Journal of Applied Research in Intellectual Disabilities 2008, 21, 70-80

Development of Parent- and Teacher-Reported Emotional and Behavioural Problems in Young People with Intellectual Disabilities: Does Level of Intellectual Disability Matter?

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Accepted for publication 9 March 2007

Background This study described similarities and differences in the 5-year stability and change of problem behaviour between youths attending schools for children with mild to borderline (MiID) versus moderate intellectual disabilities (MoID).

Methods A two-wave multiple-birth-cohort sample of 6 to 18-year-old was assessed twice across a 5-year interval using the Developmental Behaviour Checklist Primary Carer version (n = 718) and Teacher version (n = 313).

Results For most types of problem behaviour youths with MiID and MoID showed similar levels of stability of individual differences, persistence and onset of psychopathology. Whenever differences were found, youths

with MoID showed the highest level of stability, persistence and onset across informants. Mean levels of parent-reported, but not teacher-reported, problem behaviour, regardless of level of intellectual disability, decreased during the 5-year follow-up period.

Conclusions Youths with MoID and MiID are at risk for persistent psychopathology to a similar degree. Different informants showed to have a different evaluation of the level and the amount of change of problem behaviour, and should be considered complementary in the diagnostic process.

Keywords: children, development, intellectual disabilities, longitudinal, psychopathology

Introduction

Several studies have documented the developmental course, stability and continuity of behavioural and emotional problems, and psychiatric disorders in adolescents and young-adults (henceforward called youths) from the general population (e.g. Hofstra *et al.* 2000; Bongers *et al.* 2003; Costello *et al.* 2003).

In general, apart from rapid physical and biological changes, adolescence is a period of growing autonomy, and changing social relations with peers and parents. During the transition from adolescence into young-adulthood youths leave the relatively safe and familiar educational system, are likely to enter a more demanding work environment, and might start (thinking about)

living away from their parents. It is clear that such transitional periods tax personal competencies. It is expected that children with intellectual disability, especially those who are more intellectually challenged, will encounter more stress as they are faced with more personal limitations in adaptive functioning during these major transition periods, which might increase their vulnerability to developing emotional and behavioural problems. Only a few studies have investigated the development of emotional and behavioural problems(henceforward psychopathology) in youths with moderate to borderline intellectual disability (MoID), and even less is known about the development of problem behaviour that is more typical for youths with intellectual disability. These studies generally find high

levels of stability (range: 0.69-0.71) (McCarthy & Boyd 2001; Wallander et al. 2003) and high persistence (range: 41-65%) (Chess 1977; Tonge & Einfeld 2000), despite an average decline of psychopathology over time (Tonge & Einfeld 2003). Thus far, available studies only focussed on one developmental aspect and addressed small samples, selected groups (e.g. youths with Down syndrome), a limited range of problems, and/or limited age periods. Although differences in levels of psychopathology between youth with intellectual disability versus youth without intellectual disability are now well-established (e.g. Dykens 2000), and although some studies addressed the development of psychopathology in children with intellectual disability (Tonge & Einfeld 2003; Chadwick et al. 2005), the influence of the level of intellectual disability on the development of psychopathology during major transition periods is understudied.

For several reasons, the development of psychopathology is expected to differ between youth with mild to borderline intellectual disability (MiID) versus MoID. Some emotional and behavioural problems that require more advanced (cognitive) development (e.g. depressive symptoms, delinquent behaviour) might only emerge at a later chronological age or not at all in children with MoID. Similarly, young children without intellectual disability are less likely to be diagnosed with depression and more likely to show high levels of inattention (Rutter 2003), while an increase of depressive symptoms is known to occur in adolescents without intellectual disability (Giaconia et al. 1994). It is also suggested that children with MoID have more difficulties in expressing their feelings of discomfort and anxiety, and instead express these feelings through aggression (Marston et al. 1997). Children with MiID, however, are found to show high levels of depressed mood (Heiman 2001). It might be that they experience more stress while growing up than those with MoID, as they become more aware of their limited resources and adaptive skills (Kymissis & Leven 1994). Their levels of specific psychopathology (e.g. depressive symptoms, anxiety, social relating) might therefore be expected to decrease less over the years than in children with MoID. Considering the above, symptoms of depression, anxiety, social relating and delinquency are expected to have a smaller increase or a later onset with time in children with MoID compared with children with MiID.

Furthermore, differences in developmental course of psychopathology between youths with MiID versus MoID might be caused by differences in genetic and neurological make up, as well as psychological development and vulnerability. For example, neurological deficits (e.g. epilepsy) and genetic syndromes (e.g. fragile X) are stable conditions which are more prevalent in children with more severe levels of intellectual disability (Bregman & Hodapp 1991; State et al. 1997) and often co-occur with behavioural problems like aggression, inattention, communication problems and self-absorbedness (Thompson & Reid 2002). We therefore expect these problem behaviours to be especially stable in youths with MoID.

Finally, we know from general population studies that age and gender differences exist in the developmental course of psychopathology. But no information seems to be available on age and gender differences in the development of psychopathology in youths with intellectual disability. Possibly, problem behaviours in youths with MoID decrease less during the transition into adulthood than in youths with MiID, as they have less adaptive skills to cope with life changes. We expected younger children who recently went through puberty to show less decrease of problem behaviour, than older children.

Psychopathology among children without intellectual disability is known to vary by gender. The adolescent increase of emotional problems in girls is not seen in boys (e.g. Angold et al. 2002; Twenge & Nolen-Hoeksema 2002). By contrast, disruptive behaviours emerge in early and middle childhood and decrease after adolescence only in boys (Burke et al. 2002). Delinquency has also been shown to rise early in some boys and persists, at least until adulthood, while in most other boys and in girls delinquency increases during adolescence and tapers off by their mid-20s (Birmaher et al. 1996; Kovacs & Devlin 1998; Bongers et al. 2003). It is unknown whether psychopathology develops in similar or different ways in young people with different levels of intellectual disability. Thus far, we have no reason to expect other gender differences or level of intellectual disability by gender differences in children with intellectual disability.

It is generally agreed that youths behave differently in different settings. It is also accepted that informants might differ in the types of child psychopathology they observe and therefore different informants should be included when studying child and adolescent psychopathology. For example, in the general population, teachers were found to recognize depressive problems in pre-adolescents better than parents (Mesman & Koot 2000). Also in youths with intellectual disability it has been suggested that cross-context informants will provide a more complete picture of child problem behaviour (Tassé & Lecavalier 2000). Regarding the

development of psychopathology, in a recent study among 82 children with severe intellectual disability, Chadwick et al. (2005) found several differences between parent- and teacher-reports. Teacher ratings indicated that behaviour problems as assessed with the Aberrant Behaviour Checklist (Marshburn & Aman 1992) remained stable over a 5-year period, while parent ratings of irritability, stereotypy and hyperactivity decreased.

The present study aimed to identify the developmental course and the stability of psychopathology and persistence and onset of deviant levels of various types of emotional and behavioural problems in youths with intellectual disability and to compare these measures between youths with MiID versus MoID. Age and gender differences were also addressed, using both a parent and a teacher version of a standardized questionnaire designed to assess problem behaviour in youths with intellectual disability.

Considering the above, we hypothesized problem behaviour to decrease over time, as found in other studies on youths with intellectual disability (e.g. Tonge & Einfeld 2003) and without intellectual disability (e.g. Feehan et al. 1995). We hypothesized youths with MoID to show less change, higher levels of stability and persistence and lower levels of onset of deviant levels of psychopathology over time or at older ages than youths with MiID.

Method

The present study is a large longitudinal school-based study on psychopathology in youths, aged 6-18 years, with MiID, without any severe additional physical or sensory handicaps, in the Netherlands. In 1996 almost 90% of all schools for intellectual disability in the province of Zuid-Holland participated in this study. Schools were sent sampling instructions and a table with random numbers (20% of the total number of students in the school) to randomly select 20% (n = 1615) of their students. At the start of the study, about 2% (n = 48~800) of all 6- to 18-year-old Dutch youths attended a school for children with intellectual disability (about 20% of them in Zuid-Holland). Children with intellectual disability were unlikely to attend regular schools (Central Bureau of Statistics 1999). About 75% attended a school for children with MiID and 25% a school for children with MoID. Children with severe or profound intellectual disability in the Netherlands do not attend schools for MiID or MoID. They are most likely to visit day-care centres for intellectual disability and were not included in the present study.

Youths were excluded from the study in case of parental Dutch language problems, or when they were not living at home for at least 4 days a week. Further details about the initial sample and procedures can be found elsewhere (Dekker et al. 2002a; Dekker & Koot 2003). The study was approved by the academic hospital medical ethical committee.

Participants

Parents or caregivers of the youths selected (see above) were informed about the research project through the schools. All parents and youths who participated in the study signed an informed consent form, in which they could also give the researcher permission to ask the teacher to report on their child's behaviour.

In this paper, participants were eligible for analyses when parent and/or teacher completed the Developmental Behaviour Checklist (Einfeld & Tonge 1992; Koot & Dekker 2001) at the initial assessment in 1996/1997 (T1 in this paper) and the final assessment in 2002/2003 (T2 in this paper), when the youths were aged 10-24 years. Table 1 displays some sample characteristics for those youths who had data at T1 and T2.

No significant differences (all P > 0.01) in age, gender, level of intellectual disability or deviant T1 DBC Total Behaviour Problem Scores (TBPS; see Measures section) were found between youths of participating parents and non-participating parents at T2. At T1 parents, teachers and general practitioners were asked to report any

Table I Sample characteristics

	Parents	Teachers
Number of participants	718	313
(at both T1 & T2)		
Response rate (%)	71.3	31.1
Mean follow-up period (SD) (years)	5.2 (0.5)	5.3 (0.5)
Mean age T1 (years) (SD)	11.7 (3.0)	9.8 (2.3)
Mean age T2 (years) (SD)	16.9 (3.0)	15.0 (2.2)
Males (%)	59.9	59.4
Low SES (%)	50.6	48.6
Mean T1 TBPS (SD)	20.34 (16.6)	22.05 (17.6)

SD, standard deviation; SES, socio-economic status; TBPS, Total Behaviour Problem Score.

known neurological or chromosomal deficit in the child. Youths with MoID had significantly more often a neurological or chromosomal deficit (55%) than youths with MiID (12%) ($\chi^2 = 201.43$, P < 0.01). Youths of T2 participating parents had a higher mean level of T1 DBC TBPS (t = 2.7, P < 0.01) and had a higher socio-economic status (SES) ($\chi^2 = 25.88$, P < 0.01) than youths of non-participating parents at T2. Families were assigned to SES groups based on parental occupation. The middle/high SES group included families who had jobs that required middle to high levels of education, e.g. bank-employee, teacher), the low SES group included families who were unemployed or who had jobs that required no or minimal levels of education or training.

At T1 811 teachers returned a completed DBC-T (T1 response rate: 80.5%), after parental consent. In the Netherlands all children are obligated to attend a school until the age of 16, after that age schooling is voluntary. At T2 only 599 youths were still attending a school, 65.5% of them being 16-years old or younger. Youths who no longer attended school (n = 251) were either in employment or stayed at home. Of the 599 youths attending school, 506 parents and youths gave us permission to contact the current teacher for a second teacher assessment, and 415 teachers completed a DBC-T (T2 response rate: 82.0%). This paper only reports teacher-data when teachers completed a DBC-T at both assessments (n = 313). Youths for whom teacher data was available at both T1 and T2 differed from youths without this information in being more likely to be younger (t = -15.50, P < 0.01) and to have a MoID $(\chi^2 = 17.02, P < 0.01)$. Almost 75% of the youths whose teacher participated at both assessments were 16 years or younger. The gender distribution did not differ.

Measures

Emotional and behavioural problems

The Dutch versions of the Developmental Behaviour Checklist Primary Carer version (DBC-P, 96 items) and the Developmental Behaviour Checklist Teacher version (DBC-T, 94 items) were used (Koot & Dekker 2001; Einfeld & Tonge 2002) at both times to assess a wide range of emotional and behavioural problems. Each DBC-item specifies a problem, which informants can rate as 0 (not true), 1 (sometimes true) or 2 (very true/often true) in the past 6 months. The DBC contains the scales Disruptive/Antisocial, Self-absorbed, Communication disturbance, Anxiety and Social relating. Summing the individual item scores derives a Total Behaviour Problem Score. DBC scales were dichotomized for some analyses, considering sum scores above the 75th percentile to be deviant (Koot & Dekker 2001). The DBC is an instrument especially designed and sensitive to measure problem behaviour in children and adolescents with intellectual disability. It has been shown to have good reliability, validity and internal consistency in children with intellectual disability, including the current sample (Dekker et al. 2002a,b; Einfeld & Tonge 2002).

Level of intellectual disability

Youths were assigned to a MiID or MoID group, based on their initial educational level. In the Netherlands school assignment is largely based on level of IQ, but also on social functioning, which is in line with the AAMR definition of mental retardation (AAMR 2002). The MiID group had a mean IQ of 64.9 (SD = 13.5), and the MoID group an average IQ of 46.1 (SD = 9.1). These mean were based on IQ measures in 79% of the youths at T2, using a short form of the Dutch version of the Wechsler Intelligence Scale for Children - WISC III (Wechsler 1991; Kort et al. 2002). Unfortunately it was not possible to obtain an IQ-score for all the young people in this study, because of either parental or child refusal. The WISC III short form comprised of the subtests picture completion, information, block design and vocabulary. These subtests form a reliable estimator of the full IQ-score for research purposes for both children with intellectual disability (Dumont & Faro 1993) and nonintellectual disability (Kaufman et al. 1996). Tellegen & Briggs (1967) instructions were used to calculate an estimated IQ-score (sum of the four scaled subtest scores \times 1.7 + 33). The internal consistency reliability coefficient of this short form in the current sample was r = 0.95 (SE = 6.57) (Tellegen & Briggs 1967; Dumont &Faro 1993).

Data analysis

We divided the sample into groups based on level of intellectual disability (MiID versus MoID), age (T1 ages 6-12 and 13-18 years) and gender (boy, girl). These two age ranges were chosen because the majority (97%) of the children aged 6-12 years were still in primary education at T1, whereas the majority (86%) of children aged 13-18 attended secondary education, making it not only a division of age, but also of developmental/educational stage.

Repeated measures anova was conducted to assess the developmental course of DBC mean levels of problem behaviour over the 5-year period (time effect). Differences in developmental course between levels of intellectual disability, age groups, and boys and girls were tested within the same analyses.

An additional repeated measures multivariate ANOVA directly compared the developmental course of parentversus teacher-reported problem behaviour. Scale scores of each informant at the two assessments were compared using informant and time as within-subjects factors. A significant interaction between these two factors indicates that parent and teacher-reports show a different developmental course of psychopathology over a5-year period. This analysis included only the 282 participants who still attended school and for whom both a DBC-P and a DBC-T were completed at both time points. Only the 94 items that both questionnaires have in common were included in this analysis.

Pearson's correlations between T1 and T2 on DBC-P and DBC-T raw scale scores were calculated to provide a measure of stability of psychopathology. Group differences between stability coefficients were tested using Fisher's Z transformations.

Risk estimates (OR) were calculated from logistic regression analysis with deviant DBC scale scores at T2 as dependent variable and deviant DBC scale scores at T1 as predictor, and age group, gender and level of intellectual disability as covariates. These ORs provided information on the relative risk of persisting deviant problem behaviour.

In addition to change around the clinical cut-off scores, clinically significant change is a measure to assess whether a person changed so much that it could be considered clinically relevant beyond whether or not a person crossed the clinical cut-off score (Jacobson & Truax 1991). Clinically significant change in our sample was calculated according to the directions of Jacobson & Truax (1991) and Maassen (2001). According to these directions, a change of 23 points or more on the TBPS of the DBC-P and of 18 points on the DBC-T should be considered a clinically significant change.

Results

Course of psychopathology

The first three columns of Table 2 show T1 and T2 mean DBC-P and DBC-T scores for all children with intellectual disability and effect sizes for the time effect (percentage explained variance; PEV). According to Cohen's criteria the PEV were in the medium (5.9–13.8%) to large (≥13.8%) range (Cohen 1988). A significant (P < 0.05) overall decrease in parent-reported mean level of problem behaviours over the 5-year period was found for all DBC scales, except for Social relating. No significant change over the 5-year period was found in any teacher-reported problem behaviour.

Only a few and small interaction effects of level of intellectual disability with time, and age by time were found (not shown in Table 2). No significant effects were found for gender. A significant time by level of intellectual disability interaction effect (P < 0.05) for DBC-P scale Anxiety indicated that the decrease of anxiety problems was significant for both levels of intellectual disability, but youths who attended a school for children with MiID showed a larger decrease over time than youths with MoID (PEV = 0.8%). A significant time by age effect (P < 0.05) was found for the DBC-P scales Social relating and Anxiety, indicating that the decrease in social relating was only significant in older youths (PEV = 1.8%). anxiety decreased in both younger and older youths, but the decrease was significantly larger in younger youths (PEV = 0.6%).

As could be expected because of the non-significant change in mean problem behaviours reported by teachers, a difference between informants concerning change of problem behaviour over time was found for Disruptive Behaviours, Communication disturbance, Anxiety and the TBPS. PEV ranged from 1.8% to 2.9% for these time by informant interaction effects, which can be considered small to medium (Cohen 1988).

Stability of individual differences of psychopathology

Table 2 also shows the 5-year stability coefficients, separately for parent- and teacher-reported levels of problem behaviour, for the total sample, and split by level of intellectual disability and gender within intellectual disability level. In the total sample, all stability coefficients were large ($r \ge 0.50$) for the DBC-P scales and in the medium range (r = 0.30-0.49) for the DBC-T scales (Cohen 1988). For teacher ratings, stability coefficients for some subsamples, especially girls with MiID, were low and sometimes non-significant. Across informants, whenever significant differences were found between stability coefficients (in Table 2 indicated by superscripts), youths with MoID and boys had higher levels of stability.

Persistence and onset of deviant levels of psychopathology

Table 3 presents percentages of youths who were scored persistently in the deviant range of the DBC-P or DBC-T

Table 2	Five-year course and stability of individual differences of parent- and teacher-reported emotional and behavioural
problems	

	Course			Stability of individual differences							
	Total sample		Time	Total			MiID		MoID		
	T1	T2	effect PEV (%)	sample	MiID	MoID	Boys	Girls	Boys	Girls	
DBC-P				n = 718	n = 479	n = 239	n = 290	n = 189	n = 140	n = 99	
Disruptive/antisocial	12.95	9.78	11.2	0.61	0.59	0.66	0.65^{B}	0.50	0.66	0.65^{Mo}	
Self-absorbed	7.70	5.38	14.1	0.68	0.59	0.73^{Mo}	0.63^{B}	0.49	$0.76^{Mo,B}$	0.58	
Communication disturbance	4.48	3.50	6.6	0.57	0.49	0.56	0.51	0.46	0.59	0.44	
Anxiety	3.62	2.63	9.6^{Mi}	0.51	0.50	0.53	0.46	0.52	0.58	0.44	
Social relating	3.31	3.22	NS	0.52	0.49	0.56	0.49	0.47	$0.62^{\mathrm{Mo,B}}$	0.44	
TBPS	33.13	25.18	13.8	0.64	0.61	0.67	0.67^{B}	0.52	0.70	0.58	
DBC-T				n = 313	n = 188	n = 125	n = 111	n = 77	n = 75	n = 50	
Disruptive/antisocial	9.18	8.10	NS	0.47	0.46	0.49	0.45	0.47	0.51	0.37	
Self-absorbed	5.38	3.94	NS	0.40	0.30	0.49^{Mo}	0.32	0.20^{NS}	0.49	0.39	
Communication disturbance	2.14	2.18	NS	0.41	0.33	0.43	0.42	0.23*	0.45	0.25 ^{NS}	
Anxiety	2.00	1.73	NS	0.32	0.27	0.36	0.25	0.29	0.43	0.18^{NS}	
Social relating	2.70	2.88	NS	0.30	0.19	0.44^{Mo}	0.22*	0.13^{NS}	0.47	0.32*	
TBPS	22.05	19.40	NS	0.38	0.35	0.40	0.38	0.30	0.38	0.31	

All correlations are significant at the 0.01 level, except when indicated with *P < 0.05.

NS, not significant; MiID, mild to borderline intellectual disabilities; MoID, moderate intellectual disabilities; TBPS, Total Behaviour Problem Score; PEV, percentage explained variance; PEV is only displayed for significant (P < 0.05) effects; Mi, MiID had a significantly larger decrease; Mo, stability higher in MoID youths within gender; B, stability higher in boys within level of ID.

at both T1 and T2 (persistence) and the percentages of youths who developed psychopathology in the past 5 years (onset) and their corresponding risk estimates (OR).

At T1 24.7% of the youths scored in the deviant range of parent-reported TBPS, 17.5% scored in the deviant range at T2. According to parents, 42.1% of all youths who initially scored in the deviant range on the TBPS, scored also in the deviant range again 5-years later (persistence). In 57.9% of the initially deviant youths, the level of problem behaviour decreased to the normal range. Persistence of deviant problem behaviour ranged from 37.3% (communication for MiID youths) to 62.1% (self-absorbed for MoID youths) for the DBC-P scales. Highest levels of persistence (>50%) was found for social relating in all youths and in youths with MoID for selfabsorbed and disruptive/antisocial. The level of persistence of parent-reported self-absorbed was significantly higher in youths with MoID than in youths with MiID.

Of all youths who scored in the normal range on the TBPS according to parents at T1, 8.4% had deviant TBPS scores 5-years later. Onset of the various deviant problem behaviours ranged from 5.8% to 20.4%. Youths who initially scored in the deviant range, had a 5-18 times increased risk, compared with non-deviant youths, to also score in the deviant range 5-years later according to the parents. Onset of parent- and teacher-reported communication disturbance and teacher-reported anxiety, were significantly higher in youths with MoID.

Teacher-reported persistence of problem behaviour ranged from 16.7% to 66.7%. The highest level of persistence (>50%) was found for communication disturbance in youths with MoID. The percentages of teacher-reported onset of problem behaviour ranged from 2.8% to 11.5%, an exceptionally high level of onset was found for social relating (20.9% in MiID youths). Youths who initially scored in the deviant range had a 2-22 times increased risk of deviancy 5-years later, compared with non-deviant youths at initial assessment.

A final analysis computed percentages of youths showing a clinically significant amount of change inproblem behaviour (Jacobson & Truax 1991), as

Table 3 Persistence and onset of deviant parent- and teacher-reported emotional and behavioural problems

	Total sample			MiID			MoID		
	Persistence ¹ (%)	Onset ² (%)	OR ³ (95% CI)	Persistence (%)	Onset (%)	OR (95% CI)	Persistence (%)	Onset (%)	OR (95% CI)
DBC-P ($n = 718$)									
Disruptive/antisocial	44.1	8.6	8.4 (5.5–12.7)	40.1	7.9	7.8 (4.6–13.2)	53.4	9.9	10.4 (5.1–21.3)
Self-absorbed	47.5	7.5	11.1 (7.2–17.1)	41.5	7.1	9.3 (5.4–15.8)	62.1^{Mo}	8.3	18.1 (8.6-32.3)
Communication disturbance	41.3	8.1	8.0 (5.2–12.1)	37.3	5.8	9.7 (5.5–17.1)	49.3	12.8 ^{Mo}	6.6 (3.4–12.7)
Anxiety	42.8	12.0	5.5 (3.8-8.1)	41.3	10.7	5.9 (3.6–9.5)	46.2	14.4	5.1 (2.7-9.7)
Social relating	56.4	16.1	6.8 (4.7-9.7)	54.7	13.9	7.5 (4.8–11.7)	59.7	20.4	5.8 (3.7–10.6)
TBPS	42.1	8.4	7.9 (5.2–12.0)	38.4	7.9	7.3 (4.3–12.2)	50.9	9.3	10.1 (4.9–20.7)
DBC-T $(n = 313)$									
Disruptive/antisocial	36.6	9.6	5.5 (2.6–11.6)	28.6	9.6	3.8 (1.3–11.1)	45.0	9.5	7.8 (2.6–23.3)
Self-absorbed	19.5	6.6	3.4 (1.4-8.5)	20.8	9.1	2.6 (0.9-8.0)	17.6	2.8	7.5 (1.4–40.8)
Communication disturbance	42.3	6.6	10.3 (4.2–25.6)	35.0	5.4	9.5 (3.0–29.7)	66.7	8.4 ^{Mo}	21.8 (3.5–134.1)
Anxiety	22.2	8.0	3.3 (1.2-8.9)	20.0	5.8	4.1 (1.0–16.8)	25.0	11.5^{Mo}	2.6 (0.6–10.7)
Social relating	39.2	19.2	2.7 (1.6-4.7)	34.7	20.9	2.0 (1.0-4.1)	46.7	16.8	4.3 (1.8–10.6)
TBPS	17.2	8.8	2.2 (0.8–6.5)	17.4	9.7	2.0 (0.6-6.5)	16.7	7.6	2.4 (0.3–23.2)

TBPS: Total Behaviour Problem Score; OR, odds ratio; Mo, MoID youths had a significantly higher onset or persistence compared to MiID youths, according chi-square analysis.

indicated by a decrease of the DBC-P total problem score by 23 points or more. According to parentreport, 18.1% showed this large improvement in problem behaviour, while 77.7% of the youths did not show a clinically significant change, whereas 4.2% showed a clinically significant deterioration over time. On the DBC-T TBPS a change of more 18 points or more was considered clinically significant. According to teacher-report, 16.8% showed this large improvement in problem behaviour, while 68.8% of the youths did not show a clinically significant change, whereas 14.4% showed a clinically significant deterioration over time, which was not significantly different from the percentages based on parent-reports. Proportions of parent and teacher-reported clinically significant change did not differ significantly between youths with MiID and MoID.

Discussion

This longitudinal study compared the developmental course of psychopathology over a 5-year period in youths who attended a school for children either with MiID or MoID. Our main aim was to study differences in level and course of psychopathology between two levels of intellectual disability. For most problems we found a decreasing course of mean level of psychopathology for the total sample. An overall decrease was also found in the Australian study (Tonge & Einfeld 2003); however, this was a small decrease which was only found at the 8-year follow up in their epidemiological subsample. In an earlier study, reporting about the 4-year follow up, Tonge & Einfeld (2000) found no significant decrease. The Australian researchers concluded that children and adolescents with all diversities of intellectual disability have a persisting risk at an increased level of psychopathology compared with the general population. We found medium to high levels of stability, which is consistent with findings reported by McCarthy & Boyd (2001) and Wallander et al. (2003). The 5-year persistence rate (42%) found in the present study, was lower compared with the 4-year persistence rate (65%) reported in the Australian study (Tonge & Einfeld 2000). We also found a lower rate of onset (8%) than was found in the Australian study (19%) (Tonge & Einfeld 2000).

¹Percentage of all subjects initially classified as deviant who were also deviant 5-years later.

²Percentage of all subjects initially classified as normal who were deviant 5-years later.

³OR, risk at deviance at T2, based on deviancy at T1.

For the majority of the youths in this study we found no clinically significant change in psychopathology over the 5-year period according to both parents and teachers. Parents only reported a clinically significant deterioration in 4.2% of the youths, however, teachers reported a higher percentage of 14.4% of the youths to deteriorate. Still, these clinically significant changes are lower compared with the ones found for the DBC-P by Tonge & Einfeld (2003), showing a 19.6% deterioration and 16.7% improvement. It should be noted that a change of 17 points or more was considered significant in that study, whereas in the present study a difference of 23 points on the DBC-P was necessary for a clinically significant change according to the guidelines of Jacobson & Truax (1991).

Does level of intellectual disability matter?

Youths with MoID were expected to show less change in mean level and higher levels of stability of psychopathology over time, higher persistence of existing psychopathology and lower onset of types of psychopathology that tend to increase in adolescence. Contrary to this expectation, the 5-year change in mean level of psychopathology did not differ between MiID and MoID on any DBC-scale. However, we found a higher stability and persistence of some problem behaviours (self-absorbed, social relating) in youths with MoID, which is consistent with the assumption that chronic neurological deficits and genetic syndromes, which are more prevalent in youths with MoID, contribute to less overall change in mean level of psychopathology (Bregman & Hodapp 1991; State et al. 1997; Thompson & Reid 2002). Social relating was the only scale on which parents reported no significant change in mean level and it had the highest onset and persistence of all problem behaviour scales. When looking at the specific scale items that make up the Social relating scale, some are related to symptoms also seen in depression (e.g. underactive, depressed/unhappy). In a study into social development and depression, (Kovacs & Goldston 1991) social functioning was also found to be impaired in depressive adolescents without intellectual disability. It might be that the lack of mean level decrease (Table 2) and the high onset (Table 3) found in the Social relating scale represents an increase of depressive symptoms. However, we did not find a lower onset of depressive symptoms in youths with MoID. A second explanation for the stability of social relating might be high stability of autistic symptoms represented in the Social relating scale (e.g. aloof, prefers to do things on his own, avoids

eye contact). The DBC-Autism Screening Algorithm is a reliable screening instrument containing 29 items from the DBC (Brereton et al. 2002). Five out of the 10 social relating items are also present in the DBC-ASA. In a post hoc analysis, these five autism items, however, did not change less than the other five items from the Social relating scale. Further research is needed to find a valid explanation for the lack of change in the Social relating score

We expected a lower onset of delinquent symptoms in youths with MoID. However, no significant differences between MiID and MoID were found for disruptive/antisocial, except for stability, which was higher in girls with MoID than with MiID. Boys from the two intellectual disability levels did not differ significantly. From studies into delinquency among girls without intellectual disability, an increase of delinquency in adolescence is known (Silverthorn & Frick 1999). It might be that this increase of delinquency is the case in girls with MiID, but not with MoID, resulting in a lower stability of disruptive/antisocial behaviour in girls with MiID. The present study, however, only looked at differences between age-groups and was therefore not able to detect an adolescent increase of delinquency. The development of delinquency in girls with MiID versus MoID needs to be studied in more detail to reveal whether girls with MiID indeed show an increase of delinquency in adolescence.

As expected, youths who initially attended a school for MoID had a significantly higher stability and persistence of disruptive/antisocial, self-absorbed and social relating. However, the higher onset of communication disturbance and anxiety in youths with MoID was not consistent with our expectations.

Parent and teacher; complementary informants?

In the present study the mean level of teacher-reported problem behaviour showed no change over a 5-year period, while parents reported a decrease. This confirms findings in a sample of youths with severe intellectual disability, where most problem behaviour showed no significant difference between teacher ratings at two consecutive measurements, while parent-reported problem behaviour showed a significant decrease in some problem behaviours (Chadwick et al. 2005). Despite this apparent continuity based on overall mean problem behaviour, teacher-reports indicated lower levels of stability over a 5-year period than parent-reports when looking at individual differences. These results might look contradictory at first glance, but in fact changes in

overall level and individual differences should be studied as independent aspects of the developmental course of problem behaviour.

The discrepancy between indices of stability derived from parent and teacher reports is remarkable and may reflect situational differences. Here, increased social and intellectual demands and changing classmates and teachers may influence youths differently, whereas at home the demands and the setting are less likely to change. The discrepancy in level of psychopathology reported by parents (decreasing scores) and teachers (no change) may reflect youths increasing competence in the home situation that is not (yet) matched by a similar increase in school or peer competence. An alternative explanation might derive from attribution differences. De Los Reves & Kazdin (2005) suggest that discrepancies exist because of differences between informants in attribution of problem behaviour and in perspective on the child. Informants are likely to remember and therefore report problems, which are consistent with their perspective of a child (De Los Reyes & Kazdin 2005). The perspective parents have of their child is not likely to change much over a 5-year period, while the different teachers, who in addition only know the child for a year or even shorter, are more likely to have a perspective of the child which is based on this short period.

Limitations and future studies

Teacher ratings were only available for youths who still attended school at T2, therefore younger children and youths with MoID, who are more likely to attend school at older ages than youths with MiID, were overrepresented in the teacher-reports. In future longitudinal studies it might be valuable to assess the follow-up DBC-T rating from an internal job-counsellor for nonschool youths, to evaluate the development of problem behaviour in youths no longer attending schools.

Although not validated for ages over 18, it was assumed that the DBC would also apply well to the group of youths with intellectual disabled aged 19-24 at T2, as this group still has limitations in intellectual functioning and adaptive behaviour (e.g. conceptual, social and practical adaptive skills) (AAMR 2002). As stability and change over time was the main question in this study, the present study preferred to use the same instruments at both assessments. Meanwhile, an adultversion of the DBC-P has been developed in Australia (Mohr et al. 2005). This adult-version (DBC-A) was based on the DBC-P, where one DBC-P item was deleted, seven items were slightly changed and 12 items were added. As only minor changes were deemed necessary, we consider it justified to use the DBC-P in participants over age 18.

This paper relied on DBC information only. Although the use of multiple instruments (e.g. DSM-IV based instruments) would have broadened our perspective on the developmental course of psychopathology, the main focus of this paper was to show differences between two levels of intellectual disability in the developmental course of psychopathology. The DBC was especially designed and therefore sensitive to assess a wide range of problem behaviours in children with intellectual disability and was considered most valuable for the purpose of this paper.

There was an overlap in IQ scores between the MiID and MoID group among the youths that were assessed. However, we preferred to assign youths to intellectual disability-level groups based on their initial educational level, as admission to both types of educational systems in the Netherlands was usually based on both intellectual and social functioning, in accordance with the AAMR definition of mental retardation (AAMR 2002).

Implications

Findings of high stability of problem behaviour in this already vulnerable group of youths with intellectual disability show the importance of tracking the development of these individuals into adulthood. Youths with MoID and boys are especially likely to show stability in problem behaviour. This suggests that some extra attention should be paid to supporting these families in raising their children and to help them coach their children through young-adulthood by offering professional help when needed.

Early identification within school settings and appropriate psychiatric interventions might be necessary to diminish the high stability and persistence of problem behaviour found in this study, assuming interventions can help improve problem behaviour. Future studies should investigate whether interventions are effective in lowering the high stability of problem behaviour.

Parents and teachers should inform each other not only of how they view their child's or pupil's behaviour at present, but also how they think about changes over the past years. Parents can inform teachers about the development of their child over a longer period, while teachers can discuss the child's development from their perspective. This might improve the detection of changes in behaviour, which are important in the care for a child. Parents, teachers and health professionals should be aware that even though youths tend to show a decrease of problem behaviour over time, significant clinical changes are less common.

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