

Short Review

Psychopathology in young people with mild ID or borderline intellectual functioning: research findings from representative (clinical) samples & future needs

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Children, adolescents and young adults (henceforward denoted as young people) with mild intellectual disability (MID) or borderline intellectual functioning (BIF) show deficits in cognitive abilities (IQ 50–70 for MID; IQ 70-85 for BIF) and adaptive behavior and have an increased risk for psychopathology, which further compounds deficits in adaptive functioning and hinder development. Available research concerning young people with ID has several limitations: 1. young people with MID or BIF are understudied; 2. few studies differentiate between levels of ID; 3. few studies enroll a random sample of unselected children from the general population; 4. studies on psychopathology do not take adaptive functioning into account when defining ID; 5. few studies compare risk factors for psychopathology or referral to mental health care between young people with and without ID; 6. very few studies look at long term prediction and developmental course of psychopathology in young people with ID, and 7. research is scarce with respect to representative clinical samples of young people with ID to study determinants of treatment response with regard to adaptive functioning and problem symptoms. In this compact review we will discuss the latest research findings, published in the last two decades, on prevalence of ID and of psychopathology, predictors of referral to mental health care and treatment success, developmental course and risk factors related to psychopathology.

Prevalence of MID and BIF

In a meta-analysis it was estimated that the average prevalence of ID in young people (N = 35 studies) in the general population, ranged from 1.5 % to 2.1%^{1,2}. Two recent studies reported an ID prevalence of 1.2% among young people^{1,3}. Most of these studies used the DSM-IV or ICD10 classification of ID and sampled from hospital data or administrative registry, and less often from community-based studies using random household sampling strategies. None of these studies used DSM-5 or ICD-11 criteria for ID that include limitations in adaptive functioning⁴. The specific prevalence of MID and BIF are understudied, and studies that do report on level of ID have widely ranging prevalence estimates for MID: from 0.8% up to 10%^{3,5,6}. No information on the prevalence of BIF is available⁷.

Prevalence of psychopathology in young people with MID or BIF

To date, there are no prevalence studies on psychopathology among young people with ID that included adaptive functioning in their definition of ID⁸. In a 2011 review it was demonstrated that only seven studies published after 1998⁹⁻¹⁵ had acceptable methods to assess the prevalence of psychopathology in young people with ID (30%-50%). Two more recent studies report a prevalence between 42% and 63%^{16,17}. Only a few studies reported the prevalence of psychopathology specifically for young people with MID. These prevalence estimates range from 16%-57% across studies^{9-11,15}. With a general trend of depressed mood, anxiety and antisocial behaviors being more common among those with relatively higher levels of IQ or MID.

The 2011 review also showed that only four studies^{9,12,13,18} compared the prevalence of psychopathology in young people with ID to those without ID. An increased risk for young people with ID was found (relative risk 2.8-4.5)¹⁹. A recent population-based study also found a two- to threefold increased risk in young people with ID compared to those without ID¹⁶. The bigger risk for psychopathology in young people with ID continues to exist when compared to mental age-matched children without ID²⁰.

The only two studies on psychopathology in young people with BIF report estimate prevalence rates ranging from 15%-20% and odds ratios ranging from 1.6-4.3 compared to peers without BIF^{7,21}.

Developmental course of psychopathology and adaptive functioning in young people with MID or BIF

Even though ID is a developmental disorder, most studies in this field are cross-sectional and do not incorporate a developmental perspective²². Multi-cohort longitudinal studies are needed. Only a few studies have examined the course of psychopathology in young people with ID over time, even less compared their developmental course to young people without ID and no studies specifically focused on MID or BIF.

In the Netherlands, results from a 1-year²³⁻²⁵ and a 5-year follow-up study^{26,27} are available. In Australia, outcomes from a 2-year, a 4-year, and a 14-year follow-up^{21,28-30} exist. Results show a high 1-year and 5-year stability for parent-reported emotional and behavioral problems, a relatively high 5-year and 14-year persistence of psychopathology (around 40%), a 3- to 7-times increased relative risk to meet the criteria for a DSM-IV diagnosis when having a deviant level of emotional and behavioral problems the year before, and a 2- to 6-times higher relative risk of mental health problems 2 years later.

Only one study compared the developmental course of psychopathology in young people with ID to those without ID²⁶. Young people with ID continue to show greater risk for psychopathology compared to typically developing peers over time, but overall, the developmental course is quite similar.

Although adaptive functioning is critically important to the long-term outcomes of people with ID, as well as an important focus for intervention, to date we only know of two studies in young people with Williams syndrome (mild to moderate levels of ID) addressing this topic. In a study on longitudinal trajectories of intellectual and adaptive functioning in 4- to 15-year-olds with Williams Syndrome it was shown that intellectual functioning stayed stable, while adaptive behavior declined over a 3-year period. Another study, including 14- to 50-year-olds with Williams syndrome, also showed that while intellectual functioning remained stable, adaptive functioning decreased over a period of 2 to 9 years³¹.

Risk and protective factors of psychopathology and adaptive behavior in young people with MID or BIF

It has been demonstrated that young people with ID are at increased risk for psychopathology, which does not typically disappear over time. However, some young people are more at risk than others. Several hypotheses, covering the 'bio-psycho-social' spectrum have been developed to explain the greater prevalence of psychopathological disorders in young people with intellectual disabilities. In particular, they point to biopsychosocial and developmental factors such as: a. genetic factors (e.g. Fragile X syndrome, Prader-Willi syndrome); b. psychological factors (e.g. negative or unrealistic self-image, outer-directed orientation); c. familial factors (e.g. family stress, parental psychopathology); d. social factors (stigmatization, exclusion, heightened risk for exploitation); e. biological factors (e.g. higher risk for seizure disorders, sensory impairments, fetal alcohol syndrome); and f. neurological deficits³². However, only a few prospective studies exist on risk factors for psychopathology that at least include young people with MID or BIF.

One of the conclusions in a Dutch one-year follow-up study²⁴ was that the strongest predictors of a DSM-IV anxiety, mood or disruptive disorder in young people with ID were: 1. level of emotional and behavioral

problems the year before; 2. social incompetence; 3. inadequate daily living skills; 4. child health problems; 5. parental mental health problems; and 6. negative life events. Deviant levels of emotional and behavioral problems one year later were uniquely predicted by previous emotional and behavioral problems, physical symptoms, parental distress, and family dysfunction²⁵. A longer follow-up of the same Dutch study showed the strongest predictors of DSM-IV disorders five years later were a deviant level of emotional and behavioral problems, inadequate adaptive behavior and parental psychopathology²⁶. Limitations in adaptive functioning were also among the factors related to a higher risk of psychopathology in children with ID in a study from Finland³³.

In the Dutch studies some moderating effects were found for the child's age, gender, educational level and socioeconomic status. Another finding was that the accumulation of risk factors was highly predictive of later psychiatric problems (e.g. a 45.3% chance of meeting DSM-IV criteria when having five or more risk indicators). This high percentage of multiple risk indicators in people with ID might partly explain the high prevalence of psychopathology compared to the people without ID. Children with ID are more likely to grow up in lower socio-economic circumstances and to encounter adversity, both factors associated with poorer mental health in the general population³⁴.

Little is known about risk factors for adaptive functioning in young people with ID. Autistic and general behavior problems are found to be directly influencing the level of adaptive functioning and comorbid psychopathology in autism spectrum disorder is significantly correlated with the size of IQ-adaptive functioning discrepancy in young people with ID³⁵.

Predictors of referral & treatment outcome in young people with MID or BIF and psychopathology

Although there are many studies on emotional and behavioral problems of children in care, there is a scarcity of studies of young people with ID in care. Also, few studies exist on the effects of therapeutic interventions in young people with ID. Furthermore, to our knowledge no studies exist that use Routine Outcome Measuring data in young people with ID in the Netherlands. Clinical studies are needed to study predictors of individual differences in referral to mental health care and treatment outcome.

Despite the higher prevalence rates of mental health problems in young people with MID or BIF, several studies suggest a referral-gap seems to exist: only about 10% to 40% of those with ID and a clinical level of mental health problems received mental health care^{10,30,36}. Parents do not always perceive a need for help, or when they do, do not always seek or find professional help. In a large Dutch study, it was found that only 55% of parents who perceived a need for help for their child with ID and mental health problems sought professional help. Factors related to seeking professional help were: having a child with anxiety or depressive mood problems, psychopathology before the past year and negative life events³⁷. Another Dutch study demonstrated that one in seven parents with a child with MID or BIF has a need for parenting support. Determinants associated with a need for parenting support were parenting stress and child psychosocial problems³⁸. In a UK clinical sample of adolescents, mental health care needs were associated with low adaptive functioning, diagnosis of autism and a family history of mental illness³⁹.

A Spanish study showed that children with ID in care were more likely to receive psychotropic medication⁴⁰ and that the main factors related to receiving mental health care were physical neglect and sexual abuse. They also tend to stay almost 2 years longer in residential care, their family backgrounds show more risk factors (e.g. more mental health disorders and intellectual disability), and they are more likely to have a physical disease or speech problems⁴¹. Of the young people with MID admitted to specialized inpatient treatment facilities in the Netherlands, about 29% are estimated to take at least one psychotropic drug, with an increased prescription rate for boys and children with behavioral problems⁴². A meta-analysis on the effectiveness of pharmacological intervention for challenging behavior in young people with ID (n=14 studies) showed that antipsychotic medications can be effective in reducing challenging behavior in the short-term, but with risks

of significant side effects⁴³. In a small inpatient study in the UK it was found that those admitted with ID were more likely to be male and had longer lengths of stay²⁰.

The small number of studies on the effectiveness of psychosocial interventions to improve mental health in young people with MID or BIF and their families, show some promising results. In a meta-analysis on the effectiveness of psychosocial interventions in children and adolescents with MID or BIF and a psychiatric disorder, only 12 studies met the criteria of containing at least randomization and blindness⁴⁴. This review showed a small treatment effect for parent training interventions compared to care as usual (n=4 studies). A more recent study on a training adapted to young people with MID or BIF (Standing Strong Together) that combines parent management training and cognitive behavior therapy to reduce externalizing behavior problems, showed promising results⁴⁵ as was the case for a pilot study on an adaptation of multisystemic therapy (MST) in adolescents with ID and anti-social or delinquent problems and their families⁴⁶.

References

- Maenner MJ, Blumberg SJ, Kogan MD, Christensen D, Yeargin-Allsopp M, Schieve LA. Prevalence of cerebral palsy and intellectual disability among children identified in two U.S. National Surveys, 2011–2013. *Annals of Epidemiology*. 2016;26(3):222-226.
- Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of Intellectual Disability: A Meta-Analysis of Population-Based Studies. *Research in Developmental Disabilities: A Multidisciplinary Journal*. 2011;32(2):419-436.
- Westerinen H, Kaski M, Virta LJ, Kautiainen H, Pitkälä KH, Iivanainen M. The nationwide register-based prevalence of intellectual disability during childhood and adolescence. *Journal of intellectual disability research : JIDR*. 2017;61(8):802-809.
- Tassé MJ, Balboni G, Navas P, et al. Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development. *Journal of intellectual disability research : JIDR*. 2019;63(5):386-407.
- Roeleveld N, Zielhuis GA, Gabreëls F. The prevalence of mental retardation: a critical review of recent literature. In. Vol 391997:125.
- Simonoff E, Pickles A, Chadwick O, et al. The Croyden Assessment of Learning study: Prevalence and educational identification of mild mental retardation.(Clinical report). *Journal of Child Psychology and Psychiatry*. 2006;47(8):828-839.
- King TL, Milner A, Aitken Z, Karahalios A, Emerson E, Kavanagh AM. Mental health of adolescents: variations by borderline intellectual functioning and disability. *European child & adolescent psychiatry*. 2019.
- Munir MK. The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder. *Current Opinion in Psychiatry*. 2016;29(2):95-102.
- Dekker MC, Koot HM, Ende JVD, Verhulst FC. Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology and Psychiatry*. 2002;43(8):1087-1098.
- Dekker MC, Koot HM. DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. I: Prevalence and Impact. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2003;42(8):915-922.
- Einfeld SL, Tonge BJ. Population prevalence of psychopathology in children and adolescents with intellectual disability: II epidemiological findings. *Journal of Intellectual Disability Research*. 1996;40(2):99-109.
- Emerson E, Hattton C. Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*. 2007;191(6):493-499.
- Linna SL, Moilanen I, Ebeling H, et al. Psychiatric symptoms in children with intellectual disability. *European child & adolescent psychiatry*. 1999;8 suppl 4:77-82.
- Molteno G, Molteno CD, Finchilescu G, Dawes ARL. Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research*. 2001;45(6):515-520.
- Strømme P, Diseth TH. Prevalence of psychiatric diagnoses in children with mental retardation: data from a population-based study. *Developmental Medicine & Child Neurology*. 2000;42(4):266-270.
- Totsika V, Hastings RP, Emerson E, Lancaster GA, Berridge DM. A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability. *Journal of Child Psychology and Psychiatry*. 2011;52(1):91-99.
- Ruiter dKP. Five-year Development of Psychopathology in Young People with Intellectual Disabilities. In: Amsterdam: Vrije Universiteit; 2013.
- Rutter M, Tizard J, Whitmore K. *Education, health and behaviour*. London: Longman; 1970.
- Einfeld SL, Ellis LA, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, 2011, Vol36(2), p137-143. 2011;36(2):137-143.
- Caplan B, Neece CL, Baker BL. Developmental level and psychopathology: Comparing children with developmental delays to chronological and mental age matched controls. *Research in Developmental Disabilities*. 2015;37:143-151.
- Emerson E, Einfeld S, Stancliffe R. The mental health of young children with intellectual disabilities or borderline intellectual functioning. *The International Journal for Research in Social and Genetic Epidemiology and Mental Health Services*. 2010;45(5):579-587.
- Hodapp RM, Dykens EM. Intellectual disabilities and child psychiatry: looking to the future.(Report). *Journal of Child Psychology and Psychiatry*. 2009;50(12):99-107.
- Dekker MC, Nunn R, Koot HM. Psychometric properties of the revised Developmental Behaviour Checklist scales in Dutch children with intellectual disability. *Journal of Intellectual Disability Research*. 2002;46(1):61-75.
- Dekker MC, Koot HM. DSM-IV Disorders in Children With Borderline to Moderate Intellectual Disability. II: Child and Family Predictors. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2003;42(8):923-931.
- Wallander JL, Dekker MC, Koot HM. Risk factors for psychopathology in children with intellectual disability: a prospective longitudinal population-based study. *Journal of Intellectual Disability Research*. 2006;50(4):259-268.
- de Ruiter KP, Dekker MC, Verhulst FC, Koot HM. Developmental course of psychopathology in youths with and without intellectual disabilities. *Journal of Child Psychology & Psychiatry*. 2007;48(5):498-507.
- De Ruiter KP, Dekker MC, Douma JCH, Verhulst FC, Koot HM. Development of Parent- and Teacher-Reported Emotional and Behavioural Problems in Young People with Intellectual Disabilities: Does Level of Intellectual Disability Matter? *Journal of Applied Research in Intellectual Disabilities*. 2008;21(1):70-80.
- Tonge B, Einfeld S. The trajectory of psychiatric disorders in young people with intellectual disabilities. *Australian and New Zealand Journal of Psychiatry*. 2000;34(1):80-84.
- Foley K-R, Taffe J, Bourke J, et al. Young People with Intellectual Disability Transitioning to Adulthood: Do Behaviour Trajectories Differ in Those with and without Down Syndrome? *PLoS ONE*. 2016;11(7).
- Einfeld SL, Piccinin AM, Mackinnon A, et al. Psychopathology in Young People With Intellectual Disability. *JAMA*. 2006;296(16):1981-1989.
- Fisher MH, Lense MD, Dykens EM. Longitudinal trajectories of intellectual and adaptive functioning in adolescents and adults with Williams syndrome. *Journal of Intellectual Disability Research*. 2016;60(10):920-932.
- Dykens EM. Annotation: Psychopathology in Children with Intellectual Disability. *J Child Psychol Psychiat*. 2000;41(4):407-417.

33. Koskentausta T, Iivanainen M, Almqvist F. Risk Factors for Psychiatric Disturbance in Children with Intellectual Disability. *Journal of Intellectual Disability Research*. 2007;51(1):43-53.
34. Emerson E, Brigham P. Exposure of children with developmental delay to social determinants of poor health: cross-sectional case record review study. *Child: Care, Health and Development*. 2015;41(2):249-257.
35. de Bildt A, Sytema S, Kraijer D, Sparrow S, Minderaa R. Adaptive functioning and behaviour problems in relation to level of education in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research*. 2005;49(9):672-681.
36. Toms G, Totsika V, Hastings R, Healy H. Access to services by children with intellectual disability and mental health problems: Population-based evidence from the UK. *Journal of Intellectual and Developmental Disability*. 2015;40(3):1-9.
37. Douma JCH, Dekker MC, De Ruiter KP, Verhulst FC, Koot HM. Help-Seeking Process of Parents for Psychopathology in Youth With Moderate to Borderline Intellectual Disabilities. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2006;45(10):1232-1242.
38. Kleefman M, Reijneveld SA, Jansen DEMC. Prevalence and determinants of need for formal parenting support among parents raising a child with a borderline to mild intellectual disability. *Journal of Intellectual & Developmental Disability*. 2015;40(1):49-56.
39. Hassiotis A, Turk J. Mental Health Needs in Adolescents with Intellectual Disabilities: Cross-Sectional Survey of a Service Sample. *Journal of Applied Research in Intellectual Disabilities*. 2012;25(3):252-261.
40. Sainero A, Del Valle JF, López M, Bravo A. Exploring the specific needs of an understudied group: Children with intellectual disability in residential child care. *Children and Youth Services Review*. 2013;35(9):1393-1399.
41. Águila-Otero A, González-García C, Bravo A, Lázaro-Visa S, Valle JF. Children and young people with intellectual disability in residential childcare: Prevalence of mental health disorders and therapeutic interventions. *International Journal of Social Welfare*. 2018;27(4):337-347.
42. Scheifes A, de Jong D, Stolker JJ, Nijman HLI, Egberts TCG, Heerdink ER. Prevalence and characteristics of psychotropic drug use in institutionalized children and adolescents with mild intellectual disability. *Research in Developmental Disabilities*. 2013;34(10):3159-3167.
43. McQuire C, Hassiotis A, Harrison B, Pilling S. Pharmacological interventions for challenging behaviour in children with intellectual disabilities: a systematic review and meta-analysis. *BMC psychiatry*. 2015;15(303):303-303.
44. Kok L, van Der Waa A, Klip H, Staal W. The effectiveness of psychosocial interventions for children with a psychiatric disorder and mild intellectual disability to borderline intellectual functioning: A systematic literature review and meta-analysis. In. Vol 21. London, England 2016:156-171.
45. Schuiringa H, Nieuwenhuijzen M, Orobio de Castro B, Lochman J, Matthys W. Effectiveness of an Intervention for Children with Externalizing Behavior and Mild to Borderline Intellectual Disabilities: A Randomized Trial. *Cognitive Therapy and Research*. 2017;41(2):237-251.
46. Blankestein A, van Der Rijken R, Eeren HV, et al. Evaluating the effects of multisystemic therapy for adolescents with intellectual disabilities and antisocial or delinquent behaviour and their parents. *Journal of applied research in intellectual disabilities : JARID*. 2019;32(3):575.