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In plain sight but still invisible: A structured case analysis of people with mild intellectual disability or borderline intellectual functioning

Peter J. G. Nouwens, Rosanne Lucas, Petri J. C. M. Embregts, and Chijs van Nieuwenhuizen

ABSTRACT
Background: There has been substantial increase in the number of people with mild intellectual disability (MID) or borderline intellectual functioning referred to long-term care. Insight into the specific characteristics and needs of these people is essential to provide appropriate support and gain insight into the increase in referrals.

Method: This retrospective descriptive study was based on a structured case analysis of a sample of 250 participants.

Results: Mental health problems and exposure to social and familial disadvantages were common. Care provided before referral tended to be suboptimal. Individuals with borderline intellectual functioning had more personal and contextual problems than people with MID.

Conclusion: People with MID or borderline intellectual functioning are confronted with a wide range of complex problems; even after years of professional support they may still need intensive support. Differences in the characteristics and contexts between individuals with MID or borderline intellectual functioning require further exploration.

Introduction
In the Netherlands, there has been a substantial increase in the number of people with mild intellectual disability (MID) or borderline intellectual functioning who are entitled to specialist long-term inpatient or outpatient care for people with an intellectual disability (ID). Between 2007 and 2011 the demand for support increased by 7.1% for people with MID and by 14.9% for people with borderline intellectual functioning (Ras, Verbeek-Oudijk, & Eggink, 2013). This rate is 14–30 times greater than the demand among people with moderate or severe intellectual disability (Ras et al., 2013). Possible causes for this growth are (a) the complexity of current society, which complicates social participation of people with MID or borderline intellectual functioning; (b) the absence of social support networks; and (c) wider access to mental health care (Woittiez, Putman, Eggink, & Ras, 2014). However, these are only hypotheses and our current understanding of MID and borderline intellectual functioning is insufficient to explain the substantial growth of support needs. Therefore, more insight into the characteristics of people with MID and borderline intellectual functioning and the context in which they live is required to organise appropriate support for these two groups.

In the healthcare systems of the Netherlands, a distinction is made between people with MID and people with borderline intellectual functioning. According to the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association [APA], 2000), an intelligent quotient (IQ) score between 50 and 70 indicates a mild intellectual disability. However, in the Netherlands attention is shifting from IQ level towards the support needs of an individual person (de Bildt, Sytema, Kraijer, Sparrow, & Minderaa, 2005). Therefore, people with an IQ score of 70–85 and problems in their social adaptability, described as borderline intellectual functioning, also have access to health care for people with an intellectual disability (ID; Moonen & Verstegen, 2006). Besides healthcare provision for people with ID, people with MID or borderline intellectual functioning have access to other service systems in the Netherlands, for instance, youth services, criminal justice systems (Bonta, Blais, & Wilson, 2014; Court of Audit, 2007; Douma, Dekker, de Ruiter, Tick, & Koot, 2007; Herrington, 2009; James...
& Glaze, 2006; Lindsay, 2013), and mental health care (Court of Audit, 2007).

There is evidence that the prevalence of mental health problems is high in people with MID or borderline intellectual functioning (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Dekker & Koot, 2003; Douma, Dekker, Verhulst, & Koot, 2006; Einfeld, Ellis, & Emerson, 2011; Emerson, Einfeld, & Stancilfe, 2010, 2011; Wallander, Dekker, & Koot, 2006). Studies have shown a relationship between child, family, and contextual risk factors and mental health problems (Dekker & Koot, 2003; Emerson, Einfeld, & Stancilfe, 2011; Emerson, Shahtahmasebi, Lancaster, & Berridge, 2010; Wallander et al., 2006). For instance, Douma et al. (2006) reported a modest difference between people with MID and borderline intellectual functioning; that is, people with borderline intellectual functioning were more likely to report symptoms of mental health problems than individuals with MID.

Also, compared with typically developing children, people with MID and borderline intellectual functioning seem to experience restrictions in their social life (Freeman & Alkin, 2000). For example, Solish, Perry, and Minnes (2010) found that children with ID less often participated in social and leisure activities and had fewer friends than children without ID. Regarding adults, the majority of adults with MID rarely interacts socially with people without ID (Dusseljie, Rijken, Cardol, Curfs, & Groenewegen, 2011). Moreover, Seltzer et al. (2005) reported that people with an IQ score of ≤ 85 completed fewer years of education, had less prestigious occupations, and reported lower levels of psychological wellbeing than siblings with an IQ score of ≥ 100. These findings provide consistent evidence that people with MID or borderline intellectual functioning experience social disadvantages in several areas.

Given the health problems and social disadvantages associated with MID and borderline intellectual functioning, access to effective support and mental health care is very important for these two groups. However, despite acknowledgement of their vulnerability, access to appropriate treatment and support for people with MID and borderline intellectual functioning still seems limited. It is reported that people with MID or borderline intellectual functioning do not always receive appropriate support. For instance, Dekker and Koot (2003) found that less than a third of children with MID and mental health problems were in receipt of mental health care. In addition, there is a lack of evidence-based treatments for social and mental health problems in people with MID and borderline intellectual functioning (van Nieuwenhuijzen, Orobio de Castro, & Matthys, 2006). This lack of treatments may result in a gap between the demand and provision of care for individuals with MID or borderline intellectual functioning, increased risk of maltreatment, misdiagnosis, and/or exposure to ineffective or aversive interventions (Allen et al., 2011). The possibility of failure to provide appropriate mental health services to people with ID is important, because without appropriate support their mental health problems and behavioural problems may become persistent (Dekker & Koot, 2003; Einfield et al., 2006, 2011; Hodapp & Dykens, 2009).

This study aimed to describe the background and characteristics of people with MID and borderline intellectual functioning who are referred to long-term inpatient or outpatient care in the ID sector. Data were collected on the individual and family characteristics of people with MID and borderline intellectual functioning, as well as on the treatment and support that they received. Potential differences between people with MID and people with borderline intellectual functioning were also investigated.

**Method**

A retrospective, descriptive design was used. Data were collected from participants with MID (IQ range: 50–69) or borderline intellectual functioning (IQ range: 70–85). The participants were individuals who had been referred to an organisation that offers long-term inpatient and outpatient care to individuals with ID in the south of the Netherlands.

**Sampling**

Individuals referred to the organisation for long-term patient care and with an IQ score between 50 and 85 were included in this study. The most recent IQ information presented in the file data and established by a certified clinician was used to define the IQ score of each person. The mean time between the most recent IQ data and the time of this study was 4.24 (range: 0–21) years. Excluded were individuals who already received care from the participating organisation and individuals referred for short-term support (e.g., respite care or crisis care) or referred for temporary support because they were waiting for support from another healthcare provider.

**Representativeness of the sample**

Potential participants consisted of 525 individuals with MID or borderline intellectual functioning who were referred to the care provider under investigation between January 2011 and August 2012. From these individuals, a random sample of 250 participants was selected. The representativeness of this sample was checked in two ways.
First, the population who received services from the care provider was compared with the population receiving services from the ID sector in the Netherlands as a whole. The distribution of the various Care Intensity Packages among the clients of this care provider was compared with the distribution in the whole ID sector (Centrum Indicatiestelling Zorg, 2011) using a chi-square test. As no statistically significant difference was found, $\chi^2(7) = 5.29$, $p = .05$, it was concluded that the clients of the care provider in this study were representative of the population receiving care in the ID sector in the Netherlands as a whole.

Second, the representativeness of the sample of 250 respondents was examined a posteriori by comparing the gender, age, and level of development of participants with the initial population of eligible individuals. No significant differences were found, indicating that the participants in the selected sample were representative of the population as a whole.

Procedures

According to the Dutch Act of Agreement on Medical Treatment of 1995 (Civil Code, article 7:458, the Netherlands), access to information about the patient or access to documents without approval of the patient for scientific research is only possible if:

1. The research is in the public interest.
2. The research cannot be conducted without the information in question.
3. The patient in question has not explicitly objected to the possibility that information will be provided for this purpose.

Concerning the retrospective analyses of file data, we used a passive informed consent. To give participants the opportunity to expressly object to the provision of the data, participants were informed about the study by means of a brochure. This brochure provided information about the current study. Also, it was stated that participation in the study was voluntary and that the anonymity of the participants was guaranteed. It was clearly stated to whom the client had to contact when he or she did not want to participate in this study.

Although ethical approval was not necessary, we decided to take several steps regarding the ethical aspects because of the vulnerability of the participants and the level of precision we aimed to achieve. First, the Client Advisory Board of Prisma (i.e., the organisation where the study took place) was informed. On behalf of the Law Engagement Clients in Health Facilities (WMCZ in the Netherlands), the Client Advisory Board looks after the needs of the clients receiving care from Prisma. During one of the meetings between the Client Advisory Board and the researchers involved in this study, the Client Advisory Board stated that this study was relevant and gave permission to conduct this study. Also, we informed the Dutch organisations for the support of people with disability or chronic illnesses, the so-called “MEE-organisations.” These organisations are independently committed to the needs of their clients with disability or chronic illnesses. In a meeting with the MEE-organisations about this study, all acknowledged the importance of this investigation.

To guarantee the anonymity of the participants, data were coded using unique numbers instead of participants’ names. A separate Excel file provided the names of the participants in combination with the unique number for each name. The Excel file was locked with a password that was only known to the first and second author of the article, and the file was stored within a protected environment.

Case files were analysed using a structured case analysis system based on the Signalling List developed by Orobio de Castro, Veerman, Bons, and de Beer (2002) and on studies by Schalock (2004), Embregts (2009), and van Nieuwenhuizen et al. (2011). The case analysis system encompassed eight domains: demographics, level of functioning, family and parenting, life events, neglect and maltreatment, anamnesis, diagnosis and support history, and support needs. DSM-IV-TR Axis I was used to investigate the mental health problems of the sample. DSM-IV-TR Axis I classifications were only scored when they were classified by a certified clinician. Full details of the structured case analysis system are available from the first author.

Case files were analysed by three researchers; the inter-rater agreement was assessed using Cohen’s kappa and percentage interrater agreement. The researchers scored and re-scored case files separately until Cohen’s kappa was $\geq 0.70$, indicating good interrater agreement. Because it is not possible to calculate Cohen’s kappa for continuous variables, these items were re-scored until an interrater agreement of at least 80% was achieved.

Statistical analysis

Statistical analyses were performed using SPSS Version 19. Descriptive analyses of individual characteristics, family characteristics, and treatment and support were conducted. Differences between people with MID and people with borderline intellectual functioning were assessed using chi-square tests with additional binary analyses of the odds ratios (OR). These are types of effect size scores. The calculation of effect sizes has been frequently recommended, since these effect sizes give better insight in differences between groups or in the relation between
variables in comparison with probability values (Dempsey & Balandin, 2012; Dunst & Hamby, 2012). In addition to chi-square tests and ORs, effect size confidence intervals (95% CIs) were calculated in order to indicate the precision of the effect size scores (Dunst & Hamby, 2012).

Results

Individual characteristics

Significantly more male than female participants (60.8% vs. 39.2%) were referred to the care provider, $\chi^2(1) = 245.82, p = .00$. Age of the participants ranged from 3 to 65+ years, with a mean age of 26.1 ($SD = 13.8$) years. The age category with the highest frequency was 11–20 years (39.2%), followed by the categories 21–30 (21.6%), 31–40 (13.6%), 41–50 (10.4%), 51–60 (3.6%), and 61–70 years (2.8%). A significantly higher proportion of participants had borderline intellectual functioning (56.4%) than MID (43.6%), $\chi^2(1) = 245.95, p = .00$. Table 1 shows that participants faced a range of problems; the majority (66%) had difficulties with connection to their peers. More than half the participants with MID or borderline intellectual functioning (59.6%) also met criteria for an Axis I DSM-IV-TR classification (APA, 2000). For most participants (30.8%) the highest education level attained was regular secondary education. The most prevalent DSM-IV-TR classification was pervasive developmental disorder (19.2%). More than a quarter of the participants had serious financial problems and more than a fifth were under special guardianship. A third of the participants did not participate in any daytime activity. More than a fifth of participants had children, and in nearly half of these cases the Child Protection Council was involved. In almost 40% of these cases the child was placed in foster care or institutional residential care.

Family characteristics

Participants also faced a range of family problems (Table 1). In almost half the families at least one parental figure was absent, and in almost half of the families, parents had difficulties with consistent parenting. In addition, almost a third of primary caregivers had mental health problems and about a quarter of the participants were neglected by primary caregivers. The financial status of primary caregivers was often low; nearly one fifth of participants lived in material hardship.

Treatment and support

Analysis of support history indicated that about five different organisations had been involved ($M = 4.8$,
SD = 2.6, range: 0–11) before the participant was referred to the care provider in the present study. The mean age at which most participants first received support was about 18 years (M = 17.7, SD = 14.3, range: 0–66 years). More than a third of the participants had experienced an outplacement in their childhood; mean age at first outplacement was about 12 years (M = 11.3, SD = 5.3, range: 0–22 years) and almost half of these children did not return to their parents. Only a quarter of the participants received informal support, for example, from relatives or friends. About one third of participants used medication at the moment of referral; the most frequently used were antipsychotics, followed by antidepressants, hypnotics, and medication for attention-deficit/hyperactivity disorder. Although more than a fifth of the participants did not meet the criteria for any DSM-IV-TR Axis I classification, they had been prescribed medication.

**Differences between people with MID and people with borderline intellectual functioning**

Table 2 presents significant differences between people with MID and people with borderline intellectual functioning. Individual and family problems were more prevalent in people with borderline intellectual functioning than in those with MID. For example, participants with borderline intellectual functioning were 3.6 times more likely to be confronted with inconsistent parenting than participants with MID. Also, participants with borderline intellectual functioning tended to have a longer support history than participants with MID, t(249) = -2.61, p = .01.

**Discussion**

This study was a systematic investigation of the background and characteristics of people with MID and borderline intellectual functioning who had been referred to specialist long-term inpatient or outpatient care. Case files were analysed using a structured case analysis system. The results illustrate that mental health problems and exposure to social and familial disadvantages were prevalent in this group. The care provided before referral often seemed suboptimal.

A striking finding was that the average age at which people with MID or borderline intellectual functioning first received care from a professional care provider was 18 years. Some participants were only 3 years old when they first had contact with professional care providers, whereas others were aged 65+ years. Generally, the time period before appropriate care is provided to these clients is too long. This remarkable finding is in line with Allen et al. (2011), who concluded that problems are often noticed too late: they have often been present for years before they are recognised and, therefore, are more likely to be resistant to training and treatment. In the present study, it is noteworthy that, although participants had a mean support history of about five different care providers, intensive guidance and support (especially psychosocial support) was still needed. Therefore, we conclude and agree with Allen et al. (2011) that treatment and support often falls below optimal levels.

Mental health problems are reported to be common among people with ID (Cooper et al., 2007). The results of the present study underline this: almost 60% of our sample met the criteria for a DSM-IV-TR Axis I classification. However, the rate of mental health problems in our sample was higher than reported by other studies on mental health problems in people with ID. International studies have reported the prevalence of mental health problems to be 31–50% in children and adolescents with ID (Dekker & Koot, 2003; Dekker, Koot, van der Ende, & Verhulst, 2002; Emerson, 2003; Emerson & Hatton, 2007; Linna et al., 1999; Molteno, Molteno, Finchilescu, & Dawes, 2001; Større & Diseth, 2000). Cooper et al. (2007) concluded that the

<table>
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<th>Table 2. Significant differences between people with MID and borderline intellectual functioning (N = 250).</th>
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<td><strong>Borderline (n = 141)</strong></td>
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<tr>
<td><strong>Individual characteristics</strong></td>
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<tr>
<td>Homelessness</td>
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<tr>
<td>Alcohol/drug abuse</td>
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<td>Prison sentence</td>
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<tr>
<td><strong>Family characteristics</strong></td>
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<tr>
<td>Divorce of parents</td>
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<tr>
<td>Inconsistent parenting</td>
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<tr>
<td>Alcohol/drug abuse of primary caregiver(s)</td>
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<td>DSM-IV-TR classification primary caregiver(s)</td>
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<tr>
<td>Neglect by primary caregiver(s)</td>
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<td><strong>Treatment and support</strong></td>
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<tr>
<td>Treatment and support</td>
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<td>Support history</td>
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* p < .05.
** p < .01.
*** p < .001.
prevalence of mental health problems in adults with ID is 16–41%, and in adults with MID the prevalence is 34.4%. Although the prevalence may vary between countries, this is an important issue. The high percentage of mental problems in children with ID could be the result of family dysfunction (Emerson et al., 2011; Emerson & Hatton, 2007; Wallander et al., 2006). Indeed, the present study strongly suggests that people with MID and borderline intellectual functioning are frequently exposed to a variety of family risk factors. In addition, social isolation is another risk factor for mental health problems in people with ID (Allen et al., 2011). Our study suggests that people with MID or borderline intellectual functioning are at increased risk for social isolation. More specifically, lack of contact with peers was a common problem; that is, 66% of the participants had difficulties with connection to peers. This percentage is of concern and suggests a need for interventions to improve the social skills of people with MID or borderline intellectual functioning. Also, this percentage is higher than the 20–42% reported by others (Emerson & McVilly, 2004; Krauss, Seltzer, & Goodman, 1992; Solish et al., 2010). However, this discrepancy might be due to differences in the measurement of social isolation.

In our study, differences between people with MID and borderline intellectual functioning were found on several domains. Noteworthy is that participants with higher IQ scores experienced more individual and family problems, and were in greater need of treatment and support. Emerson, Einfeld, and Stancliffe (2010) associated borderline intellectual functioning with poorer mental health in later childhood and adult life. Furthermore, Dekker and Koot (2003) concluded that depressive feelings, anxiety, and antisocial behaviour are more common in children with ID with higher levels of intellectual functioning. Similarly, Podesta and Radstaak (2012) concluded that in individuals with ID, higher IQ scores are associated with more behaviour and mental health problems. All of these findings underline the need for a differentiated approach to support people with MID or borderline intellectual functioning, rather than treating them as a homogenous group.

This study was a thorough investigation of increased support needs of people with MID and borderline intellectual functioning. The results underline the vulnerability of these people and their families. Thompson et al. (2009) argued that support needs are a reflection of limitations on human functioning, which may be the result of personal or contextual factors. Our findings show that people with MID or borderline intellectual functioning face a range of personal and contextual problems and disadvantages. The support they receive is often suboptimal; even after many years of treatment and support these individuals continue to require intensive support in a broad range of domains. One potential consequence of this mismatch between service needs and service provision is that individuals with MID or borderline intellectual functioning remain dependent on long-term inpatient and outpatient care throughout their lives.

Implications

The results of this study have several implications for the health care of people with MID or borderline intellectual functioning. First, reliance on the IQ score alone seems inadequate when assessing the needs of individuals with MID or borderline intellectual functioning (Buntinx & Schalock, 2010). Instead, individual and family characteristics should receive more attention during treatment and intervention planning (Luckasson et al., 2002). Second, preventive strategies should be developed to detect individual and family problems before these become persistent or chronic (Allen et al., 2011; Dekker & Koot, 2003; Einfeld et al., 2006, 2011; Hodapp & Dykens, 2009). Given the different characteristics and contexts of people with MID compared with those with borderline intellectual functioning, future research should investigate how healthcare services can better differentiate between the needs of these two groups.

Limitations

Although we aimed for a high level of accuracy, some limitations of this study need to be addressed. First, participants were recruited from the population of people with an ID who were referred to a single care provider. Although this limits the generalisability of the findings, the service users of this care provider were shown to be representative of the population of users of services for people with an ID in the Netherlands as a whole. Second, because this study had a cross-sectional design, no causal inferences can be made. Third, because the participants already had a long history of professional support and treatment, the sample was not fully representative of the population of people with MID or borderline intellectual functioning as a whole. Finally, only file data were available to collect information about the participants. For some patients, the only available information dated back several years. For instance, this was the case for the IQ scores, with most recent IQ data ranging from 1 to 21 years ago. This could have influenced our results. For future research, file data could be complemented with professional judgements and/or patients’ own reporting, for example, by means of a questionnaire or an interview.
Conclusion

This study showed that individuals with borderline intellectual functioning have more severe personal problems and live in a more problematic environment than people with MID. Therefore, we suggest that a more differentiated approach towards people with MID and borderline intellectual functioning should be considered. Better insight and understanding of subgroups of people with ID can be of value in attempts to develop more individualised programs of treatment and support.

Note

1. In the Netherlands, long-term care for people with an intellectual disability is provided under the terms of the Exceptional Medical Expenses Act (AWBZ), and access to care requires a statement of need. Care Intensity Packages are an expression of care needs; the Care Intensity Package for an individual is determined by an independent organisation (CIZ) on a nationwide basis, using objective criteria.

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Conflicts of interest

None.

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