescents. Or both groups were included without differentiating by age. In contrast to adults and in a lesser extent to adolescents, children rarely seek mental health treatment for themselves. Motivation for coming and remaining in treatment largely depends on others, foremost parents, but also teachers and referral agents. Frequently, parents participate in their children's treatment and consequently parent and family characteristics are likely to play a central role in continuation or termination of treatment. Probably, parent and family characteristics are more significant in child therapy and less significant in adolescent therapy (Armbruster & Kazdin, 1994). It is thus important to study dropout for children and adolescents separately.

One of the important determinants of dropout is the quality of the therapeutic relationship between the child or family and the therapist (Garcia & Weisz, 2002; Hawley & Weisz, 2005; Kazdin & Wassell, 1998; J. Stevens, Kelleher, Ward-Estes, & Hayes, 2006). Therefore, developing effective therapeutic relationships with young patients and their family members may facilitate engagement and lessen resistance to treatment by providing a stable, accepting and supportive context within which therapy may take place (Karver, Handelsman, Fields, & Bickman, 2006). There is evidence from several studies that a negative or weak therapeutic relationship is predictive of therapy dropout with children and adolescents (Zack, Castonguay, & Boswell, 2007). Much variation in the moment at which the therapeutic relationship was measured limits generalizability of findings in previous studies. In some studies, it was measured in retrospect at the end of therapy by asking the parents and/or child to complete a questionnaire, while in other studies trained observers rated the therapeutic alliance

at one or two therapy sessions during the course of therapy (Cordaro, Tubman, Wagner, & Morris, 2012; Hawley & Weisz, 2005; Pereira, Lock, & Oggins, 2006; Shelef, Diamond, Diamond, & Liddle, 2005; J. Stevens et al., 2006). Each of these methods has its shortcomings. Measuring the relationship by observers may be considered a limited approach, as it does not take the patients' opinion about the relationship directly into account. It depends on the observer how the relationship is rated. Measuring the relationship after therapy is likely biased as it is influenced by the way patients and parents feel at that termination point. In addition, parents can hold a different view of the therapeutic relationship than the child. It thus makes more sense to measure the therapeutic relationship during several sessions of the therapy process (Zack et al., 2007). We therefore intend to extend and specify insights on the association between the therapeutic relationship and dropout in psychotherapy with ethnic minority children and adolescents by measuring the therapeutic alliance during the course of psychotherapy.

**Central concepts and major aims of this thesis**

*Specification of ethnicity*

Ethnic background was determined by the country of birth of both parents. Based on their parent's country of birth, children were categorized into ethnic groups. The country-of-birth criterion has been used in the Netherlands to determine ethnicity since the 1990s (Boon & Colijn, 2001; Den Heeten & Verweij, 1993). If the country of birth of both parents is the Netherlands (regardless of the country of birth of the person himself), a person is seen as native Dutch (CBS, 2012). If one or both parents are born abroad, a person is seen as ethnic minority. The term native Dutch is a difficult one to use. In countries such as the United States or Australia for instance, natives are the native inhabitants (e.g., Indians or Aboriginals), who are nowadays the minority groups while the non-native Caucasians are nowadays the majority group. In most European countries such as the Netherlands, the natives are the Caucasian majority group, while the non-natives are the minority groups. For international purpose, it is therefore better to use the term majority group versus minority groups when describing the differences between both groups and especially the disadvantaged position of the minority groups. When describing the Dutch situation, it is accepted to use native Dutch population versus the non-native population or the ethnic minority population.

The majority of non-natives in the Netherlands originate from Morocco, Turkey, Surname or the Dutch Antilles. The Moroccans and Turks are mainly descendants from labour migrants who have migrated from to the Netherlands since the 1960s and 1970s (Bocker, 2000; Nelissen & Buijs, 2000). Surinamese have come to the Netherlands since 1975, during the process of decolonisation (Van Niekerk, 2000). The Dutch Antilles consists of six islands in the Caribbean, which were part of the Netherlands until 2010, three of them still are now. After the 1960s the group that came from these islands consisted primarily of labour migrants, while before it were mainly children of white colonists and the local elite who came to the Netherlands to study at universities (Van Hulst, 2000). Besides these four main ethnic minority groups, many other groups are residing in the Netherlands nowadays. These inhabitants come from other African countries, the Middle East, Asia, and Latin America who migrated due to the processes of decolonisation, refugee movements following conflicts and civil disturbances, and the collapse of the Soviet Union.

For the purpose of our thesis, a division in seven ethnic groups was made: native Dutch, Surinamese, Antillean, Turkish, Moroccan, Other non-native western, and Other non-native non-western. Following the guidelines of the Dutch government (CBS, 2012), European countries (except Turkey), North-America, Oceania, Japan, Indonesia and the Asian part of the former USSR were considered as western countries. Turkey, Africa, Latin America and the rest of Asia were considered as non-western countries.

*Specification of dropout*

In former dropout studies, there is an enormous variation in operational definitions of premature termination and classification of dropout status. Many studies define dropout in terms of treatment duration or number of sessions completed, in which clients attending less than the specified number of sessions are categorized as dropouts (Wierzbicki & Pekarik, 1993). Some patients, although terminating treatment earlier than planned, can still be considered successful terminators, because sufficient improvement in their mental health was achieved in a shorter than planned duration. A definition based on a predetermined number of sessions will thus result in a dropout group comprised of a mixture of dropouts and appropriate premature terminators.

In this thesis, we used the opinion of the therapist, the parent, and the adolescent to determine who should be regarded as a dropout. After therapy had ended, both the therapist

and the patient (or in the case of children under the age of 12, the parents) were asked why the therapy had ended. Only when both the therapist and the patient agreed that therapy goals had been reached, or when both agreed to terminate while not all goals had been reached, was the patient classified as a completer. Completion was thus defined as “the termination of outpatient treatment at any point of time during therapy, that occurred with accordance of both the therapist and the patient or parent, while both agreed that treatment goals were (at least partly) reached”. Dropout was defined as “the termination of outpatient treatment at any point of time after inscription, that occurred on the child’s or parents’ unilateral decision, while the therapist thought that further treatment was needed”.

*Major aims*

This thesis has three major aims. The first aim is to describe the utilization of Youth Mental Health Care (YMHC) in the Netherlands: whether there are ethnic differences in this utilization between ethnic groups, between children and adolescents, and between males and females, and whether socioeconomic or ethnic background play a role in this utilization (**chapter 2 and 3**). Second, to describe ethnic differences in the psychiatric classification (DSM) in youth patients receiving mental health care (**chapter 4**). Third, to describe dropout predictors in YMHC and ethnic differences in these dropout predictors (**chapter 5 to 8**). The three major aims will be addressed by focusing on specific sub-aims in the several chapters of this thesis. These will be described in more detail below.

Three different data sets were used:

- Dataset A: the patient population. We used the data of two YMHC sites in The Hague (and its surrounding areas), one of the four main cities of The Netherlands: *De Jutters*, a general mental health care institution for children and adolescents, and *i-psy de jutters*, an intercultural specific mental health care institution for children and adolescents. Within these institutions, patients aged 0-23 can be treated on ambulatory, clinical, or day-care basis. For the patient population, we used data of all patients that were registered at the two sites in 2008 and 2009.
- Dataset B: the general population. We used data of the general population of The Hague and its surroundings (i.e., ethnic background of the inhabitants and average year income) in 2008 and 2009, drawn from municipality files.

- Dataset C: published studies. Data of published studies in English (1994-2013) on dropout in child and adolescent psychiatry were used to conduct a meta-analytic review and a literature review.

*Outline of thesis*

In **chapter 2** the aim is to describe ethnic, gender, and age differences in utilization of YMHC in The Hague. Dataset A and B were used for this aim. Patients' ethnic backgrounds were compared to the general population distribution of the same region. Relative Risk ratios (likelihood) of YMHC utilization for ethnic minority groups were calculated with native Dutch youth YMHC utilization as the reference group. **Chapter 3** aims to describe the relationship between YMHC utilization, ethnic background, and a specific socioeconomic variable (i.e., the average income of the district that the patients live in). Again, both dataset A and B were used. Regression analyses with average year income (as an indicator of SES), and the percentage of native Dutch and ethnic minority inhabitants as independent variables, and the percentage of youngsters in treatment as the dependent variable were conducted.

The aim of **chapter 4** is to describe ethnic differences in the received DSM-classifications of YMHC patients. Dataset A was used for this purpose. Odds Ratios (probability ratios) on psychiatric diagnoses made by clinicians for the ethnic minority groups were calculated with native Dutch youth as the reference group

In the **5$^{th}$ chapter** the aim is to structuralize the knowledge on dropout predictors. We conducted a meta-analytic review by using dataset C and calculated effect sizes for each predictor. The aim of **chapter 6** is to specifically extend the knowledge on dropout predictors in therapy with ethnic minority youth. We used dataset C and conducted a literature review.

**Chapter 7** aims to gain knowledge on differences in dropout predictors (such as ethnic background) between children and adolescents in YMHC in The Hague. This was done by using dataset A. We used multinomial logistic regression models to test the strength and significance of each potential predictor. In the **8$^{th}$ chapter** the aim is to study the quality of the therapeutic relationship (i.e., an important dropout predictor) in therapy with ethnic minority youth. General Estimation Equations (GEE) were used to analyse longitudinal repeated measurements within the same subjects of dataset A. Finally, the main findings of this thesis are summarized and discussed in **chapter 9**.