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

Soenen, S.M.T.A.

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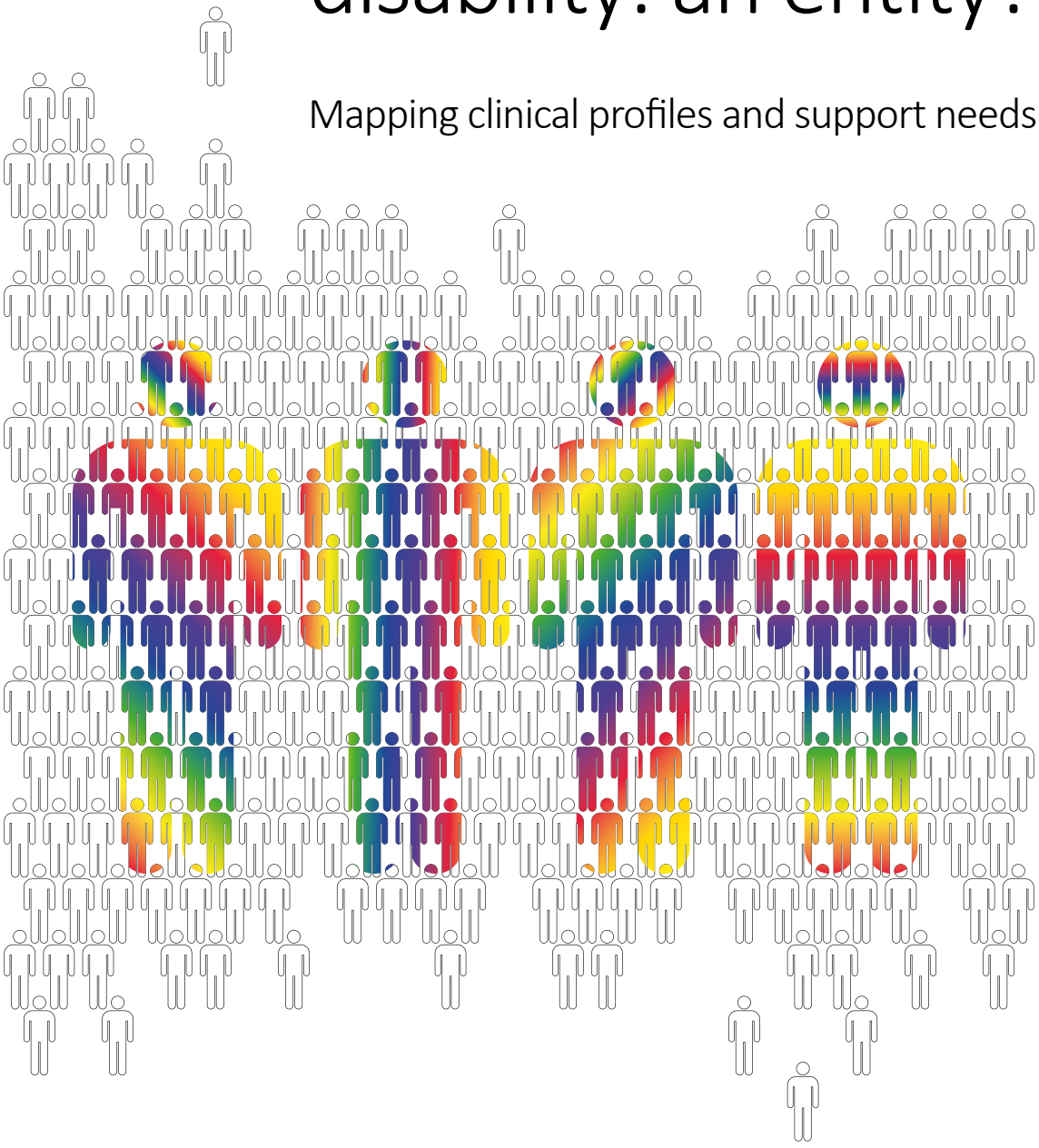

Sarah Soenen

Mild intellectual disability: an entity?

Mapping clinical profiles and support needs

Sarah Marie-Thérèse Arnold Soenen

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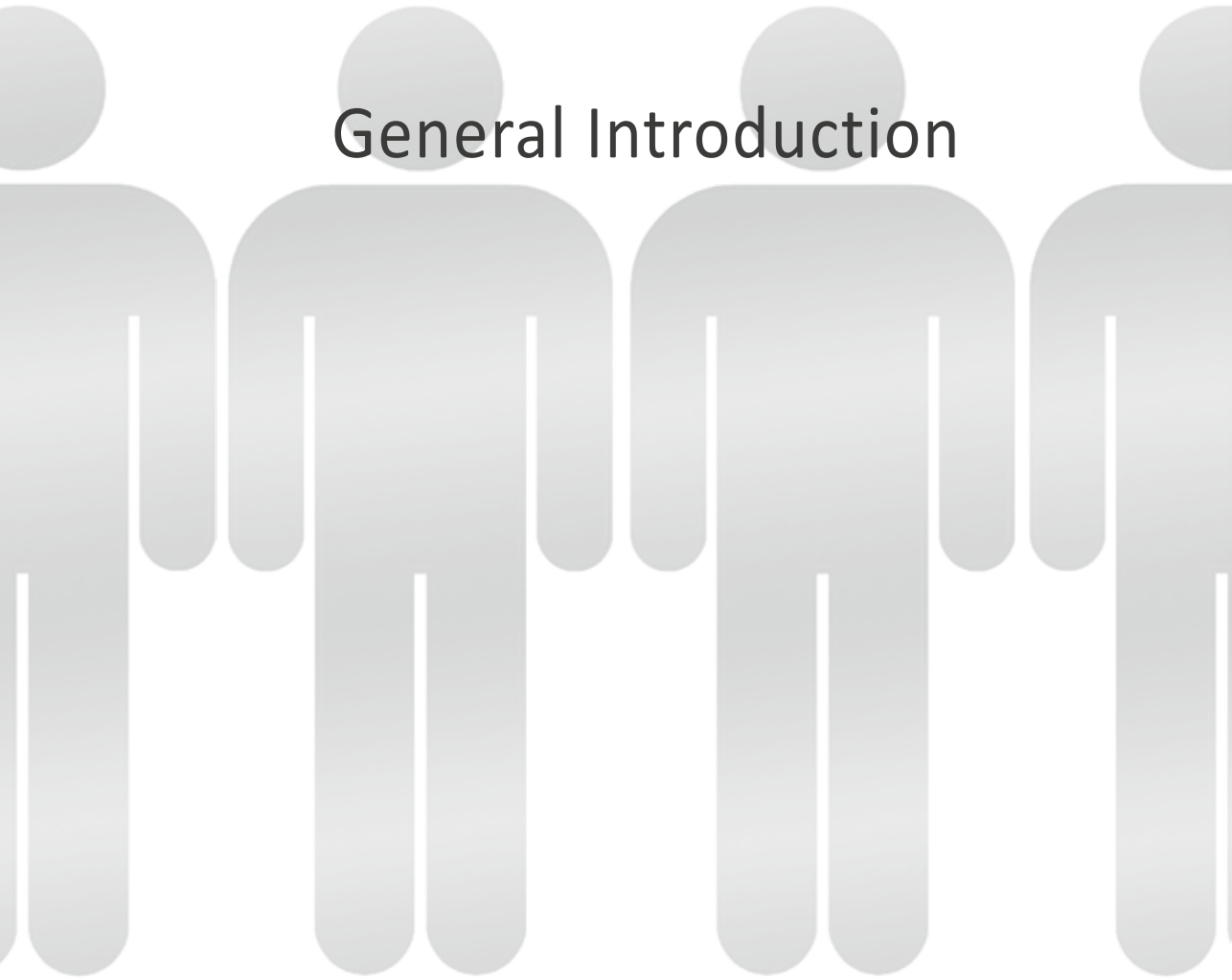
CHAPTER 1

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.

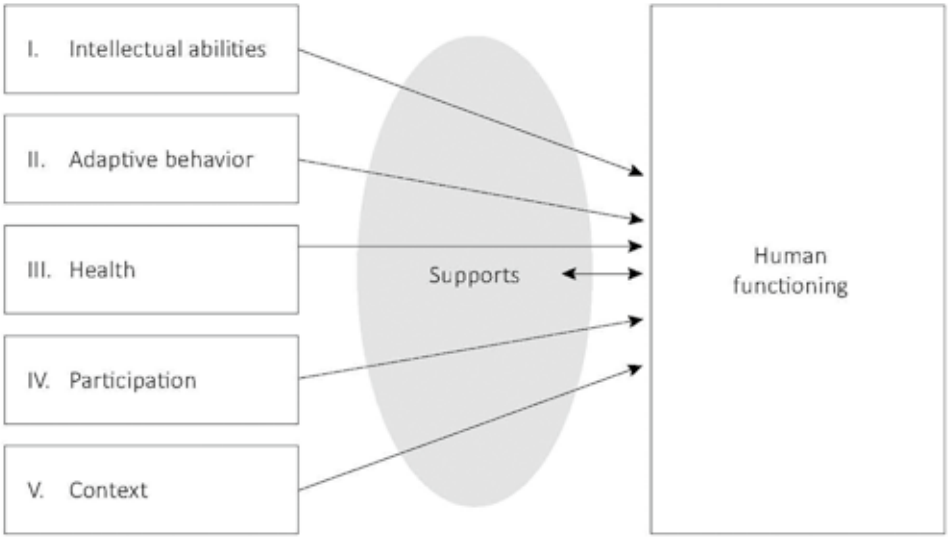


Figure 1.1. *The AAIDD model of human functioning*

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.

CHAPTER 2

Patterns of intellectual, adaptive and behavioural functioning in individuals with mild intellectual disability

Soenen, S., Van Berckelaer-Onnes, I.A., & Scholte, E. (2009). Patterns of intellectual, adaptive and behavioral functioning in individuals with mild mental retardation. *Research in Developmental Disabilities, 30*, 433-444

Abstract

Many researchers have studied the population of individuals with mild intellectual disability (MID[1]) as if it is a clear entity. Few researchers have investigated potential subtypes within the MID population. The purpose of the present study was to investigate which subtypes can be identified on the basis of intellectual, adaptive and behavioural functioning. Seventy-three individuals with MID were assessed on measures of intellectual, adaptive and behavioural functioning. An agglomerative hierarchical cluster-analytic technique was used to define potential subgroups with characteristic behavioural patterns. Four subtypes were identified. The behavioural patterns are described and implications for assessment are discussed.

1 The term mild mental retardation (MIMR) is used in the original article because the article was published in an American journal. Since this thesis is written in British English, the term mild intellectual disability is used in all chapters.

Introduction

A person's intelligent quotient score (IQ) plays an important role in determining the level of support for individuals with intellectual disability (ID). The IQ criterion, however, is too limited to determine the support they really need, in particular with regard to individuals with mild intellectual disability (MID) (IQ between 50-55 and 70). The reliance on only the IQ criterion to determine the appropriate level of support masks the true nature of their needs, with major consequences for their quality of life. These individuals usually not only have problems in finding the right type of education (Bouck, 2004) or work (Bouras & Drummond, 1992; Richardson, Koller, & Katz, 1988) but are also often left without appropriate support (Fujiura, 2003; MacMillan et al., 1993; MacMillan et al., 1996; Maughan et al., 1999; Rutter, Tizard, & Whitmore, 1970). Therefore the validity of MID, based on a single IQ criterion, can be seriously questioned (MacMillan et al., 1996). In the latest definition of ID, the American Association on Intellectual and Developmental Disabilities (AAIDD) emphasized that more criteria in addition to IQ are important and necessary. ID was redefined as a multidimensional construct based on the dimensions of intellectual abilities, adaptive behaviour, participation, interactions and social roles, health and context (Luckasson et al., 2002). In the current study three dimensions are explored: intellectual abilities, adaptive behaviour and health in terms of behavioural functioning and DSM-IV-TR classifications.

The intellectual perspective

Children with MID are often characterized as having problems with abstract thinking and problem solving. Research has been conducted to gain insight into the academic learning problems of these children (Fletcher, Scott, Deuel, & Jean-Francois, 1999; Gresham, MacMillan, & Bocian, 1996; Jones, 1996), e.g. the underlying aspects of their cognitive functioning such as difficulties in selective attention (Bergen & Mosley, 1994; Merill, Cha, & Moore, 1994; Merill & O'Dekirk, 1994), working memory (Van der Molen, Van Luit, Jongmans, & Van der Molen, 2007) and use of strategy in learning (Bray, Fletcher, & Turner, 1997; Fletcher & Bray, 1995; Wolman, Van den Broeck, & Lorch, 1997). The cognitive profiles of the individuals showed so much variability that it was impossible to define a valid group profile (Baumeister, 1997; Fletcher et al., 1998). However, Fletcher et al. (2004) recently found different patterns of cognitive abilities suggesting strengths and weaknesses in the cognition of different groups of children with MID.

The adaptive perspective

MID can also be defined in terms of adaptive functioning. The level of functioning corresponds to a developmental age of approximately between 6 -7 to 11 years (Došen, 2005a, 2005c; Kraijer & Plas, 2006). More specifically, adaptive behaviour is defined as "the performance of the daily activities required for personal and social sufficiency" (Doll, 1953; Sparrow, Balla, & Cicchetti, 1984). It can vary during the course of one's life and is not a permanent state of being (Luckasson et al., 1992). Individuals with MID need support in the areas of community activities, self-care, home living and work

(Fujuira, 2003). These problems are a result of the social aspects involved in these areas of functioning (Embregts, 2000, 2002; Guralnick, 1990, 1999; Guralnick, Connor, Hammond, Gottman, & Kinnish, 1996; Leffert & Sipperstein, 2002; Masi & Marchesi, 1998; Nabuzoka, 2000).

The behavioural perspective

The prevalence rate of severe problem behaviour is at least three times higher in children and adolescents with MID than in the normal population (for a review see Wallander et al., 2003). Following the dimensional approach, researchers have demonstrated that these individuals display more aggressive, delinquent, depressive and anxious behaviour than individuals without MID. Using a categorical approach they have shown that many DSM-IV disorders occur in children with MID; multiple disorders are present in as many as 36.8% of the individuals who meet DSM-IV symptom criteria. This co-morbidity is also associated with a high risk of pervasive limitations in adaptive functioning (Dekker, Koot, van der Ende, & Verhulst, 2002). In young adulthood, the prevalence of behavioural problems has been reported to increase (Emerson et al., 2001; Joyce, Ditchfield, & Harris, 2001).

The findings of the above-mentioned studies demonstrate that there is considerable variation in intellectual, adaptive and behavioural functioning among individuals with MID. The aim of the present study was to investigate which subtypes can be identified in the heterogeneous population of individuals with MID based on level of intellectual, adaptive and behavioural functioning.

Method

Participants

The study comprised of 73 individuals referred in the period 2002-2005 to the five institutions who take care of people with MID in the province of South-Holland. All were diagnosed with MID and complex behaviour (DSM-IV-TR classifications) by a team of qualified clinicians. Some of the individuals had an IQ in the normal range. Presumably, low adaptive functioning was used to allow admittance of these individuals into the clinical services for individuals with MID. We decided to include these persons in our sample because the goal of the present study was to search for behavioural patterns composed of several criteria besides IQ, such as adaptive functioning. Table 2.1 summarizes the age, gender and IQ characteristics of the individuals who participated in this study.

Table 2.1. *Demographic characteristics of the individuals assessed (n=73)*

Age	6-12 years	N=18	24.7%
	13-17 years	N=16	21.9%
	18-36 years	N=39	53.4%
Gender	Men	N=52	71.2%
	Women	N=21	28.8%
Level of ID (IQ)	MID (IQ < 70)	N=38	52.0%
	Borderline ID (70 ≤ IQ ≤ 85)	N=28	38.4%
	Normal (IQ > 85)	N=7	9.6%

Instruments

Intellectual functioning of the children was assessed using the Dutch version of the Wechsler Intelligence Scale for Children, third edition WISC-III (Wechsler, 1974). For individuals older than 16 years the Wechsler Intelligence Scale for Adults, revised, WAIS-R or the third edition, WAIS-III (Wechsler, 1981) was used. Only total IQ scores were included in the present study. The interview edition of the Vineland Adaptive Behavior Scales, VABS (Sparrow et al., 1984) was administered to assess the individual's *adaptive functioning*. In this study the composite score was used: higher scores indicate better functioning. The Diagnostic Interview for Social and Communication disorders, DISCO (Wing, 1993) was administered to measure *behavioural functioning*. The DISCO elicits a detailed picture of aspects of a wide range of behavioural features and developmental skills. The interview is originally made to assess autistic behaviours (Wing, Leekam, Libby, Gould, & Larcombe, 2002). However, in the current study the DISCO was used to measure a broader concept of behavioural functioning. This is also done in earlier studies by Wing and Gould (1979), Bernsen (1980) and Wing (1980). They proved that the interview was suitable for sub-grouping individuals with ID according to profile analysis. In this study, only the scales referring to behavioural functioning were used. The scales 'responses to sensory stimuli', 'routines and resistance to change' and 'behaviour affecting others (disruptive behaviour)' all had an internal consistency of at least .70 (Cronbach's Alpha) and are thus sufficiently reliable (Carmines & Zeller, 1994). The scale 'repetitive movements and vocalizations' was not used since variability of scores was not present in this domain.

Procedure

The (substitute) parents of the children signed a participation permission form; the adults (18 years and older) signed the permission form themselves. Trained clinical psychologists administered the tests of intellectual functioning, the DISCO-interview to the parent(s) or the parents' substitute or, in case of absence of the parents, to a staff member of the support service well acquainted with the individual, and the VABS-interview with a staff member.

Statistical Analyses

All data were entered into SPSS 12.0.1. An agglomerative hierarchical cluster-analytic technique was used to define potential subgroups of individuals with similar profiles. This technique initially assumes that each entity is a cluster and, using an algorithm, combines clusters until all entities have been combined into one cluster. In cluster analysis the participant is the basic unit of analysis. To conduct this analysis we computed z-scores for each dependent variable (Kaufman & Rousseeuw, 1990). To measure dissimilarity among participants, the squared Euclidian distance was used. This measure derives values which reflect the sums of squared differences between variables for each pair for all pair-wise comparisons. To combine clusters, Ward's (1963) method which combines clusters that will result in the smallest increase in the sums of squares at each step, was employed. The clusters were determined by studying the agglomeration coefficients (e.g. squared Euclidian distance between two entities to be joined). The points at which significant jumps were present were taken as indicators that heterogeneous clusters were being formed (Everitt, 1993, 1996). Subsequently the clusters were judged on their clinical merits (i.e. interpretation in clinical terms). After thus having obtained the clusters, post hoc comparisons of the cluster's means for the variables age, IQ and VABS were performed with ANOVA's. The Chi-square test or the Fisher Exact test (if expected frequencies fell below 5 for at least 25 percent of the items) were used to determine whether significant differences existed between the clusters for the variable gender and the DISCO items in detail. Because of the large number of comparisons made within the same sample, the significance level was set at $p < 0.001$ (Bonferroni correction).

Results

Cluster analysis

Table 2.2 presents the agglomeration coefficients of the cluster analysis. Examination of the jumps revealed that a four-cluster solution was appropriate.

Table 2.2. *Summary of Agglomeration Coefficients for Hierarchical Cluster Analysis (Ward's Method)*

Number of clusters (first six clusters)	Coefficient	Percent change in coefficient to next level
1	**360.056**	
2	**242.487**	**48.49%**
3	**201.337**	**20.44%**
4	**173.193**	**16.25%**
5	152.109	13.86%
6	132.883	14.47%

The intellectual, adaptive and behavioural patterns which are associated with the four clusters are displayed in figure 2.1, 2.2, 2.3 and 2.4. The black bars represent the deviations from the mean, expressed as standardized z-scores, with a z-score of 0 referring to the mean score for the total group.

Description of the clusters

IQ, adaptive and behavioural functioning

Table 2.3 displays additional data on the TIQ and the mean adaptive developmental age, according to the VABS composite score.

Table 2.3. *Mean TIQ score and VABS score (in months) for clusters 1 through 4*

	Cluster 1 (n=25)	**Cluster 2 (n=20)**	**Cluster 3 (n=16)**	**Cluster 4 (n=12)**	**F*(3,69)***
TIQ					
M	74.28 (a,c)	61.35 (a,d)	75.44 (d,f)	58.58 (c,f)	8.27*
SD	15.76	10.25	10.72	9.09	
VABS composite domain					
M	90.96 (a,c)	64.25(a,d,e)	91.38 (d,f)	42.00 (c,e,f)	26.86*
SD	20.90	17.07	16.34	14.25	

*p < .01; posthoc comparisons: 1 vs 2 (a), 1 vs 3 (b), 1 vs 4 (c), 2 vs 3 (d), 2 vs 4 (e), 3 vs 4 (f)

Based on the information presented in table 2.3 and figures 2.1, 2.2, 2.3 and 2.4 the clusters (profiles[2]) can be defined as follows.

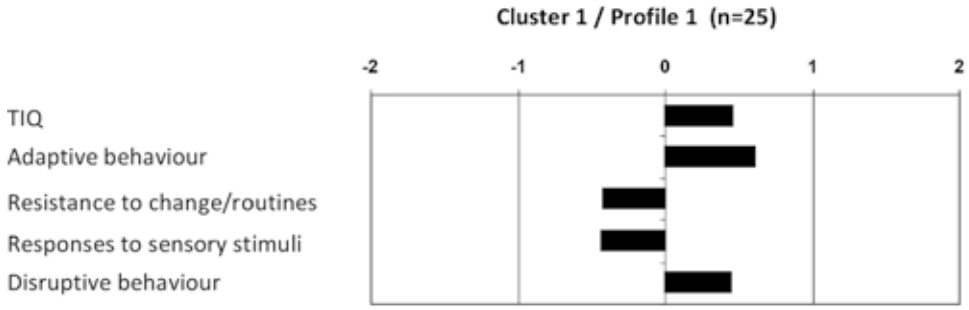


Figure 2.1. *Mean z scores for each of the five variables for cluster 1*

2 Only the term 'cluster' is mentioned in the original article. For clarification, we have added the word 'profile' to the figures since the following chapters use the term 'profile' to describe the same groups of individuals.

The individuals of cluster 1 (n=25) presented a mean TIQ of 74. Their mean total adaptive developmental age was 7 years and 6 months (SD = 90 months). They had a significantly higher TIQ and higher adaptive developmental age than their peers in clusters 2 and 4 but a score comparable to that of their peers in cluster 3. The data in figure 1 indicate that these individuals manifested a relatively high level of disruptive behaviour. Specific for this cluster in comparison with all other clusters was the presence of a significantly higher percentage of individuals who blamed other people and who exhibited apparently manipulative behaviour. In comparison with clusters 2 and 3 also significantly more individuals wandered around, showed anger towards their parents, often interrupted conversations, had temper tantrums and displayed physical aggression (see table 2.5, appendix A). In terms of DSM-IV-TR-classifications the children in this cluster had a classification of reactive attachment disorder (RAD) (24%). The young adults were diagnosed with a borderline or anti-social personality disorder (52%) or a pervasive developmental disorder (PDD) (24%).

Figure 2.2. *Mean z scores for each of the five variables for cluster 2*

This cluster (n=20) showed a mean TIQ within the MID range (TIQ = 61) and a mean adaptive developmental age of 5 years and 4 months (SD = 64 months). In comparison with clusters 1 and 3 the scores for both the TIQ and the total adaptive developmental age were significantly lower. In comparison with cluster 4, a similar TIQ score was found, but the adaptive developmental age of this cluster was significantly higher. Specific for this cluster was the presence of a higher level of routines and resistance to change and abnormal responses to sensory stimuli than the levels in clusters 1 and 3. However, these levels were still lower than those in cluster 4. Especially more individuals scored positive on the items 'fascination with specific objects' and 'repetitive questions' (see table 2.5, appendix A). A relatively lower level of disruptive behaviours was found. In terms of DSM-IV-TR classifications cluster 2 contained individuals with PDD (80%) and ADHD (20%).

Figure 2.3. *Mean z scores for each of the five variables for cluster 3*

Cluster 3 contained individuals (n=16) with a mean TIQ score in the borderline range of ID (IQ = 75) and a mean total adaptive developmental age of 7 years and 7 months. Their performances were similar to the performances of cluster 1 and significantly better than those of their peers in clusters 2 and 4. Compared to all other clusters, they manifested lower levels of disruptive behaviour, routines and resistance to change, and abnormal responses to sensory stimuli. Cluster 3 comprised young adults with immature behaviour and depressive and/or anxiety symptoms (100%).

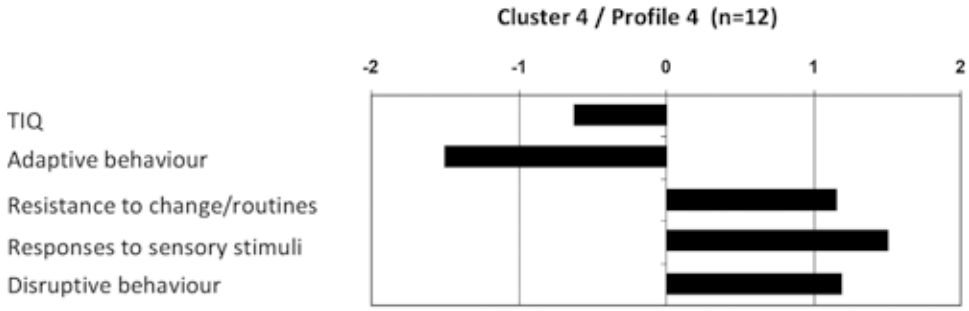


Figure 2.4. *Mean z scores for each of the five variables for cluster 4*

These individuals (n=12) had a mean TIQ score of 58 which was similar to cluster 2 and significantly lower than clusters 1 and 3. These individuals functioned adaptively at a mean developmental age of 3 years and 6 months which was significantly lower than the developmental age of all other clusters. They manifested the highest levels of disruptive behaviour, routines and resistance to change, and responses to sensory stimuli compared to their peers in the other clusters. Specific for cluster 4 was the presence of a significantly higher percentage of individuals who behaved inappropriately in public places. Compared to cluster 3 significantly more individuals of cluster 4 approached strangers (see table 2.5, appendix A). In this cluster, a lot of children with PDD (80%) and ADHD (20%) were found who presented with high levels of sensory abnormalities.

Age and gender

Table 2.4 presents the age and gender characteristics of the four clusters described in the preceding paragraphs.

Table 2.4. *Age and gender for clusters 1 through 4*

	Cluster 1 (n = 25)		**Cluster 2 (n=20)**		**Cluster 3 (n=16)**		**Cluster 4 (n=12)**		χ^2
Age									χ^2 (6,73)
6-12	n=1	4%	n=8	40%	N=0	0%	n=9	75%	39.12*
13-17	n=5	20%	n=6	30%	N=2	12.5%	n=3	25%	
18 and older	n=19	76%	n=6	30%	N=14	87.5%	n=0	0%	
Gender									χ^2 (3,73)
Men	n=14	56%	n=16	80%	N=10	62.5%	n=12	100%	9.55*
Women	n=11	44%	n=4	20%	N=6	37.5%	n=0	0%	

*p<.05

The table shows that clusters 1 and 3 had a different age distribution than clusters 2 and 4. A large proportion of the individuals in clusters 1 and 3 were 18 years and older. The individuals in cluster 2 were almost equally divided over the three age groups, while 75% of the individuals in cluster 4 were 12 years and younger. Furthermore cluster 1 contained as many females as males. This gender distribution differed clearly from all other clusters, that comprised far more males than females. Cluster 4 included only males.

Discussion

One of the motives for this study was the fact that a number of individuals diagnosed with MID drop out of the service system (Cass, Regan, & Rhodes, 1996; McCarthy & Boyd, 2002). The individuals involved in this study display a wide range of problems, which cannot be diagnosed on the basis of only the IQ-criterion. As a consequence, in this study description of subtypes has been given in terms of multidimensional profiles, as is proposed by the AAIDD (Luckasson et al., 2002). We used three dimensions of the AAIDD model in conjunction: intellectual functioning, adaptive behaviour and mental health in terms of behavioural functioning. The determination of subtypes of persons displaying MID is highly important for several reasons. First, these subtypes give preliminary insight into different behavioural patterns on which the disability can be classified. This knowledge is important as it can be used to refine assessment procedures for different clusters of individuals with MID (Soenen, Dijkxhoorn, & Van Berckelaer-

Onnes, 2003; Dijkxhoorn, Van Berckelaer-Onnes, Soenen, & Van der Wilt, 2007). Second, each subtype can point towards a specific type of support need (Soenen, Van Berckelaer-Onnes, & Scholte, 2015). This knowledge can be used to tailor existing services more appropriately to the needs of the individuals.

In this study four subtypes of individuals with MID are described. First, in the clusters 1 and 3, we identified a number of behaviours that are characteristic of personality disorders. In the clinical clusters 2 and 4 especially developmental disorders are found. Second, externalizing behaviour problems are identified in clusters 1 and 4, whereas the individuals in clusters 2 and 3 especially show internalizing behaviour problems. Figure 2.5 shows how the assessment of individuals with MID can proceed using this differentiation in four clusters (profiles).

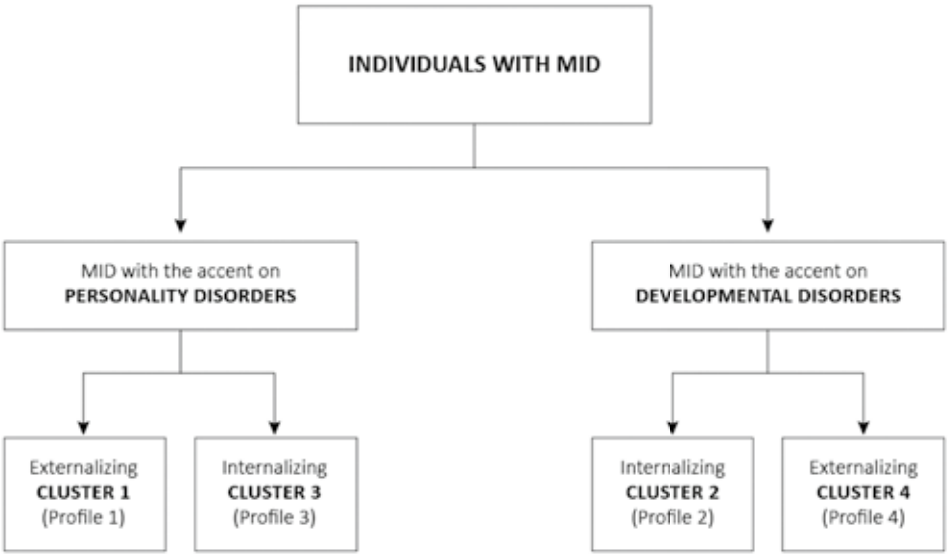


Figure 2.5. *The four subtypes (profiles) in MID*

The assessment has to be done in two phases. First, the diagnostician has to determine to which of the four clusters the individual belongs to (see figure 2.5). This study has shown that the WAIS-III/WISC-III, the VABS and the DISCO are useful to determine the appropriate subtype in the first diagnostic phase. The DISCO is found to be a very suitable instrument because it assesses behaviour problems in detail, and was valuable in pinpointing to specific psychiatric disorders. The DISCO also detects subtle social skills which are not measured with the VABS (for instance the items 'manipulative behaviour' and 'blaming other people'). In higher functioning people with MID these subtle skills are important, since basic and routine interaction skills are often developed well enough (De Bildt, Serra, Luteijn, Kraijer, Sytema, & Minderaa, 2005).

After having determined the subtype of MID, a second diagnostic phase with different diagnostic procedures for the different subtypes should be done. If an individual displays the behavioural pattern of clusters 1 or 3 further assessment should focus on their personality organization (e.g. strength of ego functions, temperament), relational attitudes (e.g. attachment styles, mental representations of self and other, social information processing, coping styles) and the social environment of the individual (e.g. social support and strain, stressors, life events). Most of the diagnostic instruments that are used for people with normal IQ can also be applied for individuals with MID in the clusters 1 and 3 (Kraijer, 2006). The assessment procedure of the individuals in cluster 2 and 4 is somewhat different than the procedure for clusters 1 and 3. Some of the disruptive behaviours of these individuals point to co-morbid conditions that cannot be classified according to the traditional descriptive phenomenological categorical psychiatric system DSM-IV-TR (Došen, 2005a; Kraijer, 2006). Establishing the level of personality development of the individuals is troublesome because a big discrepancy is found among cognitive and adaptive (social-emotional) development. In this study we noted problems with approaching strangers in a disturbing way and behaving inappropriately in public places, which are characteristic for the 'active but odd type' in PDD (Wing, 1996). These individuals fail to achieve full understanding of emotions and do not reach full development of conscience (Howlin, 1997). For these children with MID a specialized and wider assessment frame for integrative diagnosis is necessary. Došen (2005b) for instance not only describes the biological and neuropsychological aspects of the individual, but also the level of personality development that plays a role in adaptive and behavioural functioning. Special diagnostic instruments are needed for the assessment of these individuals, for instance the SAED (Schema of Appraisal of Emotional Development) (Došen, 2005c).

This exploratory study was important for three reasons. First, subtypes of individuals with MID were identified by inducing clusters of characteristics instead of imposing a single pre-constructed IQ criterion on the data. Second, a multidimensional perspective as proposed by the AAIDD (Luckasson et al., 2002) was used by integrating information on three dimensions: intellectual, adaptive and behavioural functioning. Third, different diagnostic trajectories are proposed for the MID subtypes. However, limitations of our study should also be kept in mind. First, our sample was small and comprised only individuals who were referred to a limited number of clinical services in one part of the Netherlands. It is possible that more clusters will be found or clusters with different behavioural patterns when larger groups of persons with MID are studied, or when the individuals to be studied are recruited from other areas. Second, the categories that we found may change again, if other dimensions of the AAIDD-model (Luckasson et al., 2002) are incorporated in the analysis, such as participation, interactions and social roles, and context. Therefore, more research is needed to validate the subtypes found in this study and to explore the possible existence of other subtypes. Furthermore, it now must be determined whether the services for individuals with MID may benefit from the four diagnostic categories we have established.

CHAPTER 3

Pathways to care of individuals with mild intellectual disability

Soenen, S., van Berckelaer-Onnes, I.A., & Scholte, E. (2012). Pathways to care of individuals with mild intellectual disability. *Journal of Cognitive Education and Psychology, 11*, 57-76.

Abstract

This study investigated whether clinical profiles in individuals with mild intellectual disability (MID) could be defined in terms of their histories, e.g. behavioural, social-environmental, educational and service use characteristics. Clinical psychologists administered the Diagnostic Interview for Social and Communication Disorders to the (substitute) parents and analyzed the clinical records of individuals with MID. Four subtypes of individuals with MID with specific clinical profiles participated in this study. The results of this study, which used discriminant analysis of the individuals´ histories, supported two discriminant functions. The first discriminant function differentiated clinical profiles largely based on developmental disorders from clinical profiles based on personality disorders. The second function differentiated clinical profiles based on personality disorders and externalizing behavioural problems from other clinical profiles. The characteristics in the histories of individuals with MID can be very different and need to be assessed for further understanding of their unique needs.

Introduction

Individuals with mild intellectual disability (MID) belong to the same category, but differ in many aspects. They are referred to multiple settings, like youth care, mental health care and community-based care (Holt et al., 2000). The motivation for these referrals differs enormously. It can concern learning problems, behavioural problems like delinquency, psychiatric problems like autism or a psychotic condition, and many other kinds of problems. The reason for referral is mostly based on the most severe and obvious problem. The assessment has usually focused only on that aspect, instead of taking the complexity of the problems into account (Luckasson et al., 2002; Simonoff et al., 2006). This often leads to successive, disjointed and therefore less effective treatments (Broadhurst & Mansell, 2007; Fujiura, 2003; Holt et al., 2000). In the latest definition of intellectual disability (ID), the American Association on Intellectual and Developmental Disabilities (AAIDD) emphasizes that criteria additionally to IQ are needed to assess ID adequately. ID is a multidimensional construct based on the dimensions of intellectual disabilities, adaptive behaviour, participation, interactions and social roles, health and context (Luckasson et al., 2002). Recently, researchers have differentiated clinical profiles in the MID population based on multidimensional patterns of actual functioning (Fletcher et al., 2004; Soenen, Van Berckelaer-Onnes, & Scholte, 2009; Van der Molen, Van Luit, Jongmans, & Van der Molen, 2009). To identify strategies tailored to the needs of individuals with MID, the AAIDD states that the diagnostic process should also include a description of risk factors across the life of the individual, e.g. medical, behavioural, social-environmental, educational and service use factors, that have contributed to the individual 's actual functioning (Luckasson et al., 2002; Taylor, Richards, & Brady, 2005). The outcomes of individuals with MID will be different and the institution needs to develop various programmes to meet the unique support needs of each group of individuals with MID. Literature in the medical field offers little clarification as to what the medical risk factors might be. A Finnish study showed that a genetic cause is known in only 25% of individuals with MID (Heikura et al., 2005). For those 25%, future support can be adequately planned based on evidence-based knowledge about their developmental profile of strengths and weaknesses (Dykens, Hodapp, & Finucane, 2000). In the other 75% of cases, however, classification and prognosis about future functioning remain difficult as clinicians are completely dependent on the individual's behavioural, social- environmental, educational and service use characteristics. Little research has been carried out to determine whether all individuals are affected by each of the factors or whether differentiations in an individual's history lead to a differentiation in functioning requiring alternative support. The aim of the present study is to describe those characteristics in the histories of individuals with MID, and to determine if their clinical profiles of actual functioning can be differentiated according to the characteristics in their histories and their pathways to care. The focus will be on the following AAIDD factors: behavioural, social-environmental, educational and service use.

Behavioural factors

Children with MID have far more emotional and behavioural problems than typically developing children (Dekker et al., 2002; Douma, Dekker, de Ruiter, Tick, & Koot, 2007; Wallander et al., 2003). These behavioural problems are particularly apparent in the context of the school environment (Gresham et al., 1996; MacMillan et al., 1996). MID in childhood is associated with an increased number of speech and language difficulties (Rutter, Graham, & Yule, 1970). Children with MID also have poorer social skills than children without MID (Guralnick, 1990; Nabuzoka, 2000). Those difficulties in language development and socialization are associated with an increased risk of the aforementioned behavioural problems (Dekker & Koot, 2003; Koskentausta et al. 2000; Wallander et al., 2006). Unfortunately, data are lacking concerning precursor behaviours in infants with MID. That information, gathered at an earlier stage, might provide invaluable insight, in turn allowing practitioners to treat language and social difficulties at an earlier stage and minimize behavioural problems.

Social-environmental factors

Several social- and child-rearing factors are associated with lowered intellectual and adaptive functioning and with behavioural problems in MID. The intelligence of these individuals can be negatively affected by maternal mental illness, rigid values with regard to child development and large families (Sameroff, 1990). Behavioural problems in MID are associated with social strain and stigma, abuse, exploitation, family stress, parental psychopathology (Dekker & Koot, 2003; Dykens & Hodapp, 2001), social deprivation, family composition, child management practices and a number of other stressful and negative life events (Emerson, 2003; Wallander et al., 2006). These factors are the same as those related to psychopathology in the general population (Ferdinand & Verhulst, 1995; Mesman, Bongers, & Koot, 2001). Research shows that not only the type but also the number of risk factors determines the outcome in MID (Sameroff, 1990), and that these factors play a significant role in the variation of the functioning of individuals with MID (Maughan et al., 1999). For this reason, this study will investigate such factors within different clinical profiles of individuals with MID.

Educational and service use factors

Many children with MID are supported in mainstream schooling, although they often face difficulties (Maughan et al., 1999; Simonoff et al., 2006). By the age of 11, approximately 15% (Simonoff et al., 2006) to a third of children with MID have been placed in special schools, and rates of special schooling rise further by the age of 16 (Maughan et al., 1999). From a psychiatric perspective, studies suggest only a 20 to 50% frequency of psychiatric service use in school age children (Maughan et al., 1999; Parsons, May, & Menolascino, 1984). Between childhood and adulthood, psychiatric service use falls, although the number of self-reports of psychological distress is high (Maughan et al., 1999; McCarthy & Boyd, 2002). Another indicator of the diversity in the MID population is the great variation in habituation patterns. For example, the majority of youths with MID live with their (substitute) parents and establish cohabiting relationships in their

thirties (Maughan et al., 1999). Other youths with an IQ in the lower part of the MID range, a medical condition and emotional and behavioural problems, however, are more likely to live in a community-based setting (Joyce et al., 2001) or an institution (Einfeld & Tonge, 1996).

The above-mentioned studies demonstrate that only a very few data on behavioural characteristics indicate MID in infants. The findings further suggest that considerable variation exists in social-environmental, educational and service use characteristics among individuals with MID. The aim of the present research is to reduce the gap in this information. As stated earlier, the study will describe these characteristics in individuals with MID and investigate if clinical profiles in MID can also be differentiated according to these historical characteristics.

Method

Participants

The study comprised 72 individuals with MID and complex behaviour (DSM- IV-TR classifications) that receive care from five institutions for people with MID in the province of South Holland. The study consisted of two parts. The aim of the first part was to investigate which clinical profiles could be identified in the heterogeneous population of individuals with MID based on level of intellectual, adaptive and behavioural functioning. Four clinical profiles were induced from the data by means of agglomerative hierarchical cluster analysis. Detailed information on this cluster analysis and the statistical tests that determined the differences between the clinical profiles can be found in Soenen et al. (2009). In this article the results of the second part of the study with regard to the pathways to care of individuals with MID, are presented. In this part of the study, the 72 individuals, divided into the four clinical profiles that came forward in the first part of the study, participated. Figure 3.1 summarizes the characteristics of the four clinical profiles found in the first part of the study.

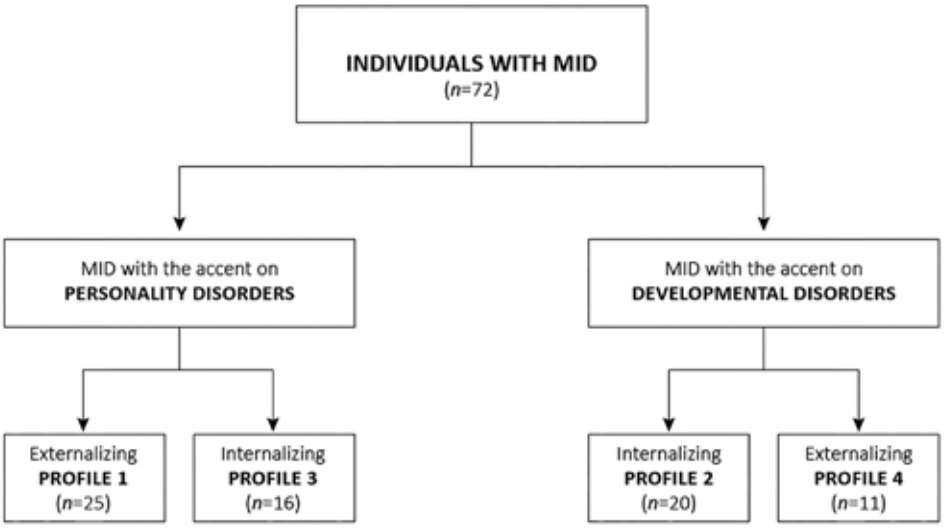


Figure 3.1. *The four clinical profiles in MID*

Clinical profile 1. This profile included individuals with a mean TIQ of 74 and a mean adaptive developmental age of seven years and six months. They were diagnosed with reactive attachment disorder, a borderline or anti-social personality disorder, or a pervasive developmental disorder (PDD).

Clinical profile 2. The children and adolescents with clinical profile 2 showed developmental disorders (PDD or ADHD). Their mean TIQ was approximately 60 and their mean adaptive developmental age was five years and four months. They exhibited relatively high levels of routines, resistance to change and abnormal responses to sensory stimuli.

Clinical profile 3. The performances of the young adults with clinical profile 3 were similar to those with clinical profile 1, but those with clinical profile 3 exhibited a higher degree of immature behaviour and depressive/anxious symptoms, and low levels of disruptive behaviour.

Clinical profile 4. The children with clinical profile 4 showed developmental disorders (PDD and ADHD). They had a mean TQ of 58 and a low mean adaptive developmental age of three years and six months. They manifested the highest level of disruptive behaviour, routines and resistance to change and responses to sensory stimuli.

The age and gender for the four clinical profiles are described in table 3.1.

***Table 3.1**. Age and gender for clinical profile 1 through 4*

	Profile 1 (n = 25)		**Profile 2 (n=20)**		**Profile 3 (n=16)**		**Profile 4 (n=11)**		χ^2
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	
Age									*χ^2 (6,72), 43.51[a]**
6-12	1	4	7	35	0	0	9	81.8	
13-16	4	16	6	30	0	0	2	18.2	
16 and older	20	80	7	35	16	100	0	0	
Gender									*χ^2 (3,72), 10.99[a]**
Men	14	56	16	80	10	62.5	11	100	
Women	11	44	4	20	6	37.5	0	0	

*p<.01, [a] Fisher exact test

Group comparison indicated that clinical profiles 1 and 3 had a different age distribution from that of clinical profiles 2 and 4. A large proportion of the individuals in clinical profiles 1 and 3 were aged 16 and older. The individuals in clinical profile 2 were almost equally divided over the three age groups, whereas 81.8% of those in clinical profile 4 were 12 years and younger. Clinical profile 1 contained as many females as males. The gender distribution of clinical profile 1 differed from all other clinical profiles, which contained more males than females.

Instruments

Information on *age and gender* was collected from the youngster or caregiver at intake or derived from the clinical record. *Behavioural characteristics during infancy* were obtained by using the Diagnostic Interview for Social and Communication disorders (DISCO) (Wing, 1993). The DISCO elicits a detailed picture of aspects of a wide range of behavioural features and developmental skills (Wing et al., 2002; Billstedt, Gillberg, & Gillberg, 2007). In this study, the behavioural items in infancy are used. Inter-rater reliability for the items proved to be high, with a kappa of 0.75 or above for over 80% of the items (Wing et al., 2002). *Social-environmental, educational and service use characteristics* were collected from the youngster or caregiver or were derived from the clinical records. The social-environmental variables comprised: physical, emotional or sexual abuse, running away, displaying criminal activities, displaying abnormal sexual behaviour, substance abuse, siblings' institutionalization or foster care placement and family history of domestic violence, substance abuse, mental illness and criminal activities. The educational variables comprised: mainstream school, school for the ´educable´ or children with mild learning problems or MID (IQ range 60-80), school for the ´trainable´ or children with moderate ID or severe learning problems (IQ range 30-60), day-care centres for children with moderate ID (IQs below 50 and additional physical or sensory handicaps), school for children with psychiatric or behavioural problems and

mainstream school for on-the-job training. It was noted in which category a child started and ended school in childhood (age 6-12 years) and adolescence (age 13-16 years). The service history was classified in nine categories: outpatient diagnostic assessment, outpatient treatment, generic residential care for mental health, generic residential youth care, residential care for mental health in ID, residential youth care in MID, community-based care in moderate ID, traditional residential care in moderate ID and independent living with mobile support in MID. The categories were scored as dummy variables in three age groups (age 6-12 years, age 13-16 years and age 16 years and older). The age at first diagnosis of MID, first psychiatric diagnosis, first service contact and first referral to (semi) residential care were derived from the clinical record.

Procedure

Ethical guidelines of the Royal Netherlands Academy of Arts and Sciences (KNAW) were followed to recruit the participants. The (substitute) parents of children signed a parental consent form; the adults (16 years and older) signed the consent form themselves. Trained clinical psychologists administered the DISCO-interview to the (substitute) parent(s). This information was only obtained from the youngsters who still had contact with their parents (n=56). The others no longer knew where their parents were living. The same clinical psychologists also analysed the clinical records to obtain information on the social-environmental, educational and service use characteristics of all participants (n=72). To increase the reliability of the data gathered from the files, the data were checked with the parents during the DISCO interview. Second, the clinical records were double-blind scored.

Statistical analyses

All data were entered into SPSS 17.0. First, multiple Chi-square tests or Fisher Exact tests (if expected frequencies fell below five for at least 25% of the items) were used to compare the clinical profiles on the DISCO items (n=56), the items of the social-environmental scale (n=72), the education history items (n=72), the service use items (n=72) and age and gender (n=72). Post hoc comparisons of the profile ‘s means for the variables age at first diagnosis of MID, first psychiatric diagnosis, first service contact and first referral to (semi) residential care were performed with ANOVAs. Because of the large number of comparisons made within the sample, the significant level was set at $p \leq .001$ (Bonferroni correction). Then, a discriminant function analysis was performed using the variables that differentiated the clinical profiles significantly (n=56). In this analysis, we did not cluster the variables according to the four AAIDD categories (behavioural, social-environmental, education, service use). Instead, we used the individual variables as we aimed to explore which combination of variables across the four categories determined the course of life of the individuals in each of the four clinical profiles in MID.

Results

Profile differences in DISCO items concerning behaviour in infancy

This first section presents the outcomes of the between-profile comparisons for the behavioural characteristics associated with MID in infants, measured with the DISCO. The percentages of the participants with a positive score for the behavioural items and the outcomes of the Chi-square or Fisher Exact tests are presented in table 3.2. The results shown in table 3.2 indicate that the four MID clinical profiles differed significantly in eight of the 26 items: responsive smile, preparing to be picked up, waving bye-bye, babbling, pre-speech "conversation", response to speech, sharing of interests and looking when others pointed. In clinical profile 3, a significant low percentage of individuals showed problems with these behaviours in infancy, compared with all other clinical profiles. In clinical profile 1, some individuals manifested behavioural problems, although far less compared with the individuals in clinical profiles 2 and 4, with the exception of problems with "preparing to be picked up" that were present in approximately half of the individuals with clinical profile 1. Significantly high percentages of individuals with clinical profiles 2 and 4 showed all of the aforementioned behavioural problems in infancy.

Profile differences in social-environmental characteristics

This section presents the results of the between-profile comparisons for the social-environmental characteristics associated with MID. The outcomes of the Chi-square or Fisher Exact tests as well as the percentage of individuals with MID who scored positive on the social-environmental characteristic items are provided in table 3.3. The results in table 3.3 indicate that the four MID clinical profiles differed significantly for the items "physically abused", "displaying abnormal sexual behaviour" and "family history of mental illness". Clinical profile 1 represents, compared with all other clinical profiles, a high frequency of individuals who display abnormal sexual behaviour, who are physically abused, and who have a family history of mental illness.

Table 3.2 *Percentage of participants with a positive score for the items on behaviour in infancy of the DISCO for clinical profiles 1 through 4*

DISCO items	**Profile 1 (n=16)**		**Profile 2 (n=17)**		**Profile 3 (n=12)**		**Profile 4 (n=11)**		**Group difference**	
Behaviour in infancy (age 0 – 2 years)	%	**n**	%	**n**	%	**n**	%	**n**	χ^2	**p**
Feeding – poor sucking	25	4	0	0	0	0	36.4	4	9.860[a]	0.005
Vomiting	25	4	17.6	3	0	0	45.5	5	7.136[a]	0.06
Excessive crying/screaming	43.8	7	35.3	6	8.3	1	18.2	2	4.990[a]	0.158
Woke up screaming	25	4	5.9	1	8.3	1	9.1	1	2.741[a]	0.420
Reasons for crying	37.5	6	29.4	5	8.3	1	18.2	2	3.403[a]	0.331
Sleep pattern	31.3	5	29.4	5	8.3	1	18.2	2	2.523[a]	0.484
Unusually good/quiet/passive	6.3	1	29.4	5	8.3	1	54.5	6	9.485[a]	0.017
Demand for social attention	31.3	5	41.2	7	8.3	1	72.7	8	10.352[a]	0.015
Response to cuddling	43.8	7	41.2	7	8.3	1	45.5	5	5.351[a]	0.147
Eye contact	25	4	52.9	9	8.3	1	45.5	5	7.299[a]	0.062
Responsive smile	25	4	47.1	8	0	0	81.8	9	17.593[a]	0.000*
Preparing to be picked up	56.3	9	47.1	8	0	0	72.7	8	15.632[a]	0.001*
Reciprocation in baby games (lap play)	43.8	7	47.1	8	16.7	2	63.3	7	5.400[a]	0.145
Waving bye-bye	6.3	1	47.1	8	8.3	1	54.5	6	15.735[a]	0.001*
Babbling	25	4	52.9	9	8.3	1	81.8	9	12.877	0.001*
Pre-speech 'conversation'	25	4	52.9	9	8.3	1	81.8	9	12.877	0.001*
Intoned pre-speech sounds	37.5	6	35.3	6	8.3	1	72.7	8	10.043[a]	0.017
Response to speech	31.3	5	52.9	9	0	0	81.8	9	16.308	0.001*

Interest in environment	18.8	3	47.1	8	0	0	45.5	5	10.387[a]	0.012
Sharing of interests (joint referencing)	37.5	6	47.1	8	0	0	81.8	9	17.474[a]	0.000*
Looking when others pointed	25	4	47.1	8	0	0	81.8	9	17.949[a]	0.000*
Special interests	37.5	6	52.9	9	0	0	45.5	5	6.634[a]	0.084
Attachment to one parent	62.5	10	47	8	16.7	2	27.3	3	0.898[a]	0.071
Dislike of care procedures	12.5	2	17.6	3	8.3	1	45.5	5	7.483[a]	0.041
Oversensitive to noise	31.3	5	41.2	7	0	0	54.5	6	9.783[a]	0.017
Odd movements	31.3	5	53.3	6	0	0	54.5	6	9.235[a]	0.022

*p≤.001, [a] Fisher exact test

Table 3.3 *Percentage of participants with a positive score on the social-environmental characteristics for clinical profiles 1 through 4 (n=72)*

	Profile 1 (n=25)		**Profile 2 (n=20)**		**Profile 3 (n=16)**		**Profile 4 (n=11)**		**Group difference**	
	%	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**χ^2**	**p**
Physically abused	48	12	10	2	18.8	3	27.3	3	11.065[a]	.001*
Sexually abused	36	9	10	2	18.8	3	18.2	2	5.020[a]	.162
Emotionally abused	64	16	45	9	37.5	6	36.4	4	3.046	.404
Run away	28	7	5	1	18.8	3	27.3	3	4.761[a]	.178
Displayed criminal activities	28	7	15	3	12.5	2	0	0	3.378[a]	.327
Displayed abnormal sexual behaviour	36	9	5	1	6.3	1	0	0	15.634[a]	.000*
Use of alcohol or drugs	8	2	10	2	0	0	0	0	3.233[a]	.156
Family history of domestic violence	64	16	30	6	25	4	45.5	5	8.290[a]	.038
Family history of substance abuse	24	6	15	3	12.5	2	18.2	2	1.006[a]	.840
Family history of mental illness	40	10	10	2	0	0	18.2	2	11.800[a]	.001*
Family history of criminal activities	12	3	20	4	6.3	1	9.1	1	.801[a]	.949
Siblings in foster care or institutionalized	36	9	20	4	0	0	27.3	3	8.089[a]	.133

*$p \leq .001$, [a]Fisher exact test

Profile differences in education history

This section provides a summary of the education history of the individuals with MID in the four clinical profiles. Table 3.4 shows the percentage of individuals with MID scoring positive on the education items as well as the Chi-square or Fisher Exact tests, used to test for differences between the four clinical profiles. The results in table 3.4 show that the MID clinical profiles differed significantly for the items "start and end in a school for educable children" (IQ range 60-80), and "start and end in a school for trainable children" (IQ range 30-60). In childhood, significantly more individuals in clinical profiles 1 and 3 started and ended education in a school for educable children whereas significantly more individuals in clinical profiles 2 and 4 started and ended education in a school for trainable children. The clinical profiles did not differ significantly with regard to the type of education followed in adolescence.

Profile differences in service use history

This section presents the results of the between-profile comparisons for the service use characteristics associated with MID. The outcomes of the post hoc comparisons of the clinical profiles' means, performed with ANOVAs, for the variables age at first service contact, age at diagnosis of MID, age at psychiatric diagnosis and age at referral to (semi) residential care are provided in table 3.5. The Chi-square or Fisher Exact tests as well as the percentage of individuals with MID who scored positive on the other service use characteristic items are provided in table 3.6. Table 3.5 reveals that the individuals in clinical profile 3 were significantly older at first service contact compared with the other clinical profiles. The individuals with clinical profiles 1 and 3 were significantly older when they were diagnosed with a psychiatric disorder and referred to community-based or residential care, compared with the individuals with clinical profiles 2 and 4. Table 3.6 shows that the individuals with clinical profiles 2 and 4 differ significantly in comparison with the individuals with clinical profiles 1 and 3 as they make significantly more use of outpatient treatment, traditional residential care in moderate ID and residential care for mental health in ID between the ages of six and twelve. Between the ages of 13 and 16 a significant difference between the clinical profiles is found concerning the item generic residential youth care which is used far more by the individuals with clinical profile 3 than those with another clinical profile. At the age of 16 years and older, the clinical profiles significantly differ with regard to the variables residential youth care in MID and independent living with mobile support in MID. These services are used more by the individuals with clinical profile 3 than those with clinical profile 1.

Table 3.4 *Percentage of participants with a positive score on the education items in childhood (n=72) and adolescence (n=51) for clinical profiles 1 through 4*

	Profile 1 (n=25)		Profile 2 (n=20)		Profile 3 (n=16)		Profile 4 (n=11)		Group difference	
Childhood (age 6-12)	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	χ^2	**p**
Starting education in:										
Mainstream school	16	4	15	3	37.5	6	18.2	2	3.192[a]	.362
School for educable children (IQ range 60-80)	72	18	30	6	43.8	7	9.1	1	14.949	.001*
School for trainable children (IQ range 30-60)	0	0	40	8	6.2	1	45.5	5	18.297[a]	.000*
School for children with psychiatric/behavioural problems	12	3	15	3	12.5	2	27.3	3	1.640[a]	.692
Day care centre	0	0	0	0	0	0	0	0	-	-
Ending education in:										
Mainstream school	4	1	5	1	25	4	0	0	5.685[a]	.091
School for educable children	80	20	20	4	50	8	9.1	1	23.225	.000*
School for trainable children	16	4	55	11	18.8	3	72.7	8	15.959	.001*
School for children with psychiatric/behavioural problems	0	0	10	2	6.2	1	9.1	1	3.073[a]	.352
Day care centre	0	0	10	2	0	0	9.1	1	3.742[a]	.145

	Profile 1 (n=24)		Profile 2 (n=11)		Profile 3 (n=16)		Profile 4 (n=0)		Group difference	
Adolescence (age 13-16)	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	χ^2	**p**
Starting education in:										
Mainstream school for training on-the-job	4.2	1	18.2	2	31.2	5	-	-	5.362[a]	.055
School for educable children	62.5	15	18.2	2	56.2	9	-	-	6.187	.048
School for trainable children	29.2	7	45.5	5	12.5	2	-	-	3.555[a]	.148
Day care centre	4.2	1	18.2	2	0	0	-	-	3.212[a]	.204
Ending education in:										
Mainstream school for training on-the-job	0	0	18.2	2	25	4	-	-	6.823[a]	.022
School for educable children	33.3	8	18.2	2	37.5	6	-	-	1.211	.627
School for trainable children	29.2	7	45.5	5	12.5	2	-	-	3.555[a]	.148
Day care centre	37.5	9	18.2	2	25	4	-	-	1.438[a]	.525

*p≤.001, [a] Fisher exact test

Table 3.5 *Mean age at first service contact, at diagnosis of MID, at psychiatric diagnosis and at referral to community-based and residential care in moderate ID for clinical profiles 1 through 4.*

	Profile 1 (n = 25)		**Profile 2 (n=20)**		**Profile 3 (n=16)**		**Profile 4 (n=11)**		**F (3,71)**	**Post-hoc tests (Bonferroni)**
	M	**S.D**	**M**	**S.D**	**M**	**S.D**	**M**	**S.D**		
Age at first service contact	74.88	50.23	70.25	73.67	154.50	101.24	39.55	21.67	7.52*	3>1,2,4
Age at diagnosis of MID	105.92	68.28	100.20	85.94	144.00	74.10	62.18	28.31	2.97	
Age at psychiatric diagnosis	163.92	89.44	131.80	94.82	198.50	115.97	68.73	24.65	4.83*	1,3>4
Age at referral to community-based and residential care in moderate ID	190.80	55.72	156.70	071.39	220.25	68.83	102.64	33.76	9.22*	1,3>4; 3>2

*p≤.001

Table 3.6 *Percentage of participants with a positive score on the service use items in childhood, adolescence and young adulthood for clinical profiles 1 through 4*

	Profile 1(n=25)		Profile 2 (n=20)		Profile 3 (n=16)		Profile 4 (n=11)		Group difference	
Childhood (age 6-12)	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**χ^2**	**p**
Outpatient diagnostic assessment	92	23	90	18	68.8	11	90.9	10	4.303[a]	.221
Outpatient treatment	24	6	40	8	6.3	1	81.8	9	18.298	.000*
Generic residential care for mental health	16	4	15	3	6.3	1	18.2	2	1.236[a]	.768
Generic residential youth care	40	10	15	3	18.8	3	36.4	4	4.429[a]	.210
Residential care for mental health in ID	16	4	55	11	0	0	63.6	7	21.536[a]	.000*
Residential youth care in MID	4	1	5	1	0	0	9.1	1	1.807[a]	.765
Community-based care in moderate ID	4	1	0	0	0	0	2.8	2	1.476[a]	1.000
Traditional residential care in moderate ID	20	5	50	10	0	0	81.1	9	24.136[a]	.000*
Adolescence (age 13-16)										
Outpatient diagnostic assessment	52	13	80	16	43.8	7	-	-	5.691	.057
Outpatient treatment	4	1	0	0	12.5	2	-	-	2.543[a]	.261
Generic residential care for mental health	8	2	5	1	0	0	-	-	1.156[a]	.778
Generic residential youth care	8	2	5	1	43.8	7	-	-	9.784	.001*
Residential care for mental health in ID	24	6	10	2	6.3	1	-	-	2.539[a]	.250
Residential youth care in MID	24	6	5	1	25	4	-	-	3.616[a]	.156
Community-based care in moderate ID	0	0	25	5	6.3	1	-	-	7.115[a]	.012
Traditional residential care in moderate ID	4	1	20	4	0	0	-	-	4.410[a]	.077

Table 3.6 *Percentage of participants with a positive score on the service use items in childhood, adolescence and young adulthood for clinical profiles 1 through 4 (continued)*

Age older than 16 years										
Outpatient diagnostic assessment	100	25	-	-	100	16	-	-	-	-
Outpatient treatment	12	3	-	-	12.5	2	-	-	.002[a]	1.000
Generic residential care for mental health	4	1	-	-	6.3	1	-	-	.106[a]	1.000
Generic residential youth care	8	2	-	-	12.5	2	-	-	.224[a]	.637
Residential care for mental health in ID	4	1	-	-	0	0	-	-	.656[a]	1.000
Residential youth care in MID	4	1	-	-	43.8	7	-	-	9.816	.001*
Independent living with mobile support in MID	28	7	-	-	81.3	13	-	-	11.072	.001*
Community-based care in moderate ID	60	15	-	-	50	8	-	-	.396	.748
Traditional residential care in moderate ID	20	5	-	-	0	0	-	-	3.644[a]	.137

*p≤.001, [a] Fisher exact test

Discrimination of the four MID clinical profiles based on behavioural, social-environmental, educational and services use characteristics

This last section investigates whether the four clinical profiles in MID can also be differentiated according to profiles based on behavioural, social-environmental, educational and service use factors. Figure 3.2 shows the group centroid plot from the discriminant analysis. In table 3.7 the pooled within-group correlations between discriminating variables and standardized canonical discriminant functions are presented. This analysis was conducted with those behavioural, social-environmental, educational and service use factors that differentiated the clinical profiles with the Chi-square tests, Fisher Exact tests or ANOVAs in the aforementioned sections.

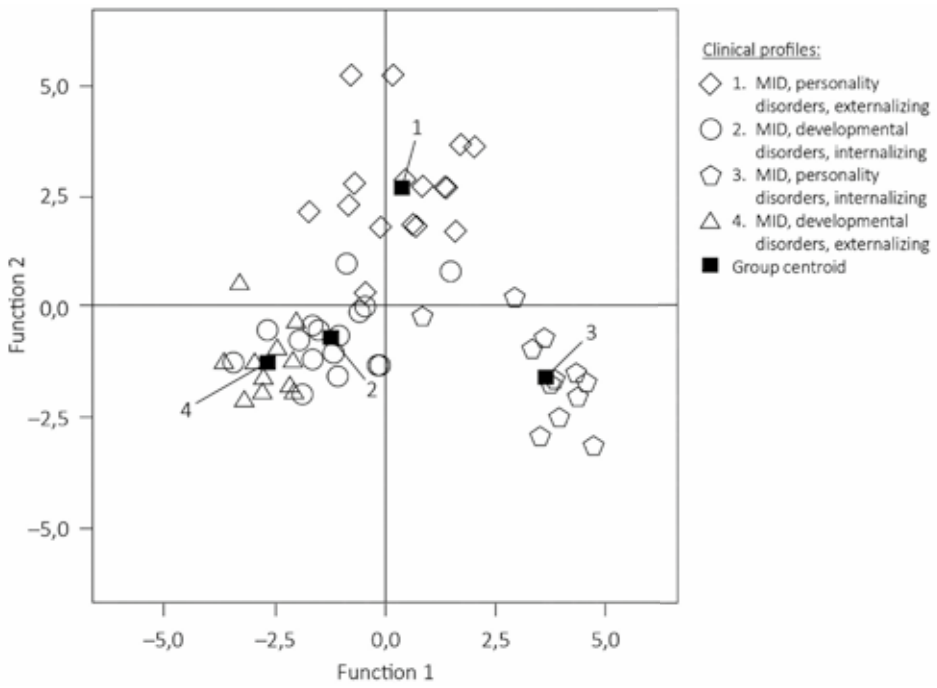


Figure 3.2. *Group centroid plot from discriminant function analysis*

Three discriminant functions were found of which two were statistically significant. This first discriminant function (Wilks's Lambda = 0.015; χ^2 =172.64, df=72, p < .000, eigenvalue = 6.837) accounted for 60.9 % of the between-group variability, and the second discriminant function (Wilks's Lambda = 0.116; χ^2 = 88.226, df = 46, p < .000, eigenvalue = 3.457) accounted for 30.8% of the between group variability. Figure 3.2 shows that the first discriminant function separated the individuals with clinical profiles 2 and 4 (MID with the accent on developmental disorders) from the individuals with clinical profiles 1 and 3 (MID with the accent on personality disorders). The second discriminant function discriminated the individuals with clinical profile 1 (MID with the accent on personality disorders and externalizing behavioural problems) from all other clinical profiles.

Table 3.7. *Pooled within-group correlations between discriminating variables and standardized canonical discriminant functions*

Functions	Function 1	Function 2
Age at referral to community-based and residential care	**.530***	.124
Independent living with mobile support in MID	**.386***	.059
Age at first service contact	**.367***	-.164
Traditional residential care in moderate ID (6-12 years)	**-.305***	-.038
Residential care for mental health in ID (6-12 years)	-.282*	-.090
Looking when others pointed	.258*	.037
Age at first psychiatric diagnosis	.256*	.072
Generic residential service for youth care (13-16 years)	.249*	-.122
Response to speech	.245*	-.047
Outpatient treatment (6-12 years)	-.239*	-.042
Sharing of interests	.227*	.000
Responsive smile	.214*	-.074
Waving bye-bye	.209*	.096
Residential youth care in MID (16 years and older)	.208*	-.089
Preparing to be picked up	.196*	-.127
Starting in school for trainable children (6-12 years)	-.193*	-.180
Ending in school for trainable children (6-12 years)	-.192*	-.160
Displayed abnormal sexual behaviour	.061	**.446***
Physically abused	.131	**.315***
Family history of mental illness	-.129	**.310***
Ending in school for educable children (6-12 years)	.176	**.303***
Starting in school for educable children (6-12 years)	.095	.177*

*Largest absolute correlation between each variable and the two significant discriminant functions

As shown in table 3.7, the loading matrix correlation between the variables and discriminant functions suggested that the variables that contributed most to the separation of clinical profiles 1 and 3 from the other clinical profiles were, in order, their older age at referral to community-based or residential care, more often living independently with mobile support, their older age at first service contact and making less use of traditional residential care for individuals with moderate ID at the ages of six to twelve ($r > .30$). The other variables that contributed to function 1 but with lower loadings ($r < .30$) were, in order, making less use of residential care for mental health in ID at the ages of six to twelve, looking more when others pointed, an older

age at first psychiatric diagnosis, more use of generic youth care at the ages of 13 to 16, more response to speech, less use of outpatient treatment at the ages of six to twelve, more sharing of interests, more responsive smiling, more waving bye-bye, more use of residential youth care in MID at the age of 16 years and older, more preparing to be picked up and less starting and ending in a school for trainable children in childhood (see also tables 3.2, 3.4, 3.5 and 3.6). The variables of function 2 that contributed most to the separation of clinical profile 1 (MID with the accent on personality disorders and externalizing behavioural problems) from all the other clinical profiles were more often displaying abnormal sexual behaviour, being physically abused, having a family history of mental illness and ending in a school for educable children in childhood (r>.30). Another variable that contributed to function 2 but with lower loadings was more often starting in a school for educable children in childhood (r<.30). Table 3.8 shows that 94.6% of the originally clustered individuals were correctly classified.

Table 3.8 *Classification of individuals using discriminant functions*

Profiles	**Profile classification results**				
	Profile 1	Profile 2	Profile 3	Profile 4	Total
Profile 1	**15 (93.8%)**	1	0	0	16
Profile 2	0	**15 (88.2%)**	0	2	17
Profile 3	0	0	**12 (100%)**	0	12
Profile 4	0	0	0	**11 (100%)**	11

94.6% of the original clustered individuals are correctly classified

Discussion

Many individuals diagnosed with MID drop out of the service system. The complexity of the problems of these individuals induced us to perform this study (Cass et al., 1996; McCarthy & Boyd, 2002). Some authors have suggested different clinical profiles in the MID population in order to identify specific diagnostic and treatment strategies that are better tailored to the needs of the individuals with MID (Fletcher et al., 2004; Luckasson et al., 2002; Van der Molen et al., 2009). In a previous study, Soenen et al. (2009) found four differentiating clinical profiles among the individuals of the MID population based on patterns of intellectual, adaptive and behavioural functioning. The present study has been carried out to determine whether these clinical profiles in MID found in the previous study can also be defined in terms of behavioural, social-environmental, educational and service use characteristics in the individual´s history, as proposed by the AAIDD (Luckasson et al., 2002). Describing clinical profiles of characteristics across an individual ‘s life span that may have contributed to an individual‘s actual functioning is highly important for accurate diagnosis and support planning. It offers professionals opportunities to recognize the profiles that are associated with specific

patterns of functioning in MID. This allows care providers to develop various support programmes so that negative influences of adverse environments might be prevented or ameliorated. This can help to streamline the referral process to appropriate care and intervention programmes between and within institutions, and reduce the risk of many individuals with MID falling between the cracks of services. Moreover, if such profiles of historical characteristics related to the clinical profiles in MID based on current functioning could be found, the results would be complementary to the clinical profiles in MID detected in the earlier study (Soenen et al., 2009).

The results of this study indicate that the characteristics in an individual 's history did indeed differ between the clinical profiles in MID. In table 3.9, the major findings are summarized. The separation of the clinical profiles found in this study was based on two underlying discriminant functions. The first function separated the MID clinical profiles with the accent on personality disorders (clinical profiles 1 and 3) from the MID clinical profiles with the accent on developmental disorders (clinical profiles 2 and 4). The service use characteristics contributed most to this separation, suggesting that the individuals with the different clinical profiles in MID have different pathways to care. The findings reveal that individuals with MID and personality disorders were older at first service contact and at referral to residential care than the individuals with MID and developmental disorders. They were less frequently referred to traditional residential care for moderate ID in childhood compared with the children and adolescents with MID and developmental disorders. In adolescence, the individuals with MID and personality disorders (especially those with internalizing behavioural problems) were more likely to be referred to generic residential youth care compared with the individuals with clinical profiles 2 and 4. At the age of 16 years and older, they received more residential youth care for individuals with MID or lived independently with support. The data also revealed the tendency that individuals with MID, personality disorders and externalizing behavioural problems lived less independently. They were more frequently referred to community-based care for individuals with moderate ID compared with those individuals with internalizing behavioural problems. The results of this study are in agreement with other related reports on this issue (see e.g. Einfeld & Tonge, 1996, Joyce et al., 2001; Van Den Hazel, Didden, & Korzilius, 2009), and add important information, especially regarding the different pathways to care of individuals with MID. Besides the attribution of service use characteristics to the first discriminant function, behavioural and educational characteristics were also found albeit with lower loadings. These results give more insight into what the specific intervention programmes for the individuals with different clinical profiles need to provide. Individuals with MID and developmental disorders (clinical profiles 2 and 4) showed, in comparison with the individuals with MID and personality disorders (clinical profiles 1 and 3), far more behaviours in infancy that are associated with a lack of joint attention and a lack of response to speech. This finding suggests that the individuals with MID and developmental disorders can be recognized before school age but individuals with personality disorders only at a later stage.

Table 3.9 *Résumé of the major findings regarding the characteristics that differentiate between the clinical profiles 1 through 4*

<table>
<tr><th></th><th>0-2 years</th><th>3-5 years</th><th>6-12 years</th><th>13-16 years</th><th>16 years and older</th></tr>
<tr><td>Clinical profile 1</td><td colspan="5">Displayed abnormal sexual behavior, physically abused, family history of mental illness</td></tr>
<tr><td rowspan="2">Clinical profile 3</td><td rowspan="2">Problems with preparing to be picked up</td><td rowspan="4"></td><td>Age at first service contact</td><td colspan="2">Age at referral to community-based or residential care in moderate ID</td></tr>
<tr><td>Starting and ending in a school for educable children</td><td>Age at first psychiatric diagnosis</td><td>(Community-based care in moderate ID)</td></tr>
<tr><td></td><td>Age at first service contact
Generic residential youth care</td><td>Age at referral to community-based or residential care in moderate ID
Residential youth care in MID
Independent living with mobile support in MID</td></tr>
<tr><td>Clinical profile 2</td><td rowspan="3">Problems with:
Looking when others pointed
Sharing of interests
Waving bye-bye
Response smile
Response to speech
Pre-speech conversation
Babbling</td><td rowspan="2"></td><td>Age at first service contact</td><td rowspan="2">Age at referral to community-based or residential care in moderate ID
(Community-based care)</td><td rowspan="2"></td></tr>
<tr><td rowspan="2">Clinical profile 4</td><td rowspan="2">Outpatient treatment
Age at first psychiatric diagnosis
Residential care for mental health in ID
Traditional residential care in moderate ID
Starting and ending in a school for trainable children</td></tr>
<tr><td>Age at first service contact</td><td>Age at referral to community-based or residential care in moderate ID</td><td colspan="2"></td></tr>
</table>

With regard to education, the study reveals that children with MID and developmental disorders more frequently attended a school for trainable children (IQ range 30-60) in childhood, whereas the children with MID and personality disorders more frequently attended a school for educable children (IQ range 60-80). Hence, children with MID and developmental disorders can benefit from early multicomponent interventions. The intervention studies associated with large effect sizes focus on a variety of areas including imitation, socialization, communication and behavior management. The interventions are intensive and they often involve the children 's parents (Dawson, & Osterling, 1997; Levy, Kim, & Olive, 2006). Examples of interventions include TEACCH (Teaching Autistic and Communication handicapped Children) (Schopler, Mesibov, & Hearsey, 1995; Mesibov, Shea, & Schopler, 2004), Discrete Trial Training (DTT) (Leaf, & McEachin, 1999), Pivotal Response Treatment (PRT) (Schreibman & Koegel, 1996), or Theory of Mind programs (TOM) (Howlin, Baron-Cohen, & Hadwin, 1999).

The second discriminant function found in this study separated clinical profile 1, consisting of individuals with MID, personality disorders and externalizing behavioural problems, from all other clinical profiles, and consisted of social- environmental and educational factors. These individuals more often ended their education in a school for educable children (IQ range 60-80) in childhood. More individuals with clinical profile 1 showed abnormal sexual behaviours, were physically abused and had a family history of mental illness. This finding is in agreement with other studies showing that externalizing behavioural problems in MID are associated with exploitation and parental psychopathology (see e.g. Dekker et al., 2003; Dykens et al., 2001). These results shed light on the need to evaluate individuals with MID for distressing life events that may lead to severe pathology, e.g. the development of posttraumatic stress disorder (PTSD). Although their cognitive impairments may make individuals with MID more susceptible to the development of PTSD, those who work with this population often lack this awareness. Negative life events that can stress the individual may be life-threatening, and others are quarrels, and unfortunate acts by teachers or other authority figures. Regarding PTSD treatment with MID individuals, trauma focused cognitive behavioural therapy (CBT) and eye movement desensitization and reprocessing (EMDR) have the strongest empirical support (Mevissen, Lievegoed, & de Jongh, 2011). In our study, the association between externalizing behavior, abuse and mental illness in the family is not found within the MID clinical profile with developmental disorders and externalizing behavioural problems. Some have hypothesized that other individual characteristics such as impulse control, control of emotions (Van Nieuwenhuijzen, Orobio de Castro, van Aken, & Matthys, 2009), reinforcement of negative behaviours (Embregts, Didden, Schreuder, Huitink, & Van Nieuwenhuijzen, 2009), abnormal neurological functioning and sensory or motor impairments (Dykens et al., 2001) could be related to externalizing behavioural problems in individuals with MID and developmental disorders.

It can be concluded that diagnostic assessment of individuals with MID should include the completion of a history checklist apart from assessing the pattern of current functioning (Soenen et al., 2009) for further understanding of their unique needs. This checklist needs to cover the behavioural, social-environmental, educational and service use characteristics that have discriminating power with regard to the clinical profiles of individuals with MID.

Several shortcomings of our study should be mentioned. Recognition is given to relatively small groups of individuals who were referred to a limited number of clinical services in one part of the Netherlands. A second shortcoming of our study is that information on the histories of these individuals could be lacking in the case files. We tried to increase the reliability of the assessment by checking the case file information with the parents during the DISCO interview. Second, the case files were analysed double blind to make sure that all information was accurately scored. A third shortcoming is that findings should be interpreted as probabilities, not as certainties. It must be emphasized that any single characteristic of a person is not sufficient to predict with which clinical profile that individual will be identified. It is the sum of observed factors which leads to predictions of cluster classification. Consequently, more research is needed into other characteristics that can contribute to the further discrimination of the clinical profiles and intervention programmes in MID. Not taking certain characteristics into account, e.g. impulse control and control of emotions, could have been the reason why we did not find a third discriminant function that separated a clinical profile with externalizing behavioural problems from a clinical profile with internalizing behavioural problems within the larger group of individuals with MID and developmental disorders.

CHAPTER 4

A comparison of support for two groups of young adults with mild intellectual disability

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Abstract

Young adults with mild to borderline intellectual disability (MBID) have varying profiles of cognitive, adaptive and behavioural functioning. There is also variability in their educational and therapeutic needs. This study compares recommended and actual provision of support for two groups of young adults with MBID and looks at young adults' satisfaction with their support. Participants' clinical files were analysed and a satisfaction interview was administered. Descriptive statistics were used to characterise the groups, and t-tests or chi-square tests were used to explore similarities and differences between the groups. A combined, supported independent living setting, a structuring and regulating support style and psychotherapy were recommended for the young adults in group 1 (MBID with externalising behavioural problems) whilst independent living with access to community support services and a meeting house, and skills training was recommended for group 2 (MBID with internalising behavioural problems). Both groups were considered capable of standard employment with support from a job coach. We found mismatches between recommended and actual provision of support. The findings suggest that service providers do not focus enough on the educational support needs, but therapeutic needs are generally more often met.

Introduction

Many adolescents with mild to borderline intellectual disability (MBID) have problems with the transition to adulthood. They have limited cognitive skills and often have problems with abstract thinking and problem solving (Fuijara, 2003; Snell et al., 2009). Many have difficulty understanding the actions and anticipating the behaviour of others (Collot d'Escury, 2007). They may also have problems with interpersonal interactions, social judgment and decision-making in everyday life (Greenspan, 2006a, 2006b). The prevalence of severe behavioural problems is at least three times higher than in the normal population (for a review see Wallander et al., 2003) and seems to increase in young adulthood (Emerson et al., 2001; Joyce et al., 2001). The seemingly mild disabilities of these young adults can lead to persistent difficulties in multiple life domains (Tymchuk et al., 2001). Many have trouble finding appropriate residential and employment settings (Fuijara, 2003; Snell et al., 2009).

To develop an adequate programme of workplace and residential support for young adults with MBID it is necessary to assess their cognitive, adaptive and behavioural functioning (Kok, 1972). Recently, researchers have distinguished several clinical groups in the MBID population (Fletcher et al., 2004; Soenen et al., 2009; 2012; Van der Molen et al., 2009). To meet the specific support needs of these MBID groups, tailored support programmes need to be developed. A support programme recognises the cognitive, adaptive and behavioural functioning level of participants and is based on a first-level strategy targeting educational support needs in specific residential and employment settings and a second-level strategy targeting the therapeutic needs (Kok, 1972). In this study, we investigated first- and second-level strategies appropriate to two clinical groups of young adults with MBID.

First-level strategy

The first-level strategy aims to provide individuals with their optimal educational environment, and uses styles of support such as providing structure, protection and regulation. In this study we focused on residential and workplace environments and styles of support which are and should be provided in these settings.

Living environment

There is considerable variability in the residential situation of young adults with MBID (Stancliff et al., 2011). A continuum of services exists from institutional accommodation to independent living settings. Haring and Lovett (1990) reported that, at the age of 21, 70% of individuals with MBID were still living with their families. A quarter of men with MBID are still living with their family of origin at age 33 years (Maughan et al., 1999). A large proportion of young adults with MBID living independently who are not known to support providers are living in stressful circumstances (Seltzer et al., 2005; Tymchuk et al., 2001). In a recent study, Stancliff et al. (2011) showed that almost half of adult service users with MBID live in a group home or institution, a third live in their own

home, and a small proportion in an agency-managed apartment. In recent years, several studies have provided evidence of the benefits of providing community-based services for young adults with MBID (Kozma, Mansell, Beadle-Brown & Emerson, 2009; Claes, van Hove, Vandevelde, van Loon & Schalock, 2012); yet there remains considerable variability in the results of these studies (Kozma et al., 2009). Young adults with MBID who have a psychiatric diagnosis or behavioural problems are less likely to be able to choose their residential setting; this has been attributed to the belief that specialised, residential care is necessary for this population (Stancliff, et al., 2011). Murphy et al. (1996) compared the pros and the cons of living in a specialist residential group home and living independently. They showed that young adults who left a specialist residential group home to live independently had a large number of placement moves; some returned to a residential care unit and some even ended up in prison. The reasons of these young adults for preferring a residential care setting included the availability of support with behavioural control, chronic mental health problems, finding independent living too stressful, a desire to avoid social isolation and inadequate support in the community. Reasons for preferring independent living included negative feelings about the restrictions on liberty in residential care and the stigma attached to living in residential care (Murphy et al., 1996). Patil, Keown and Scott (2013) reported an increase in the duration of episodes of in-patient psychiatric care for individuals with MBID, as a result of low levels of routine community support offered by generic services; but young adults with MBID and personality disorder may benefit less from inpatient treatment than clients with MID and severe behavioural problems (Tenneij, Didden, & Koot, 2011). Several studies have reported that many young adults with MBID need more support with social participation than is actually offered (Philips & Rose, 2010; Van Asselt-Goverts et al., 2013). The importance of evaluating the social characteristics of potential residential settings has been recognised (Didden, 2007; Embregts, Didden, Huitink, & Schreuder, 2009), however there is currently insufficient evidence to draw general conclusions about the optimal residential setting for young adults with MBID with different clinical profiles of functioning.

Employment environment

Individuals with MBID have a higher unemployment rate than the general population (Lysaght et al., 2012; Maughan et al., 1999; Taanila, Rantakallio, Koiranan, von Wendt, & Järvelin, 2005; World Health Organisation & World Bank, 2011). Fujiura (2003) reported that 35% of adults with MBID were employed, compared to 81% of the general population. Young adults with MBID are at risk of repeated spells of unemployment. A changing workplace environment, new co-workers and new working methods are stressful for individuals with MBID and often cause problems for them (Taanila et al., 2005). Many individuals with MBID remain unable to access the support they need to enter the workforce successfully. Several explanations for the poor employment prospects of young adults with MBID have been proposed: they need more support to retain employment because of their mental health and behavioural problems (Holwerda et al., 2013); staff working with higher functioning young adults with MBID tend to believe

that they are in control of their behaviour; resulting in negative emotional reactions to episodes of uncontrollable behaviour and less support (Stanley & Standen, 2000). Young adults with MBID may also experience problems with the social norms of a workplace (Black & Rojewski, 1998; Leffert & Siperstein, 2002). Young adults' expectations about their employment prospects have been shown to predict subsequent employment success; having realistic expectations is important (Holwerda et al., 2013). Many countries provide sheltered employment schemes and supported workplaces (Kregel, 2001; Taanila et al., 2005; Verdonschot et al., 2009). There is a lack of clear criteria for defining appropriate employment settings and employment support for young adults with MBID with different clinical profiles of functioning.

Styles of support in residential and employment environments

Categorising individuals with MBID in terms of IQ masks the variability of their needs in daily life. A large proportion of adults with MBID have similar support needs in terms of communication and social skills, self care, activities of daily living, social participation and employment to individuals with more pronounced intellectual disability (Fuijara, 2003; Seltzer et al., 2005); however, support staff in community settings are less willing to help individuals with MBID, because they are judged to be more able and more able to control their behaviour (Stanley et al., 2000; Tynan & Allen, 2002; Philips & Rose, 2010). Support staff are an important source of social, emotional and practical support for people with MBID living in the community (van Asselt-Goverts et al., 2013). Individuals with MBID perform simple and structured tasks quite well, but find more complex tasks, including many everyday tasks, difficult (Collot d'Escury, 2007). Tasks which require planning, analysis, logical reasoning or metacognitive abilities cause problems. Young adults with MBID may need support in the form of a highly structured routine. A successful transition to adulthood depends on personality factors, interpersonal skills, emotional control, impulse control and self-confidence. Young adults with borderline IQ do not have the cognitive capacity to resolve internal and external conflicts, especially when faced with stressors (Masi & Marchesi, 1998). Antisocial or emotionally unstable behaviour is more prevalent in young adults with MBID than in their age peers (Philips & Rose, 2010). Support in the form of a highly regulated environment may help with emotional and behavioural control. Other young adults with MBID need protective support, because they are gullible and vulnerable to exploitation and victimisation (Greenspan, Loughlin, & Black, 2001; Khemka & Hickson, 2006; Snell et al., 2009). Individuals with MBID often need support during the transition from school to work and support to remain in employment (Lindsay, 2011; Richardson et al., 1988). To define appropriate residential and employment contexts for a young adult with MBID, his or her level of cognitive, adaptive and behavioural functioning should be assessed, for example can the individual participate in unstructured social activities, does the individual display intimidating behaviour, can he or she tolerate loneliness? It is also important to determine what informal support would be available in a particular context.

Second-level strategy

Second-level strategy relates to the therapeutic needs of young adults with MBID and may include psychoeducation, skills training and psychotherapy. Psychoeducation might include developing awareness of one's cognitive strengths and weaknesses to improve insight into functioning and future prospects (Van Nieuwehuijzen et al., 2012), but it may also focus on developing ways of managing common stressful situations or reducing exposure to stressful situations (Hartley & Maclean, 2005). Skills trainings for individuals with MBID may take various forms including social problem solving (Anderson & Kazantzis, 2008; Loumidis & Hill, 1997), self-management training with video feedback and guidance on what constitutes inappropriate social behaviour (Embregts, 2000; 2002) and anger management (Benson, 1994; Harper et al., 2013; Rose et al., 2000; Singh et al., 2013). Challenging behaviour in people with MBID can be treated successfully by a variety of biological, psychotherapeutic and contextual interventions (Heyvaert et al., 2010). It has been reported that treatment is more likely to be successful if the therapist is directive and predictable, rehearses instructions frequently and relates skills to everyday contexts and activities (Campbell, Robertson & Jahoda, 2014; Mulder, Didden, Lenderink, & Enserink, 2006).

Taken together these findings demonstrate that there is variability in the functional and clinical 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 required is related to functional and clinical profile; the general aim of this study was to increase understanding of this relationship. We investigated three specific questions: (1) what type of support is recommended for young adults with MBID, divided in two different clinical groups, to know young adults with externalising respectively internalising behaviour problems (Soenen et al., 2009; 2012); (2) what type of support is actually provided for these two groups and (3) how satisfied are these two different groups of young adults with MBID with the support they actually receive. We also compared recommendations and provision of support for both the groups.

Materials and methods

Participants

Participants were 36 young adults with MBID and behaviour problems receiving care from three institutions for people with MBID in the Netherlands. The participants were assigned to two groups (profile-group 1 and 3[3]) based on agglomerative hierarchical cluster analysis. The two profile-groups are characterized by a specific pattern of intellectual, adaptive and behavioural pattern of functioning (Soenen et al., 2009).

3 Group 1 and group 2 are mentioned in the original article. However, In the broader context of this thesis this concerns profile-groups 1 and 3. Therefore "group 2" has been substituted by "group 3" throughout this chapter in order to improve readability.

Profile-group 1 (n=20). This group included young adults with a mean total IQ of 74, a mean adaptive developmental age of seven years and six months and externalising behaviour problems, e.g. blaming other people, apparently manipulative behaviour, wandering around, abnormal sexual behaviour, temper tantrums and physical aggression. This group were more likely to have been physically abused and have a family history of mental illness than the second group. The individuals in group 1 had further been diagnosed with a reactive attachment disorder (RAD), an anti-social or borderline personality disorder (PS) or pervasive developmental disorder (PDD).

Profile-group 3 (n=16). The young adults in profile-group 3 had similar levels of intellectual (total IQ=75) and adaptive functioning (seven years and six months) as profile-group 1 but they exhibited internalising behaviour problems, e.g. immature behaviour and depressive or anxiety symptoms.

Table 4.1. shows that the mean age of the young adults in profile-group 1 (G1; n=20) and profile-group 3 (G3; n=16) did not differ significantly (G1 M= 22.6 years; G3 M= 24.1 years). The gender profile of the profile-groups was also similar (G1: 55.0% men, 45.0% women; G3: 62.5% men, 37.5% women).

Table 4.1*. Age and gender in profile-groups 1 and 3.*

	Profile-group 1 (n=20)	**Profile-group 3 (n=16)**	
Age in months (years)			*F (1,34), p=.64*
M.	270.90 (22.6 years)	289.31 (24.1 years)	
S.D.	61.24 (5.1 years)	76.97 (6.4 years)	
Gender (number and %)			χ^2 *(1,36), p=.21*
Men	11 (55.0%)	10 (62.5%)	
Women	9 (45.0%)	6 (37.5%)	

Instruments

A questionnaire with treatment characteristics was used to assess the participants' functional profile. The characteristics were retrieved from the files of the participants and selected for inclusion in the item list of the questionnaire by mutual agreement of three qualified psychologists. The items were dichotomous scored (present/not present). The questionnaire covered all the types of support recommended and provided to the participants: recommended and actual residential environment (i.e. living independently with support and access to a neighbourhood meeting-house; combined supported independent living e.g. connected independent apartments with a central support and meeting unit; living in a community or institutional group home) and recommended and actual workplace environments (i.e. standard employment setting; supported employment setting; unemployed). We also assessed recommended support styles (i.e.

protection; structure; regulation) and recommended training and psychotherapy (i.e. psychoeducational intervention; skills training; psychotherapy and on-the-job coaching).

A structured interview protocol with dichotomous scored items was administered to participants to collect data about the provided styles of support, second-level strategies and their satisfaction with that support (did/did not receive support; satisfied/unsatisfied). The support activities as described by the American Association on Intellectual and Developmental Disabilities (AAIDD) were used as the interview frame (Luckasson et al., 2002). Then, a selection was made by a panel of three clinical psychologists to only include activities relevant for young adults with MBID. These activities were: arranging a living setting; housekeeping and cleaning; applying for a job or day care activities; performing tasks; interacting with co-workers and supervisors; socialising with family and friends; maintaining structure in daily activities; dealing with physical and mental health problems; communicating with social workers; accessing and using public services and communicating with police and other legal workers. The structure of the interview was based on guidelines of a meta-study into satisfaction research in mental health care (Lemmens & Donker, 1990).

Procedure

The Ethical Commission of ASVZ Zuid West approved the procedures for this study. Participants were recruited in accordance with the ethical guidelines of the Royal Netherlands Academy of Arts and Sciences (KNAW). Participants gave informed written consent to participation. Trained clinical psychologists analysed the clinical records of participants using the questionnaire described above (Instruments). The same clinical psychologists administered the satisfaction interview to participants in their home or at a neighbourhood meeting house.

Statistical analyses

All data were analysed using SPSS 19.0. Descriptive statistics were used to characterise participants in the two groups. The mean ages of the two groups were compared using a t-test. Other variables (gender; recommended support; actual support; satisfaction with support) were compared using the Chi-square test or, if the expected frequency fell below 5 for at least 25% of the items, the Fisher Exact Test. Within-group discrepancies were analysed using the same techniques.

Results

Recommended support

This section summarises the first- and second-level support strategies recommended by clinical psychologists. Table 4.2 shows the percentage of young adults for whom each form of support was recommended.

Table 4.2 *Percentage of participants for whom each type of support was recommended.*

	Profile-group 1		Profile-group 3		Group difference	
	%	*N*	*%*	*N*	χ^2	*p*
First-level strategy						
Residential environment						
Independent living with access to community support services and a meeting house.	25.0	5	68.8	11	6.89	.01**
Combined, supported independent living	60.0	12	18.8	3	6.22	.01**
Living in a traditional group home with 24 hour supervision.	15.0	3	12.5	2	.05ª	.61
Employment environment						
Standard employment setting	65.0	13	68.8	11	.06	.81
Supported employment setting	35.0	7	31.3	5	.06	.81
Support approach						
Supporting or protective	65.0	13	62.5	10	.02	.88
Structuring	85.0	17	56.3	9	3.66ª	.05*
Regulatory	65.0	13	18.8	3	7.70	.01*
Second-level strategy						
Educational intervention	45.0	9	31.3	5	.71	.40
Social skills training	10.0	2	43.8	7	5.46ª	.05*
Psychotherapy	50.0	10	12.5	2	5.62	.02*
Job coach	65.0	13	56.3	9	.73	.39

**p<.01, *p<.05, ª Fisher exact test

Recommended support for profile-group 1

Combined, supported independent living (connected independent living apartments with a central support and meeting unit) was recommended for most profile-group 1 participants (60%). Independent living with access to community support services including a meeting house was recommended for 25% and a traditional group home was recommended only for a small minority (15%). Standard employment was recommended for two thirds of profile-group 1 and supported employment settings were recommended for the remaining third. Support in the form of a job coach was

recommended for 65% of profile-group 1. It was recommended that the majority of profile-group 1 (85%) would benefit from structured support with activities of daily living and regulatory or protective support was recommended for 65%. Additional psychotherapy and educational interventions were recommended for half profile-group 1; skills training was recommended for a smaller number.

Recommended support for profile-group 3

The recommended residential environments for profile-group 3 were independent living with access to community support services and a meeting house (68.8%), combined, supported independent living (18.8%) and a traditional group home (12.5%). Standard employment was recommended for the majority and a supported employment setting for one third. A job coach was recommended for the majority of profile-group 3. Structuring or protective support was recommended to enable the majority to cope with activities of daily living; regulatory support was recommended for a minority. Other forms of recommended support included psychoeducational interventions (31.3%) and skills training (43.8%). Psychotherapy was rarely recommended.

Comparison of support needs

A higher proportion of individuals in profile-group 1 were recommended to live in a combined, supported independent living setting and assessed as needing structuring or regulatory support and psychotherapy. More individuals in profile-group 3 were recommended to live independently with access to community support services and a meeting house. Social skills training was recommended to a higher proportion of profile-group 3. There were no group differences in recommendations for living in a traditional group home; working in a standard employment role; working in a supported employment setting; structuring or protective support; psychoeducational intervention or job coaching.

Provision of support

This section describes the current residential and employment settings of participants. The percentage of participants receiving each form of support and the results of between-group comparisons are provided in Table 4.3.

Table 4.3. *Percentage of participants in receipt of each type of support.*

	Profile-group 1 (n=20)		**Profile-group 3 (n=16)**		**Group difference**	
	%	*n*	*%*	*n*	χ^2	*p*
First-level strategy						
Residential environment						
Independent living with access to community support services and a meeting house.	25.0	5	50.0	8	2.41	.12
Living in a traditional group home with 24 hour supervision.	75.0	15	50.0	8	2.41	.12
Employment environment						
Standard employment setting	0.0	0	12.5	2	2.65ª	.19
Supported employment setting	50.0	10	31.3	5	1.29	.32
Not in employment or day care	50.0	10	56.3	9	.14	.75
Support approach						
Organising accommodation	85.0	17	75.0	12	.57ª	.37
Housekeeping and cleaning	75.0	15	75.0	12	1.00ª	.65
Applying for a job or day care activities	90.0	18	56.3	9	5.40ª	.05*
Performing job-related tasks (n=19) (n=12)	36.8	7	50.0	6	.523	.47
Interacting with co-workers and supervisors	68.4	13	33.3	4	3.66ª	.05*
Socialising with family and friends	75.0	15	37.5	6	5.14	.02*
Structuring activities of daily living	80.0	16	43.8	7	5.06	.02*
Second-level strategy						
Managing physical health problems	40.0	8	25.0	4	.90	.34
Managing mental health problems	85.0	17	93.8	15	.69ª	.61
Communicating with a social worker(s)	80.0	16	62.5	10	1.36ª	.29
Accessing and using public services	100.0	20	68.8	11	7.26ª	.01*
Communicating with police and other legal workers	55.0	11	43.8	7	.45	.50

**p<.01, *p<.05, ª Fisher exact test

Support received by profile-group 1

Seventy-five percent of group 1 lived in a traditional group home and only 25% lived independently with access to community support services. More than 75% received support with activities of daily living, this often included help to structure activities, support to apply for jobs or daycare and support to socialise with family and friends. None of the young adults in group 1 were in standard employment roles; 50% were in a supported employment setting and 50% were unemployed. Seventy percent received support to interact with co-workers and supervisors; 36.8% had support to perform employment-related tasks. More than 80% were mental health service users, received support to communicate with a social worker or support to use public services. Attention is drawn to the proportion who received support to communicate with police and other legal workers (55%).

Support received by profile-group 3

Profile-group 3 participants were distributed evenly across two residential living settings: traditional group home (50%) and independent living with support (50%). Seventy-five percent of profile-group 3 participants received support with activities of daily living and 43.8% were supported to structure daily activities. About a third of profile-group 3 received support to socialise with family and friends and were supported in interactions with co-workers and supervisors at work. Only two profile-group 3 participants were in standard employment; 31.3% were employed in a supported employment setting and 56.3% were unemployed. The majority were mental health service users. Two thirds received support in communicating with social workers or using public services. A considerable proportion (43.8%) received support to communicate with police and other legal workers.

Group comparisons

Residential setting and employment were similar for both groups. The proportion receiving support with activities of daily living and employment-related tasks was also similar in the two groups. Profile-group 1 participants were more likely to receive support to structure in daily activities; socialise with family and friends; interact with co-workers and supervisors; apply for jobs or day care and access and use public services.

Some discrepancies between recommended and actual support are already evident in the data presented above. Many young adults are still living in a traditional group home, although a more independent residential setting has been recommended (G1: χ^2 (1,20)=14.55, p=.00; G3: χ^2 (1,16)=5.24, p=.05). In profile-group 1 more individuals had been recommended to live in a combined, supported independent living setting than were actually doing so (χ^2 (1,20)=17.14, p=.00). In both groups there was a discrepancy between the recommended employment situation and actual employment situation, many participants were unemployed although standard employment or supported employment schemes had been recommended (G1: χ^2 (1,20)=13.33, p=.00; G3: χ^2 (1,16)=12.52, p=.00). In both groups more participants had been recommended to seek

employment in a standard setting than were actually in a standard employment role (G1: χ^2 (1,20)=19.26, p=.00; G3: χ^2 (1,16)=10.49, p=.00). The only discrepancy between recommended and actual provision of support at home and at work was that fewer individuals than recommended in profile-group 1 received support from a job coach (G1: χ^2 (1,20)=4.91, p=.05). In neither group was there a discrepancy between the proportion for whom mental health support was recommended and the proportion using mental health services (G1: χ^2 (1,20)=.63, p=.70; G3: χ^2 (1,16)=3.28, p=.17).

Satisfaction with support

Data on satisfaction with support, including between-group comparisons, are provided in table 4.4.

Table 4.4. *Percentage of participants satisfied with support in each domain.*

	Profile 1-group (n=20)		**Profile 3-group (n=16)**		**Group difference**	
	%	*n*	*%*	*n*	χ^2	*p*
General satisfaction						
Has a support worker who understands the individual and the support he or she needs.	35.0	7	75.0	12	5.71	.02*
First-level strategy						
Support approach						
Arranging accommodation	60.0	12	93.8	15	5.40ª	.03*
Housekeeping and cleaning	85.0	17	81.3	13	.09ª	1.00
Applying for a job or day care activities	95.0	19	62.5	10	5.99ª	.03*
Performing job-related tasks (n=31; n=19 and n=12)	89.5	17	91.7	11	.04 ª	1.00
Interacting with co-workers and supervisors (n=31; n=19 and n=12)	63.2	12	83.3	10	1.45ª	.42
Socialising with family and friends	75.0	15	87.5	14	.89ª	.43
Structuring activities of daily living	95.0	19	62.5	10	5.99ª	.03*
Second-level strategy						
Managing physical health problems	95.0	19	100	16	.82ª	1.00
Managing mental health problems	80.0	16	68.8	11	.60	.44
Communicating with a social worker(s)	90.0	18	93.8	15	.16ª	1.00
Accessing and using public services	100.0	20	93.8	15	1.29ª	.44

**p<.01, *p<.05, ª Fisher exact test

Satisfaction with support in profile-group 1

Only 35% of profile-group 1 participants reported that their support worker understood the nature of their problems and the type of support they needed. A significant proportion (40%) were dissatisfied with support in arranging accommodation. The interview participants mentioned that they wanted to live independently rather than in a traditional group home, and some did not want any 'interference' from support workers. Almost 40% of profile-group 1 were not satisfied with the support they received to interact with co-workers and supervisors. For all other reported types of support at least 75% of participants were satisfied with the support they received.

Satisfaction with support in profile-group 3

Seventy-five percent of participants in profile-group 3 reported that their support worker understood their needs, and at least 75% of profile-group 3 were satisfied with support in arranging accommodation, socializing with family and friends, interacting with co-workers and supervisor, and performing tasks. About 40% of profile-group 3 reported that they received insufficient support to structure daily activities, apply for a job or apply for day care. Approximately one in three were dissatisfied with the support they received to deal with mental health problems.

Group comparison

Table 4.4 shows that profile-group 1 participants were more likely to report that their support worker did not understand the nature of their problems and the type of support they needed. More profile-group 1 participants were dissatisfied with their residential setting (G1=40.0%; G3=6.2%). Also 46.8% of profile-group 1 participants were dissatisfied with support to interact with co-workers and supervisor, but the difference with the profile-group 3 participants (G3=16.7%) was not significant. Profile-group 3 participants were more likely to be dissatisfied with support to structure daily activities, apply for a job or apply for day care (G1=5.0%; G3=37.5%). At interview, profile-group 3 participants mentioned that they received insufficient support to find an appropriate job; they reported that they were doing jobs that did not match their interests. Some of these participants reported that they had been told to find their own solutions for social problems. In summary, a proportion of participants in both groups were dissatisfied with at least some aspects of their employment situation.

Discussion

Many adolescents with MBID have problems with the transition to adulthood (Fuijara, 2003; Snell et al., 2009). In young adulthood, their seemingly mild disabilities can lead to persistent difficulties (Tymchuk et al., 2001). Although there is considerable variation in functional level in this population, and hence variability in support needs in both residential and workplace environments, there is little understanding of how the support needs of young adults with MBID relate to their intellectual, adaptive and behavioural

functioning. This study compared the educational (first-level) and therapeutic (second-level) support recommended and provided to two distinct profile-groups: profile-group 1 was characterised by externalising behavioural problems; profile-group 3 was characterised by internalising behavioural problems. Satisfaction with support was also investigated. Figure 4.1 summarises group differences in recommended first- and second-level support strategies.

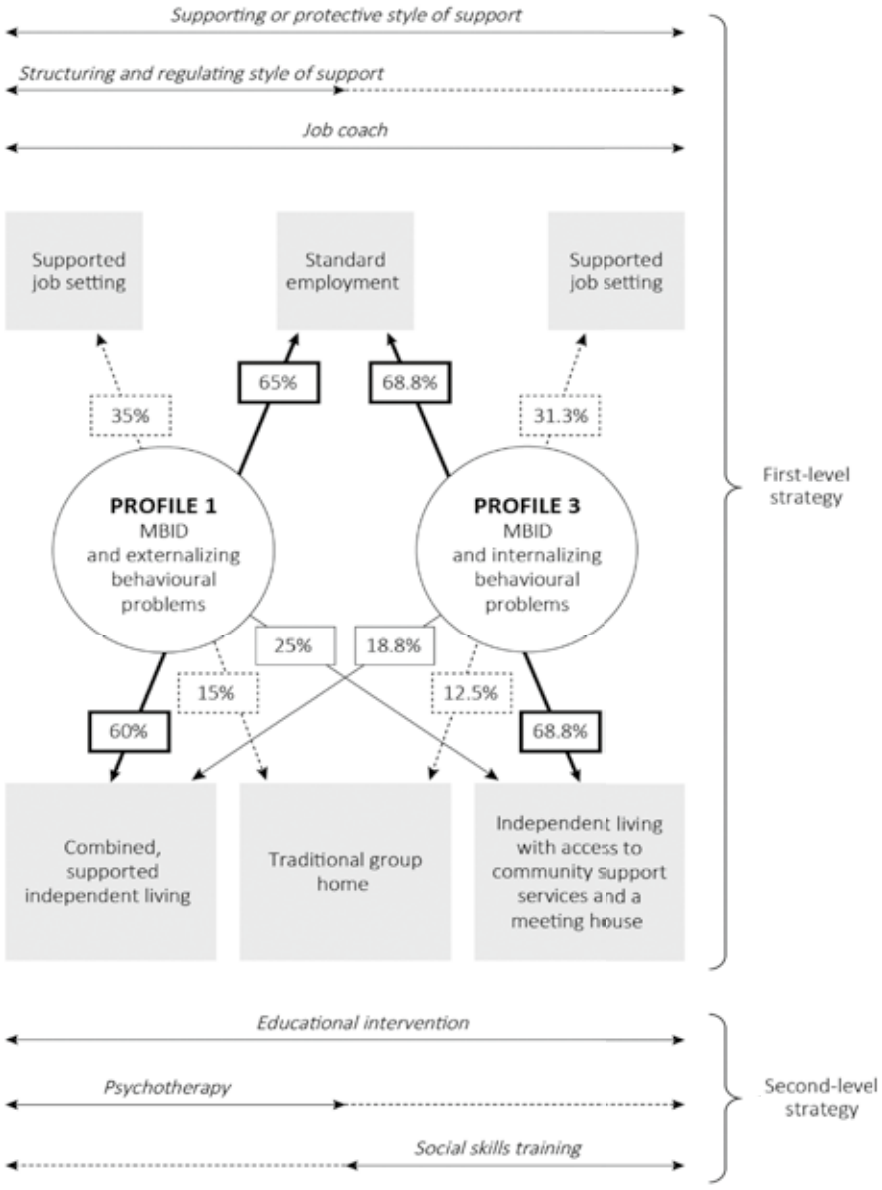


Figure 4.1. *Group differences in recommended first-level- and second-level strategies.*

Figure 4.1 shows that combined, supported independent living (connected independent living apartments with a central support and meeting unit), structuring and regulatory support with activities of daily living and psychotherapy were recommended for most participants in profile-group 1 whereas independent living with access to community support services and a meeting house, and social skills training were recommended for most profile-group 3 participants. A supportive approach and standard employment with support from a job coach were recommended for the majority of participants in both groups. Our data on recommended residential environment are in line with the promotion of individualised living settings, such as one´s own home or an agency apartment, for young adults with MBID (Stancliff et al., 2011), however the results also show that it is important to match the social environment with the functional profile of the individual (Didden, 2007; Embregts, Didden, Huitink et al., 2009; Embregts, Didden, Schreuder et al., 2009). Combined, supported independent living (e.g. connected living apartments with a central support and meeting unit) is intended to provide an individualised environment in which it is easier to control social contextual factors that contribute to the onset or persistence of behaviour problems than in independent accommodation or traditional group homes. Provision of meeting houses for young adults with MBID who live independently can prevent social isolation.

Our findings on recommended employment environment and the need for on the job support are comparable to those from other studies (Lysaght et al., 2012; Verdonschot et al., 2009): a large proportion of both groups is considerable capable of standard employment, with support from a job coach. The recommendation of a supportive approach for two thirds of both groups corroborates earlier research showing that many of these young adults often have higher support needs than is at first apparent (Fuijara, 2003; Van Asselt-Goverts et al., 2013). Profile-group 1 participants were also commonly recommended structuring and regulatory support. Although qualitative descriptions of young adults with MBID have been provided elsewhere (Masi & Marchesi, 1998), our recent work has provided additional data on different intellectual, adaptive and behavioural profiles within this population (Soenen et al., 2009, 2012) that can be related to specific support styles. Participants in profile-group 1 tended to be recommended specialised second-level support, e.g. psychotherapy, whereas skills training was more likely to be recommended for profile-group 3 participants. The recommendations for second-level support reflect the more severe psychopathology of profile-group 1. Differences between subgroups of young adults with MBID with regard to the abovementioned support needs have not previously been reported.

Our findings revealed serious shortcomings in provision of support for young adults with MBID. Many participants in profile-group 1 and a smaller, but still significant, proportion of profile-group 3 were still living in a group home, although it had been recommended that they live in a setting which offered more independence. These results are in line with other recent studies showing that many individuals with MBID, especially those with externalising behavioural problems, are still living in group homes (Murphy et al., 1996; Stancliff et al., 2011). Our study provides evidence that the majority of young

adults in profile-group 1 (MBID and externalising behavioural problems) are not satisfied with their residential environment. Securing and retaining a job in a standard workplace was very difficult for both groups. This does not reflect the recommendation for the majority of participant in both groups, namely that they are capable of working in a standard workplace environment with appropriate support. The economic recession may have worsened the employment prospects of young adults with MBID (Taanila et al., 2005), but it may also be that the recommendations for participants in this study were too optimistic; the majority participants had not received vocational training (Soenen et al., 2012). Seltzer et al. (2009) showed that lack of vocational training was associated with poor employment status. It was recommended that many of the profile-group 1 participants in this study should receive support from a job coach, but few actually received this support. This discrepancy was not found in profile-group 3. This may be because professionals assessing young adults with MBID give greater weight to externalising behavioural problems than cognitive deficits; it has been suggested that more capable young adults with MBID whose behaviour is more externally-directed are more likely be thought capable of controlling their behaviour and hence they invoke negative emotional reactions and receive less support (Stanley & Standen, 2000). It may also be that young adults with MBID have unrealistic expectations about their employment prospects (Holwerda et al., 2013).

Our results suggest that the support styles in the residential environment are generally in line with recommendations and to some extent adapted to the differing needs of the two profile-groups: more profile-group 1 participants were receiving structuring and regulatory support. However, although the support styles they were receiving seemed to be in accordance with recommendations, profile-group 3 participants wanted more support, particularly with structuring activities of daily living. Some shortcomings in the style of support offered in the workplace environment were identified. Profile-group 1 participants wanted more regulatory support, e.g. support to interact with co-workers and supervisors, than they were receiving; profile-group 3 may need more support overall in this domain, e.g. support to apply for jobs. It has already been shown that young adults with MBID need more support than is at first evident (Fuijara, 2003; Seltzer el., 2005; Lindsay, 2011). This study extends these findings by suggesting that the employment support needs of young adults with MBID vary according to functional profile.

Both profile-groups appeared to be receiving the recommended level of support for dealing with mental health problems and the groups reported similar levels of satisfaction with the therapeutic support they received. It is striking that approximately half the young adults in both profile-groups received support for communication with police and other legal workers. This result is consistent with Bexkens's (2013) finding that young people with MBID, with or without behaviour problems, have limited cognitive ability to weigh up decisions and are more easily influenced by peers than their intellectually unimpaired age peers; both cognitive and affective skills appear to play a role in risk-taking behaviour.

On the basis of these results we conclude that a majority of young adults with MBID are not yet receiving a residential and workplace environment adapted to their level of intellectual, adaptive and behavioural functioning, although the received support styles are to some extent adapted to the differing needs of the two groups of young adults with MBID. The failure to provide attuned support styles at work and employment support in the form of a job coach is widespread.

Clinical recommendations

Our main recommendation is that much more attention is paid to first-level support strategies, particularly type of residential and employment environment, and the styles of support offered in the workplace environment. First-level support should be complemented by second-level support i.e. therapeutic support. It is recommended that most young adults with MBID live more independently, provided that the physical and social environment (e.g. combined, supported independent living, independent living with access to community support services and a meeting house) is appropriate to the intellectual, adaptive and behavioural profile of the young adult concerned. Figure 4.2 provides a schematic overview of potential living environments for young adults with MBID, organised on an independence continuum.

For many young adults in profile-group 1 combined, supported independent living (CSIL), structuring and regulatory support and psychotherapy, might offer the opportunity to avoid some of the disadvantages of living in a group home (GH) or attempting to live independently (IL) (Murphy et al., 1996; Patil et al., 2013; Tenneij et al., 2011). The provision of specialist support e.g. structuring and regulatory support can probably be managed more effectively in a combined, supported independent living setting (e.g. connected living apartments with a central support and meeting unit).

Access to a meeting house, a supportive approach and social skills training are important forms of support for the majority of the young adults in the profile-group 3 living independently (ILM). We also found that this group would like more support to structure activities than is currently recommended.

Although we found that few young adults with MBID were employed in a standard workplace, there is evidence that many individuals with MBID can undertake standard employment roles if appropriate training and on the job support is provided (Mank, 2007). However it takes time for the support of a job coach to pay dividends and it is important that the needs of these young adults are recognised in the workplace. For profile-group 1, the job coach should provide support with multiple aspects of employment, e.g. performing job-related tasks, interacting with co-workers and supervisors; for profile-group 3 support with the job application process is a priority. A framework which describes different employment settings, the support styles available, and the additional support which might be required to make them suitable for individuals with MBID, should be developed.

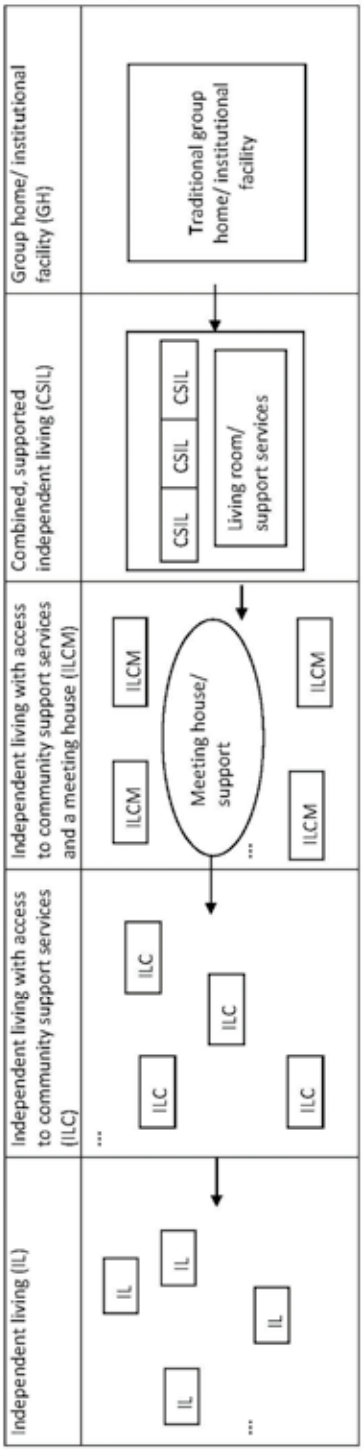


Figure 4.2. *Scheme showing different levels of independence of the residential environments for young adults with MBID*

It has been recommended that support workers receive training and coaching (Campbell et al., 2014) in delivering these different styles of support to young adults with different needs profiles. Training may take the form of video feedback training (Embregts, 2003) or emotional intelligence training (Zijlmans, Embregts, Gerits, Bosman, & Derksen, 2011). This is especially necessary for workers, including job coaches, delivering support in the workplace. Understanding the clinical and functional profile of young adults with MBID can change the attitudes of support workers (Stanley et al., 2000). The risk-taking behaviour of young adults with MBID should receive more attention. Several researchers have commented on this population's need for long-term, specialist guidance; this need should not be overlooked when reforms to integrate individuals with MBID into society are implemented (Bexkens, 2013; Taylor, 2009). This need for long-term, specialist guidance underlines the fact that the residential and workplace environments, and the style of support offered should be adapted to the functional profile of the individual, including his or her propensity for risk-taking behaviour.

Directions for future research

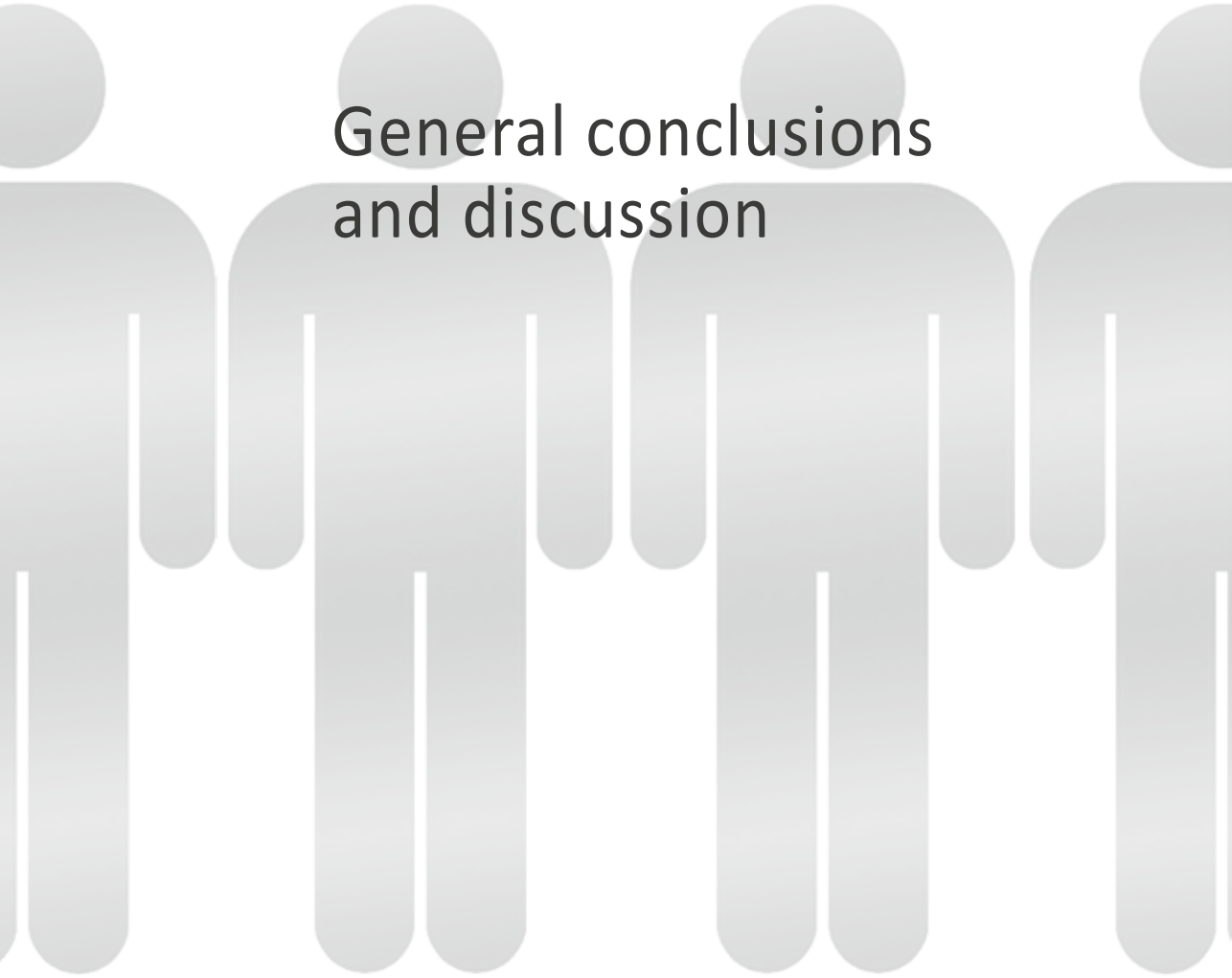
Much more research is needed on the effectiveness of the two types of support distinguished in this study. Clinical psychologists' advice is often based on research, but the practical effectiveness of this advice, particularly as it relates to the first-level support offered to both clinical groups, should be evaluated in terms of e.g. frequency and severity of behavioural problems and risk taking behaviour and quality of life. It is important to improve understanding of the reasons for the large discrepancies between recommendations and provision of support for young adults with MBID; this may provide insight into the limiting factors in provision of support and help in developing a strategy for overcoming them. Additional research is needed to determine which post-educational path (e.g. continued education, employment or day care) and what employment environments (first-level strategy) are most appropriate to the functional profile of the clinical groups we have distinguished. Although evidence on different types of psychological treatments for young adults with MBID was not the focus of this study, further research in this domain remains necessary (Campbell et al., 2014); we recommend that it should take account of the different clinical groups we have distinguished in the population of young adults with MBID.

Limitations

We studied a relatively small sample of young adults with MBID who had been referred to a limited number of clinical services in one particular region of the Netherlands. The generalisability of our findings is unknown. We explored recommendations and provision of support in relation to only two different clinical profile-groups; if the clinical profile of young adults with MBID were further differentiated a more detailed exploration of the relationship between clinical profile and support needs would be possible. A further limitation is that we did not evaluate the implementation or effectiveness of the combined advice of the clinical psychologists responsible for our participants; this is to some extent mitigated by our interview assessment of young adults' satisfaction with their support, which provides one evaluation of the effectiveness of support.

CHAPTER 5

General conclusions and discussion



Introduction

The group of individuals with mild to borderline intellectual disability (MBID) is heterogeneous with regard to their characteristics and the problems they encounter. These individuals can have problems with learning, education, behaviour, suffer psychiatric conditions, have problems finding an appropriate residential and/or employment setting, and also face other challenges. This group is also heterogeneous with regard to the support they need. They may require, for example, youth care, mental health care, community-based care, and support for all kinds of activities of daily living, social participation, and employment. The diversity and complexity of problems and the diffuse spectrum of support programs makes it difficult for individuals with MBID, as well as for support providers, to identify the correct type of support necessary (chapter 1). The main objective of this thesis was to identify whether it is possible and clinically relevant to differentiate clinical profiles within the MBID population that relate to specific support programs. A conceptualization of the heterogeneity of this group in terms of a limited number of basic clinical types can lead to an improved understanding of how to organize the needs of individuals with MBID and the types of support required. This would then aid in preventing individuals with MBID from falling through the cracks in regards to services by referring them to the appropriate support types that are optimally effective in enhancing individual functioning.

The studies in this thesis contributed to this objective. Chapter 1 introduced the thesis and provided information about the concepts used in the subsequent chapters. Chapter 2 reported on whether clinical subtypes in the heterogeneous MBID population can be identified in terms of multidimensional profiles of functioning. The dimensions of intellectual functioning, adaptive behaviour and health in terms of behavioural functioning and DSM-IV-TR classifications were explored. In chapter 3, it was investigated whether the clinical profiles of functioning can also be differentiated according to characteristics in histories and pathways to care. This chapter focussed on behavioural, social-environmental, educational and service use characteristics. In chapter 4, it was determined whether the clinical profiles of young adults with MBID are related to specific support programs. The recommendations and the provision of support for the clinical profiles were compared, and the satisfaction with the received support was studied. In this final chapter, the general conclusions of the studies will be discussed, with an emphasis on the strengths and limitations of this thesis and the implications for clinical practice and future research.

Brief overview of the study

Multidimensional clinical profiles in the MBID population

The starting point of this thesis was the most recent definitions of ID by the AAIDD, which describe a multidimensional construct (Luckasson et al., 2002; Schalock et al., 2010). This model emphasizes that a comprehensive description of people with ID must

be performed using more than one criterion. The model encompasses the relationship between individual functioning, support and five dimensions: intellectual abilities, adaptive behaviour, health, participation and context. The model also states that a description should be made of risk factors across the life of the individual (e.g., medical, behavioural, social-environmental, educational and service use factors) that have contributed to the individual's functioning. In this thesis, it was investigated whether multidimensional clinical profiles based on intellectual, adaptive and behavioural functioning in the MBID population could be induced from the data by means of an agglomerative hierarchical cluster analysis (chapter 2). Moreover, discriminant function analysis was used to explore whether the clinical profiles in MBID could also be differentiated according to characteristics of the clinical histories and pathways to care. The focus was on behavioural, social-environmental, educational and service use characteristics (chapter 3). Figure 5.1 summarizes the outcomes of the two studies.

The findings of these studies demonstrate that four multidimensional clinical profiles of actual functioning could be differentiated in the MBID population, using the actual levels of intellectual and adaptive functioning of individuals in this population and the presence of behavioural problems and psychopathology. Moreover, profiles 1 and 3 were also differentiated according to the individual's pathway to care, and behavioural, educational and social-environmental characteristics in their history. Profiles 2 and 4 could not be differentiated based on historical factors; other factors such as impulse control may be related to the problems of these individuals (see implications for further research). That multidimensional clinical profiles can be differentiated, is important both for accurate diagnosis and for the referral process to appropriate care (see implications for clinical practice). Therefore, the following question concerned whether these clinical, multidimensional profiles could also be related to specific support programs (chapter 4).

Support programs related to multidimensional clinical profiles in the MBID population

It was investigated whether clinical profiles 1 (MBID wit the accent on personality disorders and externalizing behaviour problems) and 3 (MBID with the accent on personality disorders and internalizing behaviour problems) are related to specific support programs. The strategies of Kok (1972) were used to describe the corresponding support programs. The first-level strategy aims to provide individuals with their optimal educational environment and styles of support; the second-level strategy relates to their therapeutic needs. The type of support initially recommended for clinical profiles 1 and 3 was determined, and then compared with the type of support actually provided, and how satisfied the individuals were with the support they received. The recommendations and provision of support were also compared (chapter 4). Broad outlines of recommended first- and second-level strategies are given in Figure 5.2.

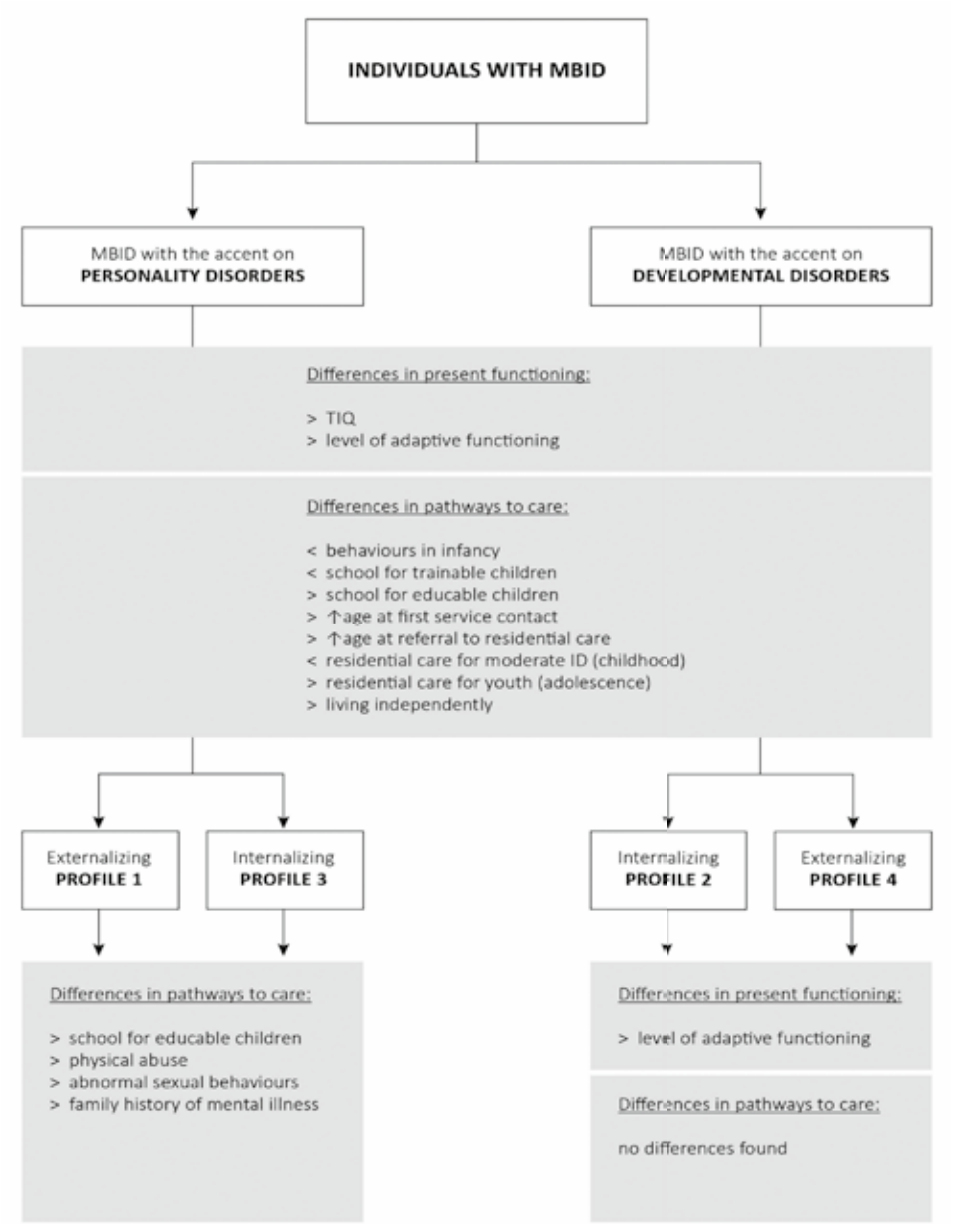


Figure 5.1. *Multidimensional profiles in MBID: characteristics, differences and similarities with regards to actual functioning and their pathways to care.*

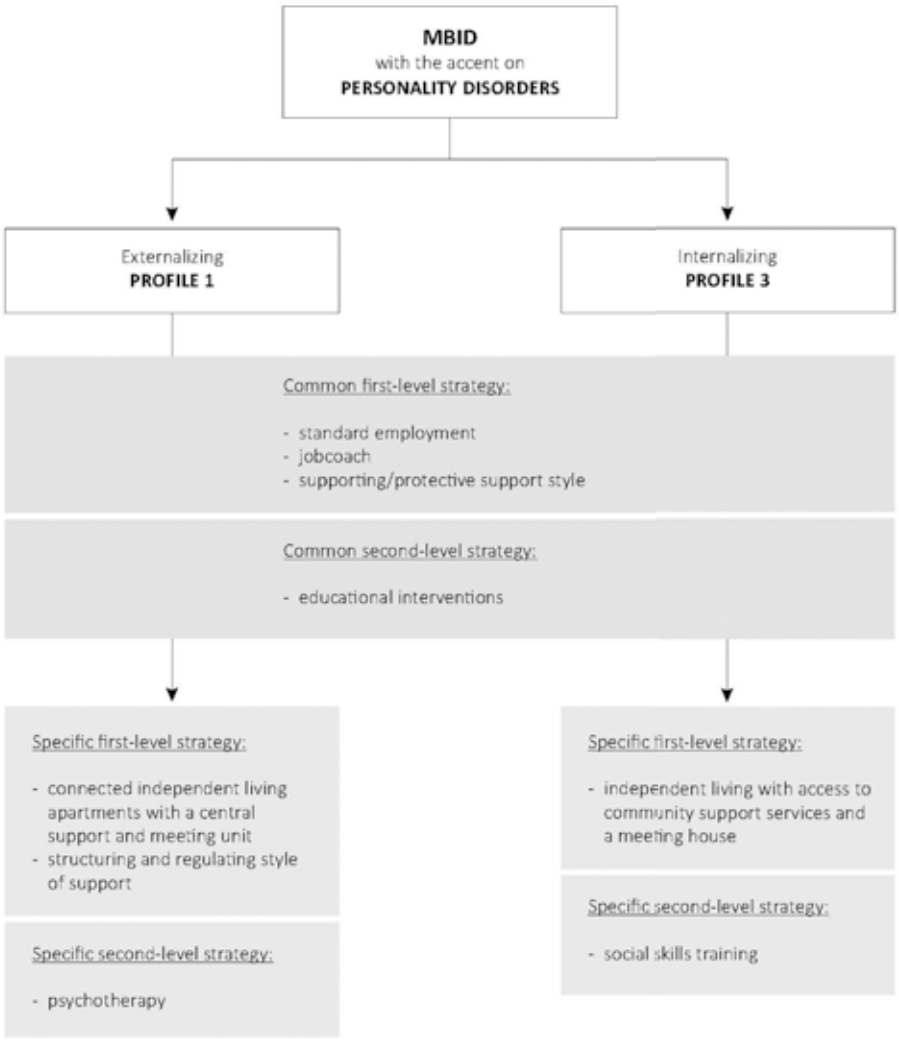


Figure 5.2. *Broad outlines of first- and second-level strategies for clinical profiles 1 and 3.*

Figure 5.2 shows that clinical profiles 1 and 3 are related to different specific support programs. It can be concluded that the majority of individuals in both groups receive the recommendation of an individualized residential setting, on the condition that the social environment and the support style match their clinical profile. The importance of evaluating the social characteristics of potential residential settings has also been emphasized by Didden (2007), Embregts, Didden, Huitink et al., (2009) and Embregts, Didden, Schreuder et al. (2009). The two profile groups especially differ with regard to the residential environment and the support style. For instance, the intent of the connected

living apartments for the clinical group 1 individuals is to provide an individualized environment in which it is easier to provide structure and regulate social contextual factors that contribute to behavioural problems than in independent accommodation or traditional group homes, whereas the provision of a meeting house can help to prevent social isolation for the clinical group 3 individuals. With regard to the second-level strategy, the individuals with clinical profile 1 were recommended psychotherapy, while the other profile was more likely to need social skills training. This finding reflects the more severe psychopathology of young adults with MBID and externalizing behaviour problems (Clinical profile 1). The final questions in this thesis concerned whether these young adults received the support initially recommended and whether they were satisfied with the support provided. This illuminated the needed support that was not provided.

Comparison of initially recommended with provided support

A comparison was made between the initially recommended and the provided support for individuals with MBID and personality disorders with clinical profiles 1 (externalizing behavioural problems) and 3 (internalizing behavioural problems), to enhance further insight into the problems of individuals with MBID concerning receiving appropriate support (chapter 4). The outcomes revealed, as expected, serious shortcomings in the provision of support. For both clinical profiles 1 and 3, the findings suggested that service providers do not focus sufficiently on first-level strategies, e.g., residential- and workplace environments. Many individuals with profile 1 (MBID with the accent on personality disorders and externalizing behaviour problems), and a smaller but significant proportion of individuals with profile 3 (MBID with the accent on personality disorders and internalizing behaviour problems) were still living in a group home, although it had been initially recommended that they live in a setting offering appropriate levels of independence. These results are in line with other studies that have shown that individuals with MBID, especially those with externalizing behavioural problems, have remained in group homes (Stancliff et al., 2011). The support styles provided in the residential environments were generally in line with the recommendations. However, as expected, the individuals with clinical profile 1 desired increased support with arranging accommodation, while those with clinical profile 3 wanted further support with activities of daily living. That the therapeutic needs were often met in both groups was a positive finding.

With regard to the workplace environment, securing and retaining a job in a standard workplace was very difficult for the individuals of both clinical profiles, although they were considered to be capable of standard employment with support from a job coach. Two important reasons for this are that the majority of these individuals had not received vocational training, and that especially the young adults with profile 1 lacked a job coach. These results corresponded to the finding that the support styles recommended are not in line with the support styles provided in the workplace. The young adults with clinical profile 1 desired an increased degree of regulated support (e.g., support in interaction

with co-workers), while the individuals with clinical profile 3 especially desired further support in applying for a job. It has already been shown that young adults with MBID require increased levels of support than is first evident (Fujiara, 2003; Lindsey, 2011, Seltzer et al., 2005). The current study adds that it is especially important to assess the required type of support.

Practical implications

In this thesis, it has been shown that describing multidimensional clinical profiles of functioning in terms of characteristics across an individual's life span is highly important for accurate diagnoses and support planning (AAIDD, Schalock et al., 2010).

Diagnostic assessment

First, the four clinical profiles, described in this study, provide an insight into the various diagnostic trajectories that can be followed by individuals with MBID.

First, the diagnostician must determine to which of the four clusters the individual belongs (Figure 5.1). The first study (chapter 2) showed that the WAIS-III/WISC-III, the VABS and the DISCO are useful in determining the appropriate clinical profile in the first diagnostic phase. The DISCO was found to be a highly suitable instrument, because it assesses behavioural problems in detail, and is valuable in pinpointing specific psychiatric disorders. The DISCO also detects subtle social skills that are not measured with the VABS (for instance, the items "manipulative behaviour" and "blaming other people"). In higher functioning people with MBID, these subtle skills are important, since basic and routine interaction skills are often developed to a sufficient degree (De Bildt, Serra et al., 2005). Apart from assessing the clinical profile of functioning, the completion of a history checklist can also help to determine the clinical profile of the individual (study 2, chapter 3). This checklist must cover the historical characteristics that have a discriminating power with regard to the four clinical profiles in the MBID population. These characteristics are: age at first service contact and at referral to community-based or residential care, traditional residential care for moderate ID in childhood, independent living with support, displayed abnormal sexual behaviour, suffered physical abuse, family history of mental illness and completed education in a school for educable children.

Second, after determining the clinical profile, a diagnostic phase containing various diagnostic procedures for the different clinical profiles can be followed. If an individual displays the behavioural pattern of clinical profiles 1 or 3, further assessment should focus on their personality organization (e.g., strength of ego functions and temperament), relational attitudes (e.g., attachment styles, mental representations of self and other, social information processing and coping styles) and the social environment of the individual (e.g., social support and strain, stressors and life events). The individuals with clinical profile 1 especially need to be evaluated in terms of distressing life events that may lead to severe pathology (e.g. the development of posttraumatic stress disorder or severe disorders of personality). The majority of the diagnostic instruments used

for people with a mean or higher IQ can also be applied to individuals with MBID with clinical profiles 1 and 3 (Kraijer, 2006).

If an individual displays the behavioural pattern of clinical profiles 2 or 4, the assessment procedure is different to the procedure for clinical profiles 1 and 3. Some of the disruptive behaviours of these individuals points to co-morbid conditions that cannot be classified according to the traditional descriptive phenomenological categorical psychiatric system or the DSM-5 alone (Došen, 2005a; Kraijer, 2006). Establishing the level of personality development of individuals is complex because a large discrepancy is found among cognitive and adaptive (social-emotional) development. For these individuals, a specialised and wider assessment frame for integrative diagnosis is necessary. Došen (2005b), for instance, described not only the biological and neuropsychological aspects of the individual but also the level of personality development that plays a role in adaptive and behavioural functioning. Special diagnostic instruments are required for the assessment of these individuals, e.g., the Schema of Appraisal of Emotional Development (SAED) (Elstner, Diefenbacher, Kirst, & Vandevelde, 2016; Došen, 2005c). As mentioned above, more of these characteristics should have been taken into account in the second study in the assessment of the histories these individuals (e.g. impulse control and control of emotions).

Support programs

Concerning support, this study focussed on young adults with MBID, with an accent on personality disorders. First-level (educational environment and support styles) and second-level strategies (psychoeducation, skills training and psychotherapy) were described. The main recommendation of this study is that increased attention should be paid to first-level strategies, namely type of residential- and employment environment, and the styles of support offered in the workplace.

In chapter 4, an overview of potential residential environments, organized on an independence continuum, is presented. In general, most young adults with MBID can live in an individualized setting, providing that the social environment is adapted to the clinical profile of functioning. For many of the young adults with profile 1 (MBID with the accent on personality disorders and externalizing behavioural problems), a combined, supported independent living arrangement (connected apartments with a support/ meeting unit), structuring and regulatory support and psychotherapy, may offer an opportunity to avoid some of the disadvantages of living in a group home or attempting to live independently (Murphy et al., 1996; Patil et al., 2013; Tenneij et al., 2011). The provision of specialist support, for example structuring and regulatory support, can likely be managed more effectively in such a setting. With regard to psychotherapy, many of these individuals will need to process negative life-evens. Trauma-focused Cognitive Behavioural Therapy (CBT) and Eye Movement Desensitization and Reprocessing (EMDR) currently have the strongest empirical support (Gildertorp, 2015; Mevissen, et al., 2011). For the majority of young adults with profile 3 (MBID with the accent on personality disorders and internalizing behavioural problems) who can live independently, access

to a meeting house, a supportive approach and social skills training is important. The present study shows that these individuals require increased levels of support with daily activities than may initially be suspected.

Concerning employment, many individuals with MBID can undertake standard employment roles, if appropriate training and on-the-job support are provided. However, time is required for the support of a job coach to pay dividends, and it is important that the needs of these young adults are recognized in the workplace. In this thesis, it has been shown that young adults with profile 1 (MBID with the accent on personality disorders and externalizing behaviour problems) require a job coach who provides support with multiple aspects of employment, e.g., performing job-related tasks and interacting with co-workers and supervisors, while young adults with profile 3 (MBID with the accent on personality disorders and internalizing behaviour problems), especially need support with the job application process. A framework which describes various employment settings, the support styles available, and the additional support that may be required to make them suitable for individuals with MBID, should be developed.

It is recommended that support workers receive training and coaching (Campbell et al., 2014; Willems, Embregts, Hendriks, & Bosman, 2016) in delivering different styles of support to young adults with varying needs profiles. Training may take the form of, for instance, video feedback training (Embregts, 2003) or emotional intelligence training (Zijlmans et al., 2011; 2015). This is especially necessary for workers, including job coaches, who are providing workplace support. Understanding the clinical and functional profiles of young adults with MBID may also affect the attitudes of support workers, which is an important factor (Stanley et al., 2000). The risk-taking behaviour of young adults with MBID requires further attention. Several researchers have commented on the need for long-term, specialist guidance; this need should not be overlooked when reforms to integrate these individuals into society are implemented (Bexkens, 2013; Taylor, 2009). This underlines the importance of adapting the residential and workplace environments and the styles of support to the clinical profile of the individual, including the propensity for risk-taking behaviour.

Although individuals with MBID and developmental disorders were not the focus of this thesis with regards to support, it was found that they were referred at a much younger age than individuals with MBID and personality disorders. Hence, these children can benefit from early multicomponent interventions, focusing on areas such as imitation, socialization, communication and behaviour management, such as Teaching Autistic and Communication Handicapped Children) (TEACCH) (Mesibov et al. 2004; Schopler et al., 1995), Discrete Trial Training (DTT) (Leaf & McEachin, 1999), Pivotal Response Treatment (PRT) (Pellecchia, Connell, Beidas, Xie, Marcus, & Mandell, 2015; Schreibman & Koegel, 1996) or Theory of Mind (TOM) (Howlin et al., 1999) programs. However, further research is required into the clinical profiles in the MBID and developmental

disorders group. It would therefore be sensible for the specialized support programs in practice to be delivered by specific support providers, instead of all providers trying to support all individuals.

Strengths and limitations of the studies

The studies in this thesis added to the knowledge in the field regarding the professional help of persons with ID, by describing the heterogeneity of the needs of individuals with MBID in terms of a limited number of basic clinical-need profiles. One of the strengths of this study is that the variability of this group was studied, and a semblance of order was established by identifying clinical profiles that point to specific support programs. This may lead to the more accurate provision of support. Secondly, a multidimensional perspective (AAIDD, Schalock et al., 2010) was used by integrating more factors than IQ alone, such as adaptive and behavioural functioning. In this way, the diversity and complexity of the problems and support needs of individuals with MBID, were acknowledged to an increased degree. Another strength of this study is that initially-recommended support was compared with the support that was actually provided. This shed further light on the support that individuals with MBID may require, but which they do not receive. For the evaluation of support, multiple measures were used and both objective (functional assessment) and subjective (personal appraisal) data were analysed. A large amount of time was reserved for trained, independent health psychologists to administer the interviews or questionnaires with the participants in the natural environments of these individuals. In this way, more participants could be reached and their trust could be gained.

A number of limitations of the present research should also be taken into account during the interpretation of the results of the different studies. A first limitation involves the small sample size, which comprised only those individuals who were referred to a limited number of clinical services in one area of the Netherlands. It is possible that further clinical profiles with different behavioural patterns will be identified when a larger group of persons with MBID is studied, or when the individuals to be studied are recruited from other areas. Secondly, the clinical profiles that were identified may change, when other dimensions of the AAIDD model are incorporated into the initial cluster analysis, such as participation and context. Compensation of this limitation was attempted through the inclusion of aspects of these factors into the second and third studies, where for instance social-environmental factors and living- and workplace environment were described. Thirdly, the findings regarding the cluster analysis should be interpreted as probabilities, not as certainties. It must be emphasized that any single characteristic of a person is insufficient to predict the clinical profile with which that individual will be identified. It is the sum of observed factors that leads to predictions of cluster classification; for example, not taking certain characteristics into account in the second study, such as impulse control and control of emotions, could have been

the reason why a third discriminant function was not found that separated the clinical profiles of externalizing and internalizing behavioural problems within the larger group of individuals with MBID and developmental disorders. A further weakness of this study is that information concerning the histories of these individuals in the case files may have been lacking. An attempt was made to increase the reliability of the assessment by cross-checking the case file information with the individual with MBID or with the parents during the anamnestic interview. The case files were also analysed using a double-blind method to ensure that all information was accurately scored.

Recommendations and provisions of support in relation to only two different clinical groups were compared; if the clinical profiles of individuals with MBID were further differentiated, a more detailed exploration of the relationship between clinical profile and support needs would be possible. Unfortunately, it was not possible to gather sufficient data regarding the support needs for the two clinical profiles in the group of people with MBID and developmental disorders. A final limitation is that the implementation or effectiveness of the recommended advice was unable to be evaluated; this was to some extent mitigated by the interview assessments of the satisfaction of the young adults with their support, which in any event provides an evaluation of the effectiveness of the support.

Future research

Further research is needed to validate the clinical profiles described in this study, in order to explore the possible existence of other clinical profiles, and to relate these profiles to support programs. It would be interesting to study a larger group of individuals with MBID located in other areas of the Netherlands and from all age groups from childhood to young adulthood. Further research is also required into other characteristics present in the history that can contribute to the further discrimination of the clinical profiles. Future studies should take into account factors such as impulse control, control of emotions (Van Nieuwenhuijzen et al., 2009), reinforcement of negative behaviours (Embregts, Didden, Schreuder et al., 2009), abnormal neurological functioning and sensory or motor impairments (Dykens et al., 2001), as these are important factors involved in the functioning of individuals with MBID and developmental disorders.

This area of study would benefit from a study of the effectiveness of the two support programs for young adults with MBID and personality disorders that were distinguished in this study. An evaluation could be made in terms of quality of life, and also in terms of the frequency and intensity of behavioural problems and risk taking behaviour. Moreover, an increased understanding of the discrepancies found between the recommended and provided support for young adults with MBID, may provide an insight into the limiting factors involved in the provision of support and help in developing a strategy for overcoming them.

Additional research is required to determine which post-educational path (e.g., continued education, employment or day care) and which employment environments (first-level strategy) are most appropriate to the functional profile of the clinical groups distinguished.

Although the evidence concerning different types of psychological treatments for young adults with MBID was not the focus of this study, further research in this domain is necessary (Campbell et al., 2014; Kok et al., 2016). It is therefore recommended that further research should take into account the different clinical groups here distinguished in the population of young adults with MBID.

In the Netherlands, the method of "Digicontact" was developed. With Digicontact, individuals with ID can ask for support "24/7" by digital communication means. This could also be a valuable, additional way to support individuals with MBID who live in the community. Future research should focus on the effectiveness of this method for the clinical profiles here differentiated. Further research into E-health programs should also be performed, in order to determine whether these programs, additional to face-to-face contact with a psychotherapist, are effective in the treatment of mental health problems in young adults with MBID.

APPENDIX A

Table 2.5

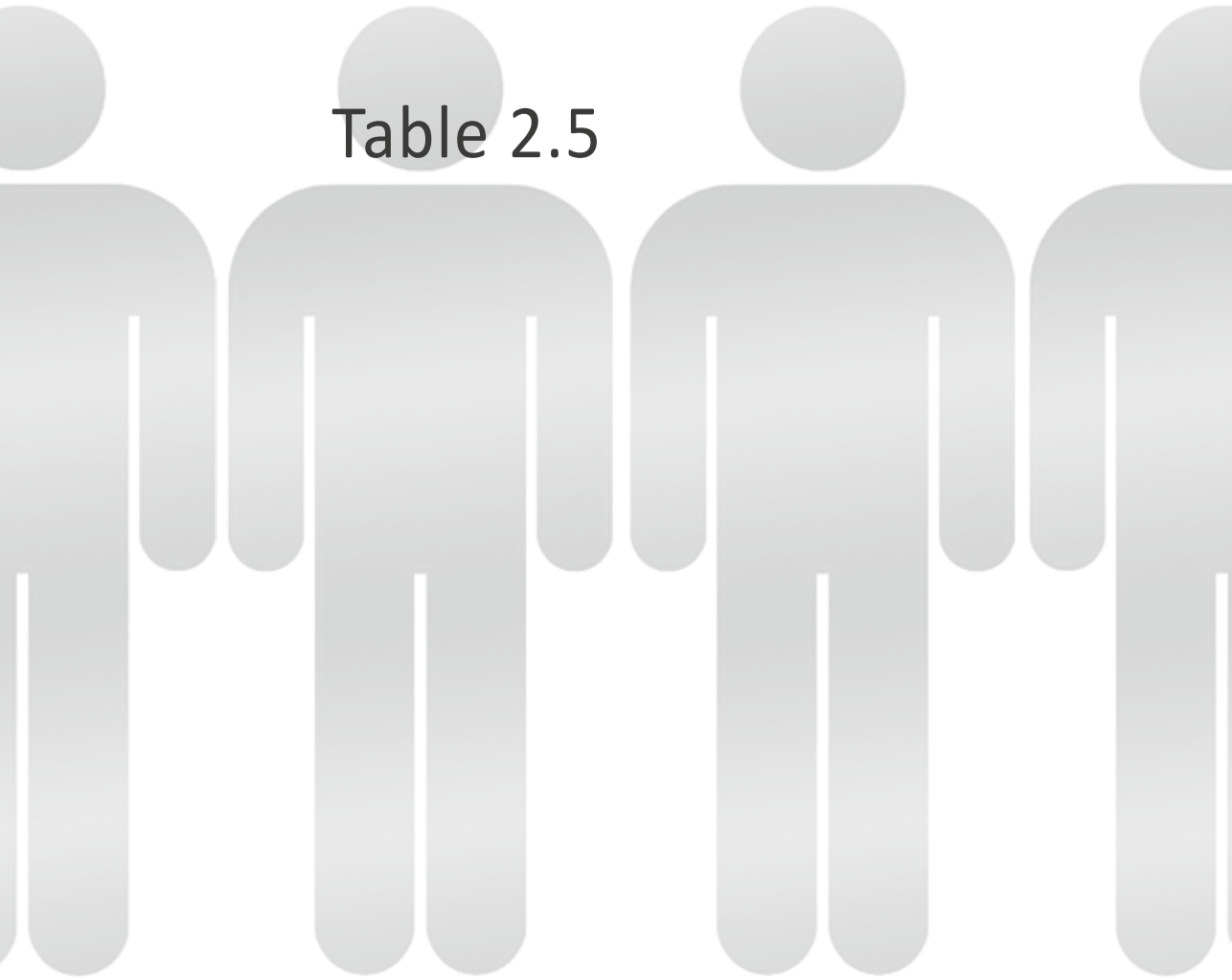


Table 2.5 *Percentage of participants with a positive score for the domains of the DISCO*

DISCO items	Cluster 1 (n=25)		Cluster 2 (n=20)		Cluster 3 (n=16)		Cluster 4 (n=12)		Group difference	
Domain disruptive behavior	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	χ^2	**p**
Wandering	56	14	15	3	12.5	2	66.7	8	16.678	0.001*
Destructiveness	40	10	35	7	18.8	3	75	9	9.363	0.025
Noisiness	76	19	45	9	43.8	7	83.3	10	9.077	0.028
Temper tantrums	84	21	55	11	37.5	6	100	12	17.115	0.001*
Physical aggression	68	17	50	10	12.5	2	83.3	10	17.312	0.001*
Anger towards parents	76	19	25	5	37.5	6	83.3	10	20.301	0.000*
Blaming other people	88	22	55	11	31.3	5	58.3	7	15.947	0.001*
Harassment of others	56	14	25	5	37.5	6	75	9	9.978	0.019
Behavior in public places	28	7	30	6	6.3	1	75	9	15.412	0.001*
Personal modesty	60	15	25	5	18.8	3	66.7	8	12.203	0.007
Psychological barriers	56	14	30	6	25	4	66.7	8	7.904	0.048
Approaching strangers	40	10	60	12	6.3	1	75	9	16.186	0.001*
Embarrassing remarks in public	56	14	40	8	25	4	58.3	7	0.440	0.092
Interrupting conversations	88	22	90	18	25	4	91.7	11	25.891[a]	0.000*
Inappropriate response to emotions	56	14	50	10	37.5	6	83.3	10	6.078	0.108
Difficult personal habit	52	13	35	7	12.5	2	75	9	12.466	0.006
Scatters or throws objects around	44	11	60	12	31.3	5	75	9	6.398	0.094
Lack of co-operation	64	16	50	10	43.8	7	91.7	11	7.790	0.051
Needs constant supervision	60	15	55	11	31.3	5	100	12	13.565	0.004

Table 2.5 Percentage of participants with a positive score for the domains of the DISCO

Apparently manipulative behavior	83.3	20	36.8	7	12.5	2	50	6	20.973	0.000*
Demands caretaker's attention	76	19	75	15	43.8	7	75	9	5.820	0.121
Difficulties with other people	72	18	65	13	43.8	7	81.8	9	5.646	0.130
Socially shocking behavior	32	8	15	3	12.5	2	75	9	14.195	0.002
Lying, cheating, stealing	68	17	45	9	37.5	6	50	6	4.891	0.180
Clinging to objects	20	5	35	7	25	4	41.7	5	2.402	0.124
Collecting objects	28	7	60	12	31.3	5	50	6	5.640ª	0.125
Fascination with specific objects	4	1	55	11	12.5	3	66.7	8	24.270ª	0.000*
Arranging objects	16	4	35	7	6.3	1	58.3	7	11.163ª	0.008
Interest in parts of objects	4	1	15	3	0	0	50	6	13.848ª	0.001*
Elaborate repetitive actions with objects	0	0	15	3	0	0	33.3	4	10.577ª	0.003
Abstract properties of objects	0	0	5	1	6.3	1	8.3	1	2.576ª	0.448
Maintenance of sameness of environment	52	13	45	9	18.8	3	66.7	8	7.218	0.065
Insistence on perfection	32	8	30	6	18.8	3	41.7	5	1.832ª	0.625
Eats only a small range of foods	12	3	10	2	18.8	3	16.7	2	0.010ª	0.874
Maintenance of sameness in routines	44	11	35	7	12.5	2	91.7	11	18.250	0.000*
Clinging to home or familiar places	28	7	30	6	43.8	7	50	6	2.452	0.484
Repetitive questions	40	10	70	14	6.3	1	91.7	11	24.774	0.000*
Repetitive themes	56	14	80	16	25	4	83.3	10	14.420	0.002
Activities related to special skills	4.0	1	20	4	6.3	1	41.7	5	8.970ª	0.017
Collecting facts on specific subjects	20	5	25	5	12.5	2	8.3	1	1.466ª	0.674
Fascination with TV/videos	16	4	40	8	18.8	3	41.7	5	4.970ª	0.174
Intense interest in a person	32	8	40	8	12.5	2	58.3	7	6.704	0.082

Table 2.5 *Percentage of participants with a positive score for the domains of the DISCO (continued)*

DISCO items	Cluster 1 (n=25)		Cluster 2 (n=20)		Cluster 3 (n=16)		Cluster 4 (n=12)		Group difference	
Domain responses to sensory stimuli	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	χ^2	**P**
Smearing	4	1	10	2	0	0	25	3	5.244[a]	0.090
Mouthing or swallowing of objects	4	1	5	1	0	0	25	3	5.394[a]	0.064
Self injury	28	7	20	4	0	0	50	6	10.499[a]	0.011
Self stimulation without injury	12	3	5	1	0	0	8.3	1	2.270[a]	0.538
Smelling objects or people	4	1	20	4	0	0	41.7	5	11.417[a]	0.003
Touching objects	0	0	20	4	0	0	50	6	17.329[a]	0.000*
Scratching and tapping surfaces	0	0	10	2	0	0	41.7	5	13.221[a]	0.000*
Repetitive destructive activities	20	5	25	5	0	0	50	6	10.287[a]	0.011
Repetitive, aimless manipulation of objects	8	2	5	1	0	0	58.3	7	17.272[a]	0.000*
Being spun around	0	0	10	2	0	0	41.7	5	13.230[a]	0.000*
Indifference to pain, heat, cold	28	7	45	9	12.5	2	58.3	7	7.912	0.048
Reaction to gentle touch	28	7	30	6	25	4	41.7	5	0.931[a]	0.861
Reaction to firm touch	28	7	30	6	31.3	5	41.7	5	0.777[a]	0.902
Overbreathing	0	0	5	1	18.8	3	8.3	1	5.108[a]	0.099
Distress caused by sounds	20	5	20	4	6.3	1	75	9	16.400[a]	0.001*
Fascination with sounds	8	2	30	6	0	0	33.3	4	9.398[a]	0.016
Acuteness of hearing	20	5	30	6	12.5	2	58.3	7	7.538[a]	0.050

Table 2.5 Percentage of participants with a positive score for the domains of the DISCO

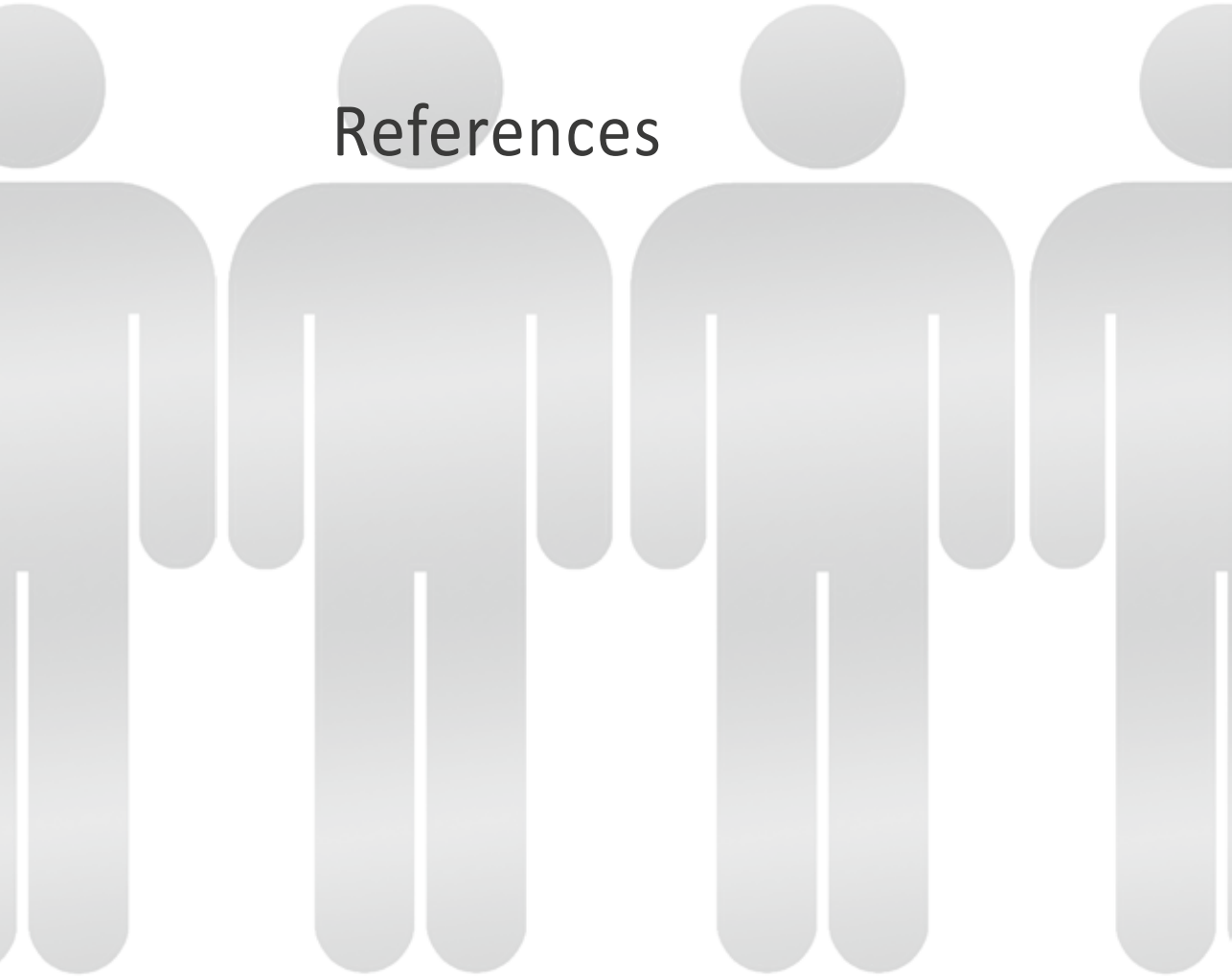
Bright lights and shiny objects	4	1	20	4	6.3	1	41.7	5	8.970ª	0.17
Interest in watching things spin	0	0	10	2	6.3	1	33.3	4	8.615ª	0.011
Twisting hands or objects near eyes	0	0	0	0	0	0	16.7	2	5.549ª	0.025
Interest in studying objects from different angles	0	0	5	1	6.3	1	25	3	6.287ª	0.034

ª Fisher exact test

*Significance level: $p \leq 0.001$

APPENDIX B

References



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APPENDIX C

Nederlandse samenvatting (Dutch summary)

Inleiding

Mensen met een lichte verstandelijke beperking of zwakbegaafdheid (LVB) hebben lichte cognitieve beperkingen. Ze hebben moeite met abstract denken en het oplossen van problemen. In het leven van alledag ondervinden ze moeilijkheden met de sociale interactie, het sociaal oordeelsvermogen, en de besluitvorming. Hoewel de cognitieve beperkingen licht zijn, kan de behoefte aan ondersteuning groot en complex zijn, vaak van vergelijkbaar niveau als van mensen met een matige tot ernstige verstandelijke beperking. Personen met een LVB hebben naast leerproblemen vaak ook gedragsproblemen en psychiatrische stoornissen; ze hebben moeite met maatschappelijk participeren, zoals het verkrijgen en behouden van werk. Door deze diversiteit aan problemen doen personen met een LVB een beroep op uiteenlopende hulpverleningsvoorzieningen, zoals de jeugdhulpverlening, de psychiatrie en forensische instanties. Daarbij worden ze meestal verwezen op basis van hun meest in het oog springende tekort. De integratieve beeldvorming van het functioneren, die voor een passende verwijzing nodig is, ontbreekt veelal. Dit leidt tot opeenvolgende doorverwijzingen, waarbij ze vaak niet de ondersteuning krijgen die nodig is. Personen met een LVB bevinden zich hierdoor dikwijls in een soort niemandsland.

Het onderzoek

Deze studie beoogt een geïntegreerd beeld te vormen van de LVB doelgroep, van de zorg die ze krijgen en de zorg die ze daadwerkelijk nodig hebben. Hiertoe is de complexiteit van de problematiek van personen met een LVB onderzocht, evenals de geïndiceerde en de verstrekte hulp. De volgende drie studies zijn uitgevoerd:

- In studie 1 is onderzocht of de complexe problematiek van personen met een LVB herleidbaar is tot een aantal typerende profielen van functioneren (hoofdstuk 2);
- In studie 2 is nagegaan of deze typerende profielen ook onderscheiden kunnen worden op basis van gedrags-, sociale, pedagogische en hulpverleningskenmerken in de voorgeschiedenis van deze mensen (hoofdstuk 3);
- In studie 3 is bekeken of deze typologie te koppelen is aan bepaalde vormen van geïndiceerde hulpverlening. Vervolgens is in kaart gebracht of deze hulp ook daadwerkelijk aangeboden is, en of de personen met LVB tevreden zijn met de hulp die ze krijgen. Tevens is nagegaan welke begeleidingswensen bij hen leven.

Aan de studie hebben bij aanvang 73 individuen met LVB deelgenomen, die in de periode 2002-2005 verwezen waren naar vijf zorginstellingen voor mensen met LVB in de provincie Zuid-Holland. Deze individuen (n=73) zijn voor de eerste studie door de onderzoekers uitgebreid diagnostisch onderzocht waarbij onder andere het intellectueel en adaptief functioneren, en de gedragsproblemen en DSM-IV-TR classificaties in kaart zijn gebracht (hoofdstuk 2). In het kader van de tweede studie is een ontwikkelingsanamnese afgenomen bij de individuen met LVB die nog contact

hadden met hun ouders (n=56) en is een uitgebreid dossieronderzoek uitgevoerd (n=72) (hoofdstuk 3). Voor de derde studie (n=36) is een vragenlijst ingevuld met betrekking tot kenmerken van de geadviseerde en daadwerkelijk ontvangen ondersteuning. Tevens werd een gestructureerd interview afgenomen van de individuen met LVB om gegevens te verzamelen over de ontvangen begeleidingsstijl en therapieën, en over hun tevredenheid met de daadwerkelijk ontvangen ondersteuning. Alle individuen en/of hun ouders zijn gevraagd om toestemming voor deelname aan het onderzoek.

Resultaten

In de eerste studie (hoofdstuk 2) hebben we onderzocht of er typerende klinische profielen te onderscheiden zijn onder mensen met een LVB op basis van drie dimensies: het intellectueel functioneren, het adaptief functioneren en de gezondheid in termen van gedragsproblemen en DSM-IV-TR-classificaties. Er werden vier klinische profielen gevonden. Profielen 1 en 3 werden gekenmerkt door een gemiddeld intellectueel functioneren op zwakbegaafd niveau, terwijl het gemiddelde adaptief functioneren op licht verstandelijk beperkt niveau lag. Bij beide profielen was sprake van persoonlijkheidsproblematiek. Daarnaast kampten de personen met profiel 1 met externaliserende gedragsproblemen zoals het beschuldigen van en fysieke agressie tegen anderen, terwijl de personen met profiel 3 internaliserende gedragsproblemen hadden, zoals depressies en angsten. De profielen 2 en 4 werden gekenmerkt door een gemiddeld intellectueel functioneren op licht verstandelijk beperkt niveau, terwijl het gemiddelde niveau van adaptief functioneren op matig verstandelijk beperkt niveau lag. Het niveau van adaptief functioneren van profiel 4 lag zelfs nog lager dan dat van profiel 2. Bij beide profielen was sprake van ontwikkelingsstoornissen zoals autismespectrumstoornissen en ADHD. De personen met profiel 2 hadden internaliserende gedragsproblemen, zoals het zich vasthouden aan herhalende routines en afwijkende reacties op sensorische prikkels. Degenen met profiel 4 daarentegen hadden externaliserende gedragsproblemen, zoals inadequaat gedrag in openbare ruimtes en het inadequaat benaderen van vreemden.

In de tweede studie (hoofdstuk 3) hebben we onderzocht of de vier, bij de eerste studie gevonden, profielen ook te onderscheiden zijn op basis van risicofactoren in de voorgeschiedenis, namelijk gedragsmatige, pedagogische, sociale, en hulpverleningskenmerken. We vonden ten eerste dat personen met profielen 1 of 3 (LVB met het accent op persoonlijkheidsproblematiek) een andere hulpverleningsgeschiedenis hadden dat mensen met profielen 2 of 4 (LVB met accent op ontwikkelingsstoornissen). Ze waren bijvoorbeeld ouder bij het eerste contact met een hulpverleningsinstantie, ze werden in de adolescentie vaker doorverwezen naar residentiele jeugdzorg dan naar residentiele zorg voor mensen met een verstandelijke beperking, en ze woonden vaker begeleid zelfstandig. De mensen met LVB en profielen 2 en 4 hadden vaker afwijkende gedragingen gedurende de eerste twee levensjaren en volgden vaker ZMLK- dan MLK-onderwijs in vergelijking met mensen met LVB en profielen 1 en 3.

Ten tweede vonden we dat er bij de personen met profiel 1 in vergelijking met alle andere profielen vaker sprake was van afwijkende seksuele gedragingen, fysieke mishandeling en een familiegeschiedenis met psychiatrische problematiek. Ze maakten ook vaker dan de anderen het MLK-onderwijs af. Voor de personen met profielen 2 en 4 vonden we geen verschillen in de voorgeschiedenis.

Nadat we middels de eerste en tweede studie meer zicht hadden gekregen op vier typerende profielen van personen met een LVB, gingen we na of deze vier profielen gekoppeld zijn aan een verschillend, specifiek hulpaanbod. Helaas hadden we te weinig gegevens om iets te kunnen zeggen over profielen 2 en 4. Daarom hebben we ons in de derde studie gericht op profielen 1 en 3: LVB met persoonlijkheidsproblematiek (hoofdstuk 4). Naar voren kwam dat de personen met klinische profielen 1 en 3 zijn aangewezen op een verschillende woonvorm en begeleidingsstijl. Personen met klinisch profiel 1 hadden vooral een indicatie voor een vorm van “gemeenschappelijk, begeleid zelfstandig wonen” . Dit zijn geschakelde appartementen met een centrale ondersteunings- en ontmoetingsplek. Tevens was doorgaans een structurerende en regulerende begeleidingsstijl geïndiceerd, evenals psychotherapie. De personen met LVB en klinisch profiel 3 kregen als begeleidingsadvies “alleen begeleid zelfstandig wonen”, waarbij zij in de buurt toegang hebben tot een inloophuis. Tevens zouden zij middels een sociale vaardigheidstraining verder worden geholpen. Beide profielen kenden ook gemeenschappelijke hulpverleningskenmerken. Alle personen hebben ondersteuning nodig en uitleg over hun sterke en zwakke kanten in hun functioneren. Ze behoeven ook regelmatig een beschermende begeleidingsstijl. Tevens zijn ze allen aangewezen op een reguliere werkplek met hulp van een jobcoach.

Waar de vorige studies zich richtten op typerende profielen en het daarbij voorgestelde hulpverleningsaanbod, wilden we in het tweede deel van de derde studie uitzoeken of de mensen met LVB en persoonlijkheidsproblematiek (profielen 1 en 3) ook de ondersteuning kregen die was geïndiceerd. Ook wilden we weten of ze tevreden waren met de aangeboden ondersteuning. Het doel was om zicht te krijgen op eventuele ondersteuningsbehoeften waar niet aan tegemoet gekomen werd (hoofdstuk 4). We vonden voor de personen met beide profielen dat de hulpverleningsinstanties zich niet genoeg focusten op de woon- en werkomgeving. Veel mensen met LVB en klinisch profiel 1, en een kleiner deel maar nog steeds relatief veel van de mensen met LVB en profiel 3, woonde nog in een traditionele groepswoning. Dit was in tegenstelling tot het advies waarin meer zelfstandige woonvormen werden geadviseerd. De begeleidingsstijlen daarentegen, waren over het algemeen wel conform het advies. Zoals enigszins verwacht kon worden, gaven de individuen met klinisch profiel 1 aan meer ondersteuning te willen met het zoeken naar een geschikte woning. De individuen met klinische profiel 3 wilden vooral meer praktische ondersteuning bij de dagelijkse activiteiten krijgen. Aan de therapeutische behoeften werd over het algemeen voldoende tegemoet gekomen. Wat betreft de werkomgeving kwam naar voren dat het vinden en behouden van werk in een reguliere werkomgeving moeilijk was voor alle individuen met LVB

en persoonlijkheidsproblematiek. Dit resultaat week af van de indicatie dat een groot deel van deze mensen een reguliere werkplek aan zou moeten kunnen op voorwaarde dat er hulp is van een jobcoach. De mensen met LVB met profiel 1 (externaliserende gedragsproblemen) wilden vooral een meer regulerende begeleidingsstijl (o.a. ondersteuning bij interactie met collega's), terwijl de mensen met klinisch profiel 3 (internaliserende gedragsproblemen) vooral ondersteuning wilden hebben bij het zoeken naar werk en bij het solliciteren.

Conclusies en aanbevelingen

In dit proefschrift hebben we de complexiteit van de problemen van mensen met LVB kunnen reduceren tot vier typerende, klinische profielen. Twee klinische profielen werden gekenmerkt door LVB en persoonlijkheidsproblematiek (met externaliserende of internaliserende gedragsproblemen), terwijl bij de andere twee klinische profielen sprake was van LVB en ontwikkelingsstoornissen (met externaliserende en internaliserende problematiek). Hun hulpverleningsgeschiedenis zag er anders uit, en ze hadden deels te maken gehad met verschillende gedragsmatige, sociale en pedagogische risicofactoren. De hulpverlening voor de mensen met de profielen "LVB en persoonlijkheidsproblematiek" bleek in vergelijking met de geïndiceerde hulp te kort te schieten wat betreft het organiseren van geschikte woon- en werkplekken. Deze mensen woonden nog vaak in traditionele vormen van groepswonen, terwijl ze zelfstandigere vormen van wonen zouden aankunnen. Tevens hadden velen geen reguliere werkplek en/of ontbrak het hen aan een jobcoach. Het aanbieden van een specifieke begeleidingsstijl ging relatief goed bij het wonen, en ook aan hun therapeutische behoeften werd tegemoet gekomen. Dit was niet het geval op de werkplek. Samengevat mogen we aannemen dat deze mensen met LVB en persoonlijkheidsproblematiek volgens hun indicaties zelfstandiger kunnen wonen, en dat velen tevens een reguliere werkplek aankunnen, als de sociale omgeving en de begeleidingsstijl beter is afgestemd op hun klinische profiel van functioneren, al zal dit in een vervolgstudie nog nader onderzocht moeten worden. Het beschrijven van deze klinische profielen is belangrijk gebleken om te komen tot een nauwkeurige, integratief beeld van de zeer complexe LVB-populatie, en een alomvattende beschrijving van de ondersteuningsbehoeften.

In hoofdstuk 5 worden de klinische implicaties van het onderzoek uitgebreid beschreven. De belangrijkste aanbeveling ten aanzien van de diagnostiek, de geïntegreerde beeldvorming, is om na te gaan hoe de persoon met LVB te typeren is in termen van zijn typerende klinisch profiel van functioneren. Dit kan middels de afname van de WISC-III of de WAIS-III, de VABS, de DISCO, en een vragenlijst met specifieke risicofactoren uit de klinische voorgeschiedenis. Vervolgens kan een bijpassend diagnostisch vervolgtraject in gang worden gezet. Voor de klinische profielen met "LVB en persoonlijkheidsproblematiek" zal de vervolgdiagnostiek zich moeten richten op de persoonlijkheidsorganisatie, de relationele attitudes en de sociale omgeving. Tevens zal nagegaan moeten worden in

welke mate de betreffende personen stressvolle gebeurtenissen hebben meegemaakt waar zij mogelijk nog onder lijden. De meeste instrumenten die gebruikt worden voor mensen met een gemiddeld of hoger IQ, kunnen ook voor deze personen worden gebruikt. Voor de klinische profielen met “LVB en ontwikkelingsstoornissen” zal er naast het beschrijven van de biologische en neuropsychologische aspecten van het individu, ook aandacht moeten zijn voor het niveau van persoonlijkheidsontwikkeling dat een rol speelt bij het adaptief functioneren en de aanwezige gedragsproblemen. Specifieke, diagnostische instrumenten zijn daarbij nodig, zoals de SEO.

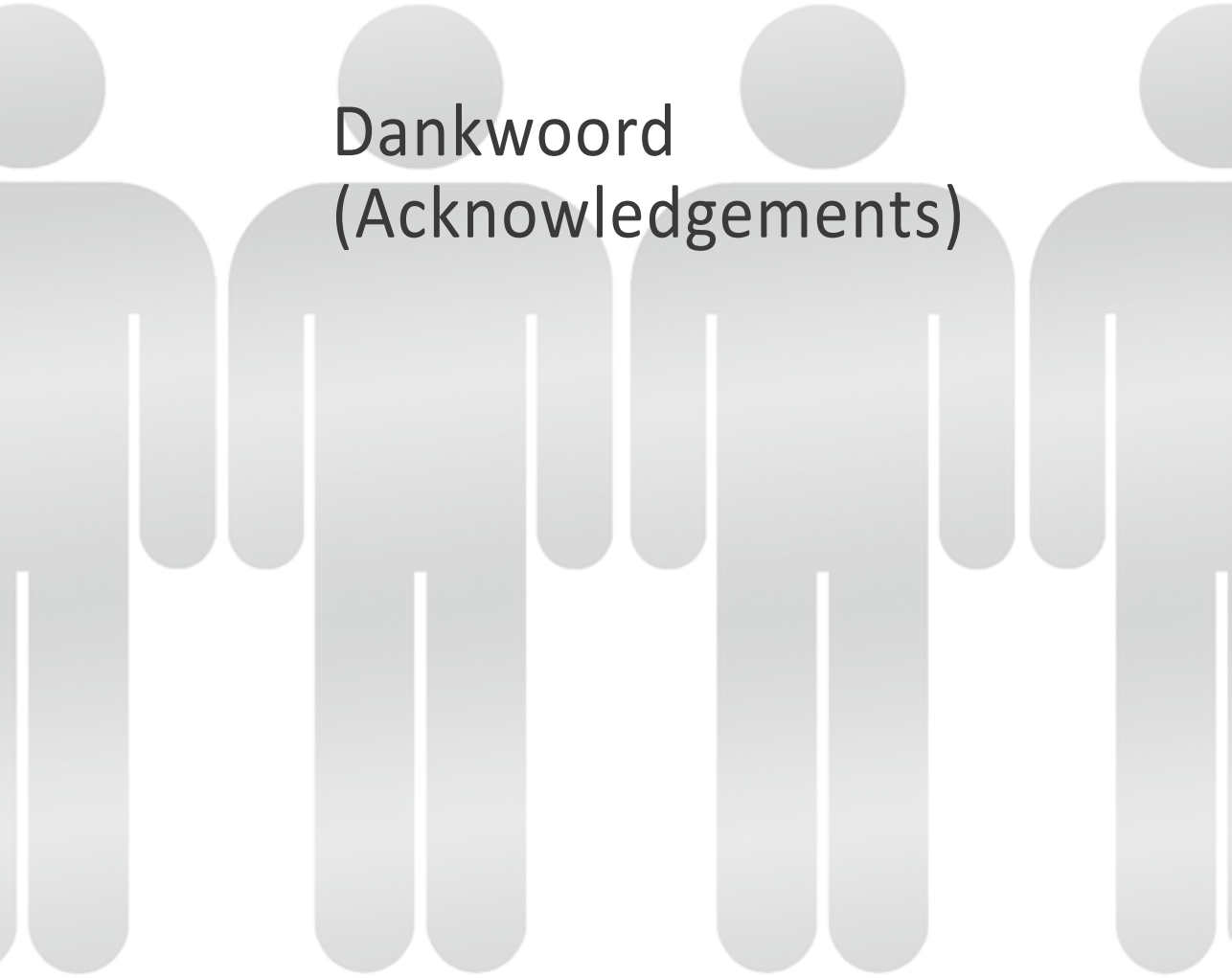
De belangrijkste aanbeveling ten aanzien van de ondersteuning is een voorstel voor een continuüm van zelfstandige woonvormen, met aandacht voor de kenmerken van de sociale omgeving en waarbinnen ook specialistische begeleidingsstijlen kunnen worden georganiseerd. Tevens is aandacht nodig voor het feit dat mensen met LVB die goed begeleid zelfstandig kunnen wonen, meer ondersteuning willen met praktische, dagelijkse vaardigheden dan hetgeen ze krijgen aangeboden (hoofdstuk 4). Op vlak van werken zal er nog een richtlijn opgesteld moeten worden, waarin de werkomgevingen, de nodige begeleidingsstijlen en de behoefte aan aanvullende ondersteuning voor de verschillende klinische profielen worden beschreven. Alle personen met LVB en persoonlijkheidsproblematiek zouden volgens hun indicatie in een reguliere werkplek moeten kunnen werken, met hulp van een jobcoach. Voor de ene persoon zal de focus moeten liggen op ondersteuning bij de interactie met collega’s, terwijl dit voor de ander meer op de uitvoering van de taken zal liggen.

Er worden in hoofdstuk 5 ook nog een aantal aanbevelingen gegeven ten aanzien van het trainen en coachen van begeleiders en aandacht gevraagd voor de risico’s die deze cliënten lopen wanneer zij meer zelfstandig gaan wonen, voor het belang van behandeling voor kinderen met LVB en ontwikkelingsstoornissen en het meer inzetten van moderne internet gerelateerde methodes zoals “Digicontact” en “E-health”. Tevens wordt benadrukt dat de beschreven gespecialiseerde ondersteuningsprogramma’s in de praktijk wellicht beter door specifieke zorgaanbieders kunnen worden uitgevoerd, in plaats van dat alle zorgaanbieders alle zorgprogramma’s voor deze personen proberen aan te bieden.

Tot slot hebben we in hoofdstuk 5 aandacht gegeven aan de sterktes en beperkingen van de studies, en hebben we aanbevelingen gedaan voor toekomstig onderzoek.

APPENDIX D

Dankwoord (Acknowledgements)



Het schrijven van dit proefschrift was niet mogelijk geweest zonder de medewerking en steun van velen. Ik ben hen allen daarom dank verschuldigd. Een aantal van hen wil ik hier in het bijzonder noemen.

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Daarnaast ben ik dank verschuldigd aan de medewerkers en stagiaires van de onderzoeksgroep 'Ontwikkelingsstoornissen' van de sectie Orthopedagogiek, Universiteit Leiden voor hun hulp, steun en de boeiende gesprekken over het onderzoek. In het bijzonder wil ik Yvette Dijkxhoorn bedanken voor haar inhoudelijke expertise ten aanzien van de diagnostische onderzoeken van de cliënten.

Ik wil ook Curium-LUMC bedanken, in de persoon van Bart Siebelink, omdat ik verder kon werken aan mijn proefschrift tijdens de uren praktijkonderzoek van de opleiding tot klinisch psycholoog.

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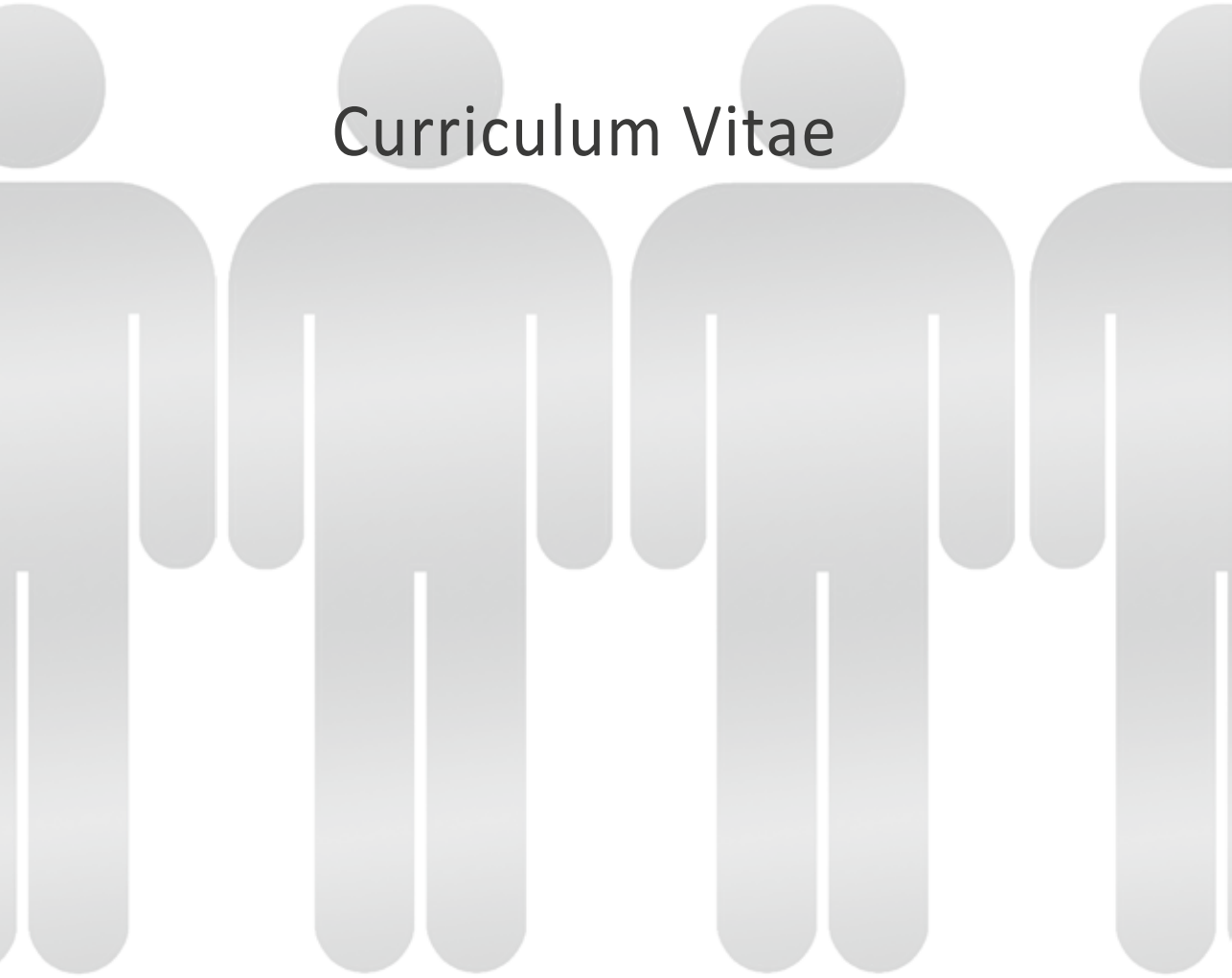
Tot slot, last but not least, mijn lieve partner Erik! Erik, hoewel je me ook voor gek hebt verklaard, ben je me blijven steunen. In de tussentijd hebben wij ook samen twee prachtige dochters gekregen, Sofia en Anna, hetgeen ons leven heeft verrijkt. Bedankt voor de energie en de liefde die ik van jullie krijg!

APPENDIX E

Curriculum Vitae



Sarah Soenen was born on the 7th of February 1977 in Bruges, Belgium. She finished high school in 1995 and subsequently attended the Catholic University of Leuven, Belgium. She studied Orthopedagogics and simultaneously finished her academic teacher education; she obtained both degrees cum laude in 2000. During her study, she did her traineeship in Leiden at the Ambulatorium as part of the Erasmus exchange program. The Ambulatorium is an outpatient clinic at the Faculty for Social Studies of the University of Leiden, which offers help to families with various problems in upbringing and the development of children. After a work experience placement with children with developmental disorders in Curacao for half a year, in 2001 she was appointed as a junior researcher in the department of Orthopedagogics of the University of Leiden and was trained as a psychological diagnostician at the Ambulatorium. In 2006 she left the university to start working at Zonnehuizen in Zeist, a centre for child and adolescent psychiatry for people with and without intellectual disability. She relocated in this position to The Hague in 2008. During this period she was also educated to be a 'GZ-psychologist' and a cognitive behavioural therapist. In 2011 she started her training as clinical psychologist (specialist) at Curium-LUMC, an academic centre for child and youth psychiatry in Oegstgeest. After graduating as a clinical psychologist in 2014, she combined the completion of her PhD-thesis with clinical work as a clinical psychologist / psychotherapist in her own outpatient practice, where she currently still works. She is also supervising 'GZ-psychologists' in training. Starting in 2001 she has also been working as an independent case manager and consultant for the Centre for Consultation and Expertise (CCE). The CCE is a supplementary service to standard healthcare services, which focuses on all clients in need of exceptional care who already receive long-term care.

Sarah Soenen is geboren op 7 februari 1977 in Brugge, België. Ze beëindigde de middelbare school in 1995 en begon daarop haar studie aan de Katholieke Universiteit van Leuven, België. Ze studeerde Orthopedagogische wetenschappen en volgde tegelijkertijd de academische lerarenopleiding. Ze behaalde in 2000 beide diploma's met grote onderscheiding. Tijdens haar studie liep ze, in het kader van het Erasmus uitwisselingsprogramma, een klinische stage bij het Ambulatorium. Het Ambulatorium is een polikliniek waar hulp geboden kan worden aan gezinnen bij allerlei problemen in de opvoeding en de ontwikkeling van kinderen, verbonden aan de Faculteit der Sociale Wetenschappen van de Universiteit van Leiden. Na een werkervaringsplaats van zes maanden op Curaçao in instellingen voor kinderen met ontwikkelingsstoornissen, werd ze aangesteld als junior onderzoeker bij de vakgroep Orthopedagogiek (Universiteit Leiden) en bij het Ambulatorium als diagnosticus in opleiding. In 2006 verliet ze de universiteit en maakte ze de stap naar de Zonnehuizen te Zeist, een centrum voor kinder- en jeugdpsychiatrie voor kinderen en jongeren, al dan niet met een verstandelijke beperking. Ze werd in 2008 binnen dezelfde setting naar Den Haag overgeplaatst. Tijdens deze periode volgde ze ook de opleidingen tot GZ-psycholoog en cognitief gedagstherapeut. In 2011 begon ze met de specialistische opleiding tot klinisch psycholoog bij Curium-LUMC, een academisch centrum voor kinder- en jeugdpsychiatrie te Oegstgeest. Na de afronding van de KP-opleiding in 2014, combineerde ze het afmaken van haar doctoraat met klinisch werk in haar eigen praktijk, waar ze tot op heden werkzaam is. Ze geeft tevens supervisie aan psychologen in opleiding tot GZ-psycholoog. Sinds 2001 is ze ook werkzaam als een onafhankelijke casemanager en consulent voor het Centrum voor Consultatie en Expertise (CCE), een aanvullende dienst aan reguliere gezondheidszorg, die zich focust op cliënten met een bijzondere zorgvraag in de langdurige zorg.