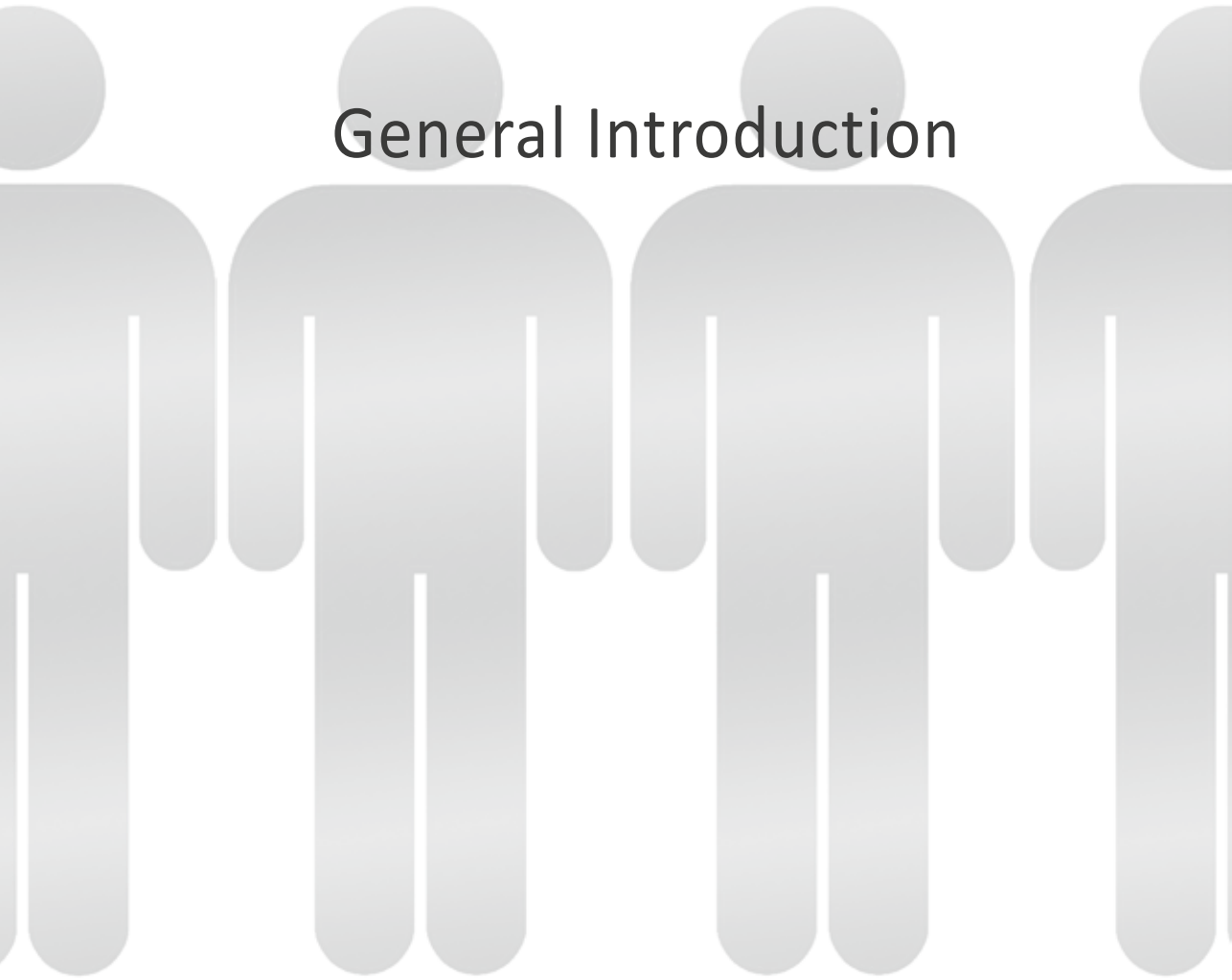
Mild intellectual disability : an entity? Mapping clinical profiles and support needs

Soenen, S.M.T.A.

CHAPTER 1

General Introduction



Introduction

The group of people with mild to borderline intellectual disability (MBID) encompasses individuals who have limited cognitive skills. These people often have difficulties with abstract thinking and problem solving, and are challenged by interpersonal interactions, social judgments and decision-making processes in everyday life (Bexkens, Jansen, van der Molen, & Huizinga, 2016; Fuijara, 2003; Snell et al. 2009). Mild ID has a prevalence of 0.5% to 0.8% in the general population (David et al., 2014; Roeleveld, Zielhuis, & Gabreëls, 1997; Simonoff et al., 2006), whereas the group of people with borderline ID encompasses a further 14.0%. Although this large group of people have seemingly mild cognitive disabilities, their support needs can be unexpectedly high, and can be similar to individuals with more pronounced ID (Fujiara, 2003; Peltopuro, Ahonen, Kaartinen, Seppälaä, & Narhi, 2014; Snell et al., 2009). In addition to possible learning problems, also behavioural problems, psychiatric conditions and various problems with activities of daily living, social participation and employment, may be present. People with MBID may be referred to multiple care settings. The reason for referral is usually based on the most severe and obvious problem, rather than on a careful analysis of the complexities of all the problems present. This often leads to successive, disjointed, and therefore less effective support. Many individuals with MBID do not receive the support they need, which leads them to disappear from the service system, and they could eventually become evolved in the criminal circuit (Broadhurst & Mansell, 2007; Emerson, 2011; Holt et al., 2000).

As a result of the variety of support needs, support providers metaphorically grope in the dark with regards to the form of support these individuals require. Care providers working with individuals with MBID have therefore requested an establishment of criteria upon which decisions about the types of support for these individuals can be based. To realize this, it must be determined whether this population can be defined in terms of a limited number of needed support types and corresponding support programs. This study aims to contribute to answering this question by describing basic clinical profiles in the MBID population, studying whether these profiles relate to specific support programs, and comparing initially recommended forms of support with the support provided in order to determine the forms of support individuals with MBID need but do not receive.

In this introductory chapter, a number of issues are addressed. First, MBID is defined, along with the criteria that were used to differentiate this group from others over time. Second, the theoretical framework and a brief summary of the relevant literature are presented. Finally, the implications of the findings are discussed along with an outline of the present study and the specific research questions addressed.

Mild intellectual disability

Definition

The American Association on Intellectual and Developmental Disabilities (AAIDD) has had a leading role in the definition of intellectual disability (ID). People with ID have been described in very different ways at various times in recent history. The definition of ID has evolved from a definition based solely on IQ towards a definition based on adaptive behaviour and support needs (Luckasson et al., 2002; MacMillan & Reschly, 1997; Schalock et al., 2010). The most recent definition provided by the AAIDD is as follows: "Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18" (Schalock et al., 2010).

This definition includes three key elements:

1. Intellectual functioning refers to general mental capacity, such as learning, reasoning and problem solving. An IQ-test score of 70 to 75 indicates a limitation in intellectual functioning;
2. Adaptive behaviour includes conceptual, social and practical skills that are learned and performed by people in their everyday lives. Standardized tests can determine limitations in adaptive behaviour; and
3. Age of onset; there is evidence of the disability during the developmental period before the age of 18.

This definition has been widely adopted by mental health professionals and also largely covers the definition of intellectual disability in the 'Diagnostic and Statistical Manual of Mental Disorders', Fifth Edition (DSM-5), classification system (APA, 2013).

Criteria for levels of severity: a historical reflection

In the past definitions, individuals with ID were subdivided into groups according to level of intellectual functioning or level of needed support. We will discuss both criteria in relation to the group of people with mild to borderline intellectual functioning.

Differentiation based on intellectual functioning

In the earlier definitions provided by the American Association on Mental Retardation (AAMR, Grossmann, 1983), the ICD-10 (World Health Organization, 1993) and the DSM-IV (American Psychiatric Association, 1994), individuals with ID were subdivided into levels of intellectual functioning. Individuals with an IQ of 50/55 to approximately 70 were classified as having MID. In addition, the DSM-IV, used at the commencement of this study, speaks of borderline intellectual functioning at an IQ of 70 to 85. This approach was criticized because it mainly revolved around the limitations of the individual. MID is not a defect, but a limitation that results from the interaction of a person with his environment (Luckasson et.al., 1992). In the DSM-5, IQ boundaries no longer form part of the classification of borderline intellectual functioning. IQ scores do not remain stable during the course of development (Hodapp & Dykens, 1996; Jenni, Fintelmann, Caflisch, Latal, Rousson, & Chaouch, 2015), and the description of an individual solely

based on their IQ masks the true nature of their support needs (Fuijara, 2003). However, one positive aspect of the approach based on intellectual functioning is that it offers an objective criterion that is easy to apply by professionals due to the use of standardized IQ tests.

Differentiation based on level of support

In 1992, the AAMR did away with levels of severity for the definition of ID. They emphasized that the lack of adaptive skills that individuals with ID display determines the intensity of support needed by these individuals. However, MacMillan and colleagues have been critical of this omission, as it has led to the elimination of MID and the borderline categories of ID. They argued that such individuals are often also in need of special support (MacMillan, Gresham, Bocian, & Lambros, 1998; Macmillan, Gresham, & Siperstein, 1993; MacMillan, Siperstein, & Gresham, 1996). In the 2002 definition, the AAMR distinguished four levels of support: intermittent, limited, extensive and pervasive. The upper limit of the group was operationalized as an IQ limit that must be flexibly applied (Luckasson et al., 2002). From this perspective, MID does not imply that these individuals have "mild needs" for support. Furthermore, individuals who are not classified as having MID on the basis of their IQ may still be classified due to their apparent need for special support (Ras, Woittiez, van Kempen, & Sadira, 2010). However, there is a risk that a number of people from low socio-economic environments as well as people with learning disorders and behavioural and/or emotional problems are (unjustly) included in the MID group (MacMillan et al., 1993; 1996). In this approach, the identification of people with MID is relative, because it can vary depending on age, context and the expert's capacity for detection (Tymchuk, Lakin, & Luckasson, 2001).

Criteria applied in the Netherlands

The IQ limits indicating MID are loosely applied in the Netherlands. People with an IQ between 70 and 85 can also be included in this group, depending on their limitations in adaptive functioning (De Wit, Moonen, & Douma, 2012; Ras et al., 2010). For this reason, this thesis uses the term "mild to borderline intellectual functioning" (MBID). The wide range of variability in this group stems from the changing definitions of MID and the current focus on adaptive functioning and support needs.

As shown above, the classification of individuals with MBID based on IQ is only slightly useful for the professional field in terms of support, and the classification based on the need for support is relative. The extension and diversity of the group is emphasized. These reflections are in accordance with the problems encountered by individuals with MBID and service providers in the Netherlands. The aim of this study is to identify further and/or improved criteria upon which individuals with MBID can be classified into a limited set of basic clinical profiles, which are then related to specific support programs. The AAIDD (2002; 2010) proposed a multidimensional model of ID with five interrelated dimensions. This model is of interest because it emphasizes that a comprehensive description of people with ID must be performed using more than one dimension.

Criteria included in the AAIDD multidimensional model

In the most recent definitions of ID, the AAIDD redefined ID as a multidimensional construct. This model denotes the relationship between human functioning, support, and five dimensions: intellectual abilities, adaptive behaviour, health, participation and context (Schalock et al., 2010) (Figure 1). Note that the first study in this thesis used the model published in 2002; the model was refined in 2010 with minor changes.

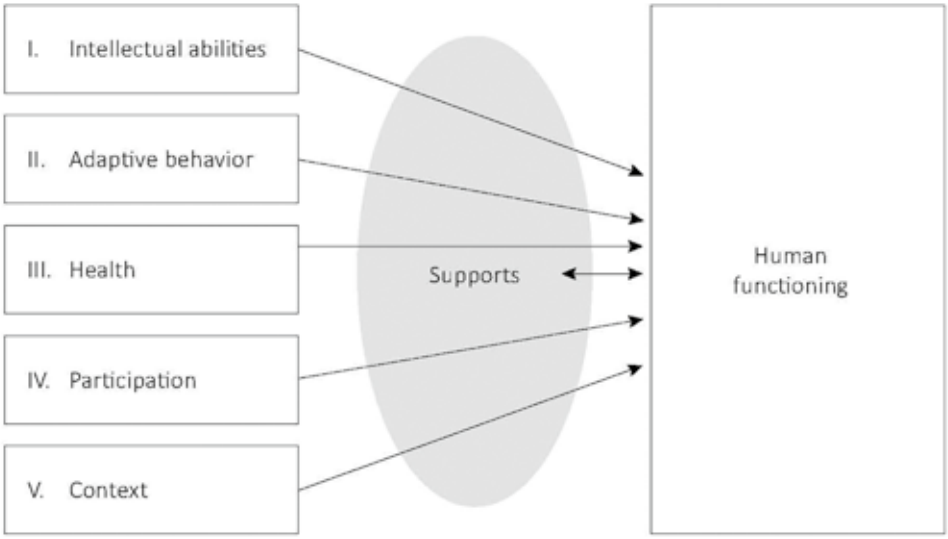


Figure 1.1. *The AAIDD model of human functioning*

Research has been performed into the characteristics of individuals with MBID on each of the five dimensions of the AAIDD model. As a result of the heterogeneity of the group, it could be expected that a high degree of variability would be found. A selection of findings will now be briefly summarized to substantiate this expectation.

MBID on the five dimensions of the AAIDD model

- *Dimension I: Intellectual abilities*
  Studies into the underlying aspects of cognitive functioning show that the cognitive profiles of people with MBID show such a high degree of variability that is difficult to define a valid group profile (Baumeister, 1997; Fletcher, Huffman, Grupe, & Bray, 1998). Patterns of cognitive abilities suggesting both strengths and weaknesses are found in the cognition of subgroups of individuals with MBID (Fletcher, Blair, Scott, & Bolger, 2004; Van der Molen, Luit, Jongmans, & Van der Molen 2009).

- *Dimension II: Adaptive behaviour*
  The developmental age of these individuals ranges from approximately 6/7 to 12 years (Došen, 2005a, 2005c; Kraijer & Plas, 2006); however, this varies during their course of life. Several factors, such as psychopathology, family stress, and child management

practices, play a significant role in the variation of the adaptive functioning (Embregts, Grimbel du Bois, & Graef, 2010; Maughan, Collishaw, & Pickles, 1999). Consequently, lower (De Bildt, Sytema, Kraijer, Sparrow, & Minderaa, 2005) as well as higher levels of adaptive functioning are found in individuals with MBID. Some individuals are even not identified because of good adaptive skills (David et al., 2014). Papazoglou, Jacobson, and Zabel (2013) also found that a group of people characterized with low intelligence could not be differentiated from a group with behavioural dysregulation based on adaptive impairment.

- *Dimension III: Health*
  The prevalence of behavioural problems is at least three times higher in youth with MBID than in the normal population (Einfeld, Ellis, & Emerson, 2011; Wallander, Dekker, & Koot, 2003). A diversity of behavioural problems is found. These problems can result from psychopathology (Dekker, & Koot, 2003; Kok, van der Waal, Klip, & Staal, 2016; Simonoff, 2015) and/or from problems with child-rearing practices (Embregts et al., 2010; Schuiringa, Van Nieuwenhuijzen, Orobio de Castro, & Matthys, 2015). Other risk factors also play a role, e.g. social incompetence, inadequate daily skills, single parent household, low parental income and stress-related life events (Dekker, & Koot, 2003; Emerson, 2003). Physical health is also an important factor, but falls beyond the scope of this thesis.

- *Dimension IV: Participation*
  Variability is found in levels of participation in individuals with MBID. Several factors play a role in this variance in participation, e.g. limitations in adaptive behaviour, behavioural or mental health problems, type of residential setting, the presence of activities (leisure, work) and the support provided, the presence of family, and high quality interpersonal relationships between professional and client (Holwerda, van der Klink, de Boer, Groothoff, & Brouwer, 2013; Philips, & Rose 2010; Van Asselt-Goverts, A., Embregts, P., Hendriks, A., & Frielink, N., 2014; Van Asselt-Goverts, A., Embregts, P., Hendriks, A., 2015; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009).

- *Dimension V: Context*
  The contexts within which people with MBID live their lives vary enormously. The residential settings vary from living with parents to living in community-based settings, institutions and to independent living (Stancliff et al., 2011). Employment environments vary from standard to supported employment settings (Luecking, 2011; Lysaght, Quellette-Kuntz, & Lin, 2012). A large percentage of these individuals live in low socio-economic settings (Snell et al., 2009). Others live in more stable environments, but may live in an environment consisting of unrealistic expectations, or are raised in a protected manner and do not develop the skills to live independently (Van Berckelaer-Onnes, 1996).

The findings of the above-mentioned studies demonstrate that there are considerable variations in intellectual, adaptive and mental health in terms of behavioural functioning and psychopathology. These factors are interrelated and are also interconnected with further factors of participation and context. In the past, individuals with MBID were grouped according to a single dimension of the model; however, this was recognised as suboptimal. For this reason, the first research question addresses whether individuals with MBID can be grouped according to clinical profiles based on the dimensions of intellectual, adaptive and health (in terms of behavioural functioning) from the AAIDD model (chapter 2). The other dimensions of the AAIDD model will be addressed in the other research questions (chapters 3 and 4).

MBID and its aetiology: the risk factors of the AAIDD model

The five dimensions of the AAIDD model in terms of present functioning have been described above. However, the AAIDD emphasizes that the diagnostic process should also include a description of risk factors that, across the life of the individual, have contributed to the individual's present functioning. Several factors have been defined, e.g. biomedical, behavioural, social-environmental, educational and service use factors (Luckasson et al., 2002; Schalock et al., 2010). It is expected that a high degree of variability in risk factors can be found in the MBID population. The main findings of this research will now be discussed.

- *Biomedical*
  An organic cause for MBID is not often identified (Strømme & Hagberg, 2000; Vissers, Gillsson, & Veltman, 2016). The proportion of known aetiologies ranges from 20% to 50% for individuals diagnosed with MBID (Croen, Grether, & Selvin, 2001). A large proportion of individuals with MBID have ID of a non-organic cause (familial MBID). This group has a higher prevalence of psychosocial causes, such as lower socio-economic status and parents with lower intellectual functioning (Hodapp, Burack, & Zigler, 1998).

- *Behavioural*
  Children with MBID may have language difficulties (Hunt & Marshall, 1994) or have poorer social skills than children without MBID (Nabuzoka, 2000). These difficulties are associated with an increased risk in the development of emotional and behavioural problems (Dekker & Koot, 2003: Koskentausta, Livanainen, & Almqvist, 2007; Wallander, Dekker, & Koot, 2006). However, data are lacking concerning precursor behaviours in infants with or at risk for MBID.

- *Social-environmental*
  Several social-environmental factors are associated with reduced intellectual and adaptive functioning and with behavioural problems in MBID (Emerson & Hatton, 2007). As mentioned above, a large proportion of individuals with MBID live in low socio-economic settings, which are related to, for instance, low income (Snell et al., 2009), difficulty accessing appropriate health services (Emerson, 2011), increased risk for all types of victimization (Euser, Alink, Tharner, van Ijzendoorn, & Bakermans-

Kranenburg, 2016; Nettelbeck, & Wilson, 2002; Svensson, Bonehag, & Janson, 2011) or becoming an offender in the criminal justice system (Kaal, Nijman, & Moonen, 2015; Murphy, Harrold, Carey, & Mulrooney, 2000). Intelligence can be negatively affected by maternal illness during childhood and rigid values regarding child development (Sameroff, 1990).

- *Educational and service use*
  The educational outcomes of individuals with MBID vary from mainstream to special schools (De Bildt, Sytema, et al., 2005; Hall, Strydom, Richards, Hardy, Bernal, & Wadsworth, 2005). Many children commence their education in mainstream schooling, but an increasing number of children are placed in special schools as they get older (Maughan et al., 1999). Children with MBID in mainstream schools are less likely to receive social services because of their disability than children in special schools (Olsson, Andersson, Granlund, & Huus, 2015). Individuals with MBID can receive different types of services, such as youth care, care for people with ID and psychiatric hospitals (Holt et al., 2000), depending on the main problem at hand.

It can be concluded that with regards to risk factors, a high degree of variability is also found in the MBID population. The second research question addresses whether clinical profiles in the MBID population, based on the dimensions of intellectual, adaptive and behavioural functioning from the AAIDD model, can be differentiated according to characteristics present in the clinical history (chapter 3).

Support

As mentioned in the introduction, service providers encounter difficulties in providing the support needed for individuals with MBID. An important reason for this is that the essential support needs of individuals with MBID are difficult to define, due to the heterogeneity of the need characteristics of this group of individuals. Service providers are uncertain as to which forms of support are required because they do not know how to organize a comprehensive response to this diverse support needs. Support is defined as resources and strategies that aim to promote the development, education, interests and personal well-being of a person and that enhance individual functioning (Luckasson et al., 2002; Schalock et al., 2010). Kok (1972) differentiated two strategies by which support for people with MBID can be described.

The first-level strategy

The first-level strategy aims to provide individuals with their optimal educational environment. It uses styles of support such as providing structure, protection and regulation. There is a continuum of residential and employment settings that people with MBID can access. However, where an individual lives or is employed is related to several factors such as the presence of behavioural problems (Stancliff et al., 2011), the availability of needed support (Murphy, Estien, & Clare, 1996), and the possibility for social participation (Van Asselt-Govers, Embregts, & Hendriks, 2013).

The second-level strategy

The second-level strategy relates to the therapeutic needs of young adults with MBID, and may include psychoeducation, skills training and psychotherapy. The second-level strategy may focus on, for example, developing an awareness of one's cognitive strengths and weaknesses to improve insight into functioning and future prospects (Van Nieuwenhuijzen & Vriens, 2012), managing stressful situations (Hartley & Maclean, 2005), problem solving (Anderson & Kazantzis, 2008; Loumidis & Hill, 1997), self-management of inappropriate social behaviours (Embregts, 2000, 2002) and anger management (Benson, 1994; Harper, Webb, & Rayner, 2013; Rose, West, & Clifford, 2000; Singh et al., 2013). The behavioural problems of people with MBID can be successfully treated by a variety of biological, psychotherapeutic and contextual interventions (Heyvaert, Maes, & Onghena, 2010; Kok et al., 2016).

Taken together, these findings demonstrate that there is variability in the functional profile of young adults with MBID and therefore variability in their educational and therapeutic needs. However, there is little understanding of how the type of educational and therapeutic support is related to the functional and clinical profile. This will be addressed in the third research question (chapter 4).

Thesis outline

The aim of this study is to investigate whether a description of subtypes in the heterogeneous MBID population can be provided in terms of a limited number of multidimensional profiles of functioning, and whether these basic clinical profiles of functioning relate to certain support programs. In chapter 2, an investigation is performed into whether clinical profiles can be identified in the population of individuals with MBID based on the dimensions of intellectual functioning, adaptive behaviour, and health in terms of behavioural functioning and DSM-IV-TR classifications. In chapter 3, it is determined whether these clinical profiles of present functioning can also be differentiated according to history characteristics and pathways to care. The focus remains on behavioural, social-environmental, educational and service use characteristics. In chapter 4, it is investigated whether the clinical profiles of young adults with MBID are related to specific support programs. It is determined which type of support is recommended for the subtypes of young adults with MBID, which type of support is provided, and the degree of satisfaction shown by the young adults with MBID with the support they receive. We will also compare the recommendations with the provision of support for the subtypes. Finally, in chapter 5, the research findings presented in the previous chapters are briefly summarized and discussed, along with the strengths and limitations of the study and the implications for clinical practice and future research.