

Psychopathology in Young People With Intellectual Disability

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INTELLECTUAL DISABILITY AFFECTS approximately 1% to 3% of the population in developed countries.¹ Young people with intellectual disability have been found to have levels of psychopathology approximately 3 to 4 times higher than that of typically developing children.²⁻⁷ Given these figures, the number of young people with intellectual disability and psychopathology is comparable with schizophrenia, a disorder that is the subject of extensive research and well recognized by the medical community. Psychopathology with intellectual disability is a major cause of failure of community residential placement,^{8,9} reduced occupational opportunity in the postschool period,¹⁰ and leads to major restrictions in participation in recreational and educational programs.¹¹

Despite this, little attention has been given to the public health issue of psychopathology in intellectual disability. This problem was highlighted by a major US report, the Surgeon General's Conference on Health Disparities and Mental Retardation.¹² In particular, little research has examined the course of these problems in this popu-

Context Comorbid severe mental health problems complicating intellectual disability are a common and costly public health problem. Although these problems are known to begin in early childhood, little is known of how they evolve over time or whether they continue into adulthood.

Objective To study the course of psychopathology in a representative population of children and adolescents with intellectual disability.

Design, Setting, and Participants The participants of the Australian Child to Adult Development Study, an epidemiological cohort of 578 children and adolescents recruited in 1991 from health, education, and family agencies that provided services to children with intellectual disability aged 5 to 19.5 years in 6 rural and urban census regions in Australia, were followed up for 14 years with 4 time waves of data collection. Data were obtained from 507 participants, with 84% of wave 1 (1991-1992) participants being followed up at wave 4 (2002-2003).

Main Outcome Measures The Developmental Behaviour Checklist (DBC), a validated measure of psychopathology in young people with intellectual disability, completed by parents or other caregivers. Changes over time in the Total Behaviour Problem Score and 5 subscale scores of the DBC scores were modeled using growth curve analysis.

Results High initial levels of behavioral and emotional disturbance decreased only slowly over time, remaining high into young adulthood, declining by 1.05 per year on the DBC Total Behaviour Problem Score. Overall severity of psychopathology was similar across mild to severe ranges of intellectual disability (with mean Total Behaviour Problem Scores of approximately 44). Psychopathology decreased more in boys than girls over time (boys starting with scores 2.61 points higher at baseline and ending with scores 2.57 points lower at wave 4), and more so in participants with mild intellectual disability compared with those with severe or profound intellectual disability who diverged from having scores 0.53 points lower at study commencement increasing to a difference of 6.98 points below severely affected children by wave 4. This trend was observed in each of the subscales, except the social-relating disturbance subscale, which increased over time. Prevalence of participants meeting criteria for major psychopathology or definite psychiatric disorder decreased from 41% at wave 1 to 31% at wave 4. Few of the participants (10%) with psychopathology received mental health interventions during the study period.

Conclusion These results provide evidence that the problem of psychopathology comorbid with intellectual disability is both substantial and persistent and suggest the need for effective mental health interventions.

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lation over time. Longitudinal studies, with data subject to appropriate modern methods of analysis, are desirable to describe the nature and course of a problem, examine risk and protective factors in the development or amelioration of pathology, and thus inform the development of preventative and intervention programs. A workshop convened by the National Institutes of Health, "Emotional and Behavioral Health in Persons With Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities,"¹³ specifically recommended "longitudinal studies to examine key life-stage transitions regarding risk and protective factors."

Although there have been a number of cross-sectional¹⁴⁻¹⁶ and short-term follow-up studies,¹⁷⁻²¹ only 1 study⁵ has previously examined behavioral and emotional problems in children and adolescents with intellectual disability from childhood through adulthood. A birth cohort in Scotland of 221 children with predominantly mild intellectual disability found that 65% of those who had behavioral problems as children continued to present with problems at 22 years.⁵

The studies to date have had several shortcomings. A number of studies were not community samples, were limited in terms of the range of intellectual disability that was included in the sample, or did not use psychometrically strong measures of psychopathology. Furthermore, findings have been based on changes in group means, which may obscure substantial individual change. In addition, the effect of age, sex, and degree of intellectual disability on psychopathology and on the level and course of behavioral and emotional problems has yet to be documented.

Our study goal was to address these questions using the Developmental Behaviour Checklist (DBC) as a measure of psychopathology and by applying modern methods of analysis that are able to accommodate individual differences.

We described psychopathology in 2 ways in our study. First, we examined psychopathology as a continuous variable, measuring severity of psychopathology. Then, we addressed change in psychopathology as a categorical variable, equivalent to meeting criteria for psychiatric disorder.

METHODS

Sample

The Australian Child to Adult Development Study (ACAD) was an epidemiological cohort of 578 children and adolescents aged 4 to 19.5 years at wave 1 (1991-1992), who were recruited in 1991 from every health, education, and family agency that provided services to children with intellectual disability of all levels and whose families lived in 6 census districts in the states of New South Wales and Victoria, Australia. For those children and adolescents with moderate and severe or profound intellectual disability, ascertainment was likely to be virtually complete. However, as in other studies, some young people with the mildest forms of intellectual disability blend in to the normal population and may not have been identified because they may not have impairments that required services. Those children and adolescents in the cohort with mild intellectual disability may therefore be biased toward higher levels of disturbance. This sample has been shown to be representative of the general Australian community in terms of mix of social class, ethnic diversity, and rural-urban environment.²² Further details of the sample are given in a previous article.³

Institutional review board and ethics approval was obtained from the Monash University Standing Committee on Ethics in Research on Humans, Melbourne, Australia; South Eastern Sydney Area Health Service Research Ethics Committee—Eastern Section, Randwick, Australia; and the University of New South Wales Committee on Experimental Procedures Involving Human Subjects, Kensington, Australia. All participants were provided with information and consent

forms. When participants were capable of signing the consent form themselves, they signed it; however, when they were not capable of signing it, legal guardians consented on their behalf.

Outcome Measures

Developmental Behaviour Checklist. The DBC^{23,24} was the key measure of psychopathology in young people with intellectual disability aged 4 to 19 years. It is a 96-item instrument that is completed by parents or other primary caregivers (primary care version [DBC-P]). The DBC is structurally similar to the Child Behavior Checklist,²⁵ a widely used measure of psychopathology in young people without intellectual disability. It shares the same stem instructions, although the items of the DBC were derived entirely independently. The concepts of psychopathology it measures are also similar to those measured by the Child Behavior Checklist.

The DBC provides measures of overall behavioral and emotional disturbance (Total Behaviour Problems Score [TBPS]) and 5 subscale scores derived from factor analysis. To assess the relationship between DBC TBPS and psychiatrists' ratings of psychopathology, psychiatrists experienced in the mental health of children and adolescents with intellectual disability assessed participants blind to the DBC TBPS. The psychiatrists provided a rating of severity of psychopathology on 3 domains, each scored on a 0, 1, and 2 rating. These subscales quantified the components of the definition used by Rutter and Hersov in the Isle of Wight studies.²⁶ This is similar to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* concept of mental disorder.²⁷ These domains are abnormality or clinical significance; distress to person or caregivers; and impairment to adaptive functioning, beyond that resulting from intellectual disability itself.

The TBPS was strongly associated with child psychiatrists' ratings of severity of psychopathology in instrument validation studies ($r=0.81$,

$P < .001$), and again during the course of this study ($r = 0.82$, $P < .001$). The TBPS has been shown to be sensitive to change as rated independently by expert assessors.²⁸ When psychiatrists' rating on the sum of the 3 subscale ratings totalled 4 or higher (out of 6 total), the participant was regarded as having a definite psychiatric problem. A score of 46 or higher on the TBPS corresponded with the psychiatrists' diagnosis of a definite psychiatric disorder, with a sensitivity of 0.80 and a specificity of 0.88 and with an area under the receiver operating curve of 0.92.

The TBPS was also associated with biological factors, such as genetic cause of intellectual disability,^{29,30} psychosocial factors including parental distress³¹ and family functioning, and intervention factors including type of special education received.¹¹ The 5 subscales scores were named "disruptive," "self-absorbed," "communication disturbance," "anxiety," and "social-relating disturbance." Sample items from these subscales are shown in the BOX, providing an indication of the constructs they measure. Some psychometric properties of the DBC are test-retest reliability (intraclass correlation coefficient = .83), internal consistency (Cronbach $\alpha = .94$), interrater reliability between parents (intraclass correlation coefficient = .80), interrater reliability between parents and nurses (intraclass correlation coefficient = .83), and interrater reliability between teachers and teacher aides (intraclass correlation coefficient = .60).^{23,24}

Beginning at 19 years in wave 4 (2002-2003), behavioral problems were measured using an adapted form of the DBC, the DBC-Adult (DBC-A). The DBC-A contains 12 new items and drops 1 item from the DBC-P (parent), which was used at the younger ages. For the current analysis, to maximize comparability of scores between the child and adult versions, the adult measure was scored according to the child factors, and missing values due to the dropped item were prorated.

Degree of Intellectual Disability. Children were categorized as having a

Box. The Developmental Behaviour Checklist Subscales and Sample Items

Disruptive

Abusive, swears at others
Tells lies
Stubborn, disobedient, or uncooperative
Tries to manipulate or provoke others

Self-absorbed

Hums, whines, grunts, squeals, or makes other nonspeech noises
Bangs head
Eats nonfood items (eg, dirt, grass, soap)
Chews or mouths objects or body parts

Communication Disturbance

Arranges objects or routine in a strict order
Confuses the use of pronouns (eg, uses "you" instead of "I")
Talks to self or imaginary people or objects
Repeats back what others say like an echo
Speaks in whispers, high-pitched voice, or other unusual tone or rhythm

Anxiety

Excessively distressed if separated from familiar person
Distressed about being alone
Fears particular things or situations (eg, the dark or insects)
Upset and distressed over small changes in routine or environment

Social-Relating Disturbance

Doesn't show affection
Appears depressed, downcast, or unhappy
Aloof, in his/her own world
Resists being cuddled, touched, or held

mild, moderate, or severe or profound degree of intellectual disability. Categorization was based on the results of IQ assessments, according to the ranges of mental retardation specified by the *DSM-IV*.²⁷ In our analysis, there were 96 boys and 70 girls with mild intellectual disability, 112 boys and 94 girls with moderate intellectual disability, and 81 boys and 54 girls with severe or profound intellectual disability.

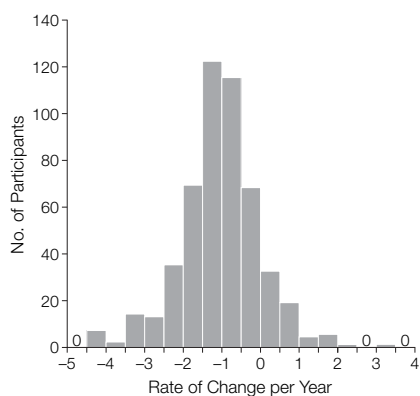
Procedure

The ACAD study gathered data on a range of demographic variables, including receipt of mental health services.²² Data collection took place at 4 time points: wave 1 (1991-1992), wave 2

(1995-1996), wave 3 (1999), and wave 4 (2002-2003) by means of a mail-out survey of a questionnaire booklet to the parents and caregivers of young people with intellectual disability. In addition, psychiatric interviews were conducted by clinicians who are experts in the mental health of individuals with intellectual disability on a subsample of participants between waves 1 and 2 and waves 3 and 4 to extend validity data on the DBC.

We also asked informants whether the participant had received any professional intervention to address any identified behavioral problems. We ranked the interventions as to whether they were received from a specialist in

Figure 1. Histogram of Individual Slopes of Developmental Behaviour Checklist Total Score (Points per Year)



both mental health and intellectual disability, a specialist in one but not the other, or a nonspecialist in either. We rated the first of these as specialist mental health interventions.

Statistical Analysis

Random coefficients (multilevel) modeling was used to perform what is also known as growth curve analysis.³² Growth curve analysis serves as a primary analytic method when the outcome is measured on a continuous scale. Conceptually, these models involve estimating individual regressions of the DBC-P on time and adding, at the next level, predictors of the regression parameters of individual trajectories (ie, each participants' intercept and slope). The level 1 model summarizes individual DBC-P values on each occasion of measurement in terms of "true" initial level of disturbance (intercept), slope (rate of change), and error (residual) parameters. The level 2 model estimates average (fixed) effects and random (ie, varying according to the randomly sampled individuals in any study) intraindividual differences. The level 2 component of a model can include predictors of individual differences, group differences, or both in level 1 intercept and slope parameters. The advantage of these methods over standard analysis of variance or regression techniques is their emphasis on individual trajectory

rather than on average values at each occasion. Furthermore, random coefficient models take into account the lack of fit of the imposed model for individual participants. Detailed descriptions of these methods are available elsewhere.³²⁻³⁵

The univariate random coefficients model is expressed as

$$y_{ij} = \beta_0 + \beta_1(\text{time}_{ij}) + U_{0i} + U_{1i}(\text{time}_{ij}) + R_{ij}$$

where y_{ij} is the dependent variable (ie, TBPS) measured at occasion j in person i ; time_{ij} is, for this model, the length of time person i has been in the study at occasion j ; β_0 is the average fixed intercept; β_1 is the average fixed slope (rate of change) over time; U_{0i} is the random intercept for person i ; U_{1i} is the random slope over time for person i ; and R_{ij} is the residual for person i at occasion j . The between-person variance components, $\text{var}(U_{0i})$ and $\text{var}(U_{1i})$, reflect individual differences in level and rate of change, respectively. The within-person variance component, $\text{var}(R_{ij})$, reflects the variability of individuals from their predicted values at each measurement occasion.

Models were fitted using SAS version 9.1 PROC MIXED (SAS Institute Inc, Cary, NC) using restricted maximum likelihood and were based on a time-in-study data structure that permits individually varying intervals between occasions of measurement. Evaluation of initial status and change over time made use of maximum likelihood estimation methods that adjusted for attrition effects to the extent that such effects were differentially related to level of intellectual deficit, sex, or age of the child. Maximum likelihood and multiple imputation methods yield unbiased population estimates conditional on covariates that are responsible for differential missingness and attrition under the assumption that observations are missing at random.

A univariate model was estimated for the TBPS. The intercept was specified at the first occasion of measurement, and age at wave 1 was centered at the

mean (12.0 [SD, 3.9]). Follow-up occurred an average of 4.5, 7.5, and 11.5 years later for waves 2, 3, and 4, respectively. Predictors included sex (boys as the referent) and intellectual disability (mild, moderate, or severe or profound; mild as the reference groups). The intercept represents the average score for boys at 12 years who have mild intellectual disability.

We first examined the shape of the TBPS trajectory and then the extent to which trajectory parameters varied between individuals. A model including fixed effects for linear and quadratic components of time was compared with a model with the same fixed effects of time but in which the linear effect of time was allowed to vary randomly over individuals (an unstructured covariance matrix was specified). The difference in the deviance statistics (-2 times the log likelihood value) between these 2 models was significant for each outcome, indicating that the rate of change (in addition to the intercept) varied significantly across individuals for all of the outcomes. The quadratic effect of time was not significant, so it was not retained; change was therefore modeled as a straight line.

All main effects and their interactions with the linear effect of time remained in the model regardless of the significance of the effect. Higher-order interactions were allowed to remain in the residual. The linear effect of time (ie, slope) was negative, indicating that severity of problems decreased over time, for all scales except social-relating disturbance.

RESULTS

Participant Characteristics

The mean (SD) age of the entire epidemiological cohort at wave 1 was 12.1 (4.4) years; at wave 2, 16.5 (4.5) years; at wave 3, 19.5 (4.5) years; and at wave 4, 23.5 (4.5) years. Participation was consistently high throughout the study. The response rate, excluding the 31 participants who died since wave 1, at wave 2 was 82.5% ($n=477$), 78.5% ($n=448$) at wave 3, and 84.0% ($n=438$)

at wave 4. Analyses were limited to individuals who were aged 5 to 19.5 years at wave 1. Thus, the total number of participants at wave 1 was 507.

TBPS Values

Mean TBPS values for 12-year-old boys with mild intellectual disability (reference group) was initially 44.14 of a possible 190 (95 items with a maximum score of 2). That is, the mean TBPS values in this group were close to the clinical cutoff score for psychiatric disorder. On average, TBPS values decreased significantly over time in this group, by about 1 point (−1.05) per year. FIGURE 1 shows a histogram of slope coefficients for all participants. Reflecting the diversity of patterns of change over time, rates of change varied from −4.37 to 3.17 (95% of slopes decreased between −2.83 and 0.62). Although the majority of participants showed a decline in scores (negative slope), 62 (12%) had a positive slope, indicating a tendency for TBPS values to increase over time in these individuals. The variances of the intercepts and the slopes

were statistically significant ($P < .001$). The coefficient estimates and SEs for each predictor are shown in the TABLE.

Although girls scored on average 2.61 points less than boys on psychopathology at the first occasion of measurement, this difference was not statistically significant. However, the girls show a significantly slower rate of decline in problem behaviors (−1.05 + 0.45 = −0.60 per year; $P = .03$).

Differences between initial TBPS values for the intellectual disability groups were not significant. However, the scores of those participants with mild intellectual disability declined more rapidly than those with severe or profound intellectual disability ($P = .02$). The rate of change for the moderate group was in between the mild and severe or profound groups. These factors suggest that the more severe the intellectual disability, the less rapidly problem behaviors decline. FIGURE 2 presents the expected 11.5-year trajectories for boys and girls with mild and severe or profound intellectual disability aged 12 years at the outset of the study.

DBC Subscales

Parallel information for each of the DBC subscales is provided in the Table and Figure 2. All subscale scores declined significantly over time, except social-relating disturbance, which increased. However, age, severity of intellectual disability, and sex affected this change as follows. For the disruptive subscale, those participants with mild intellectual disability scored significantly higher than those with severe or profound intellectual disability, but showed larger decreases over time. For the self-absorbed subscale, those participants with severe or profound intellectual disability had the highest scores. Older individuals had lower self-absorbed scores, but decreased at a slower rate. Similarly, older individuals had lower anxiety scores that decreased at a slower rate. Anxiety in girls decreased at less than half the rate for boys, and individuals with severe or profound intellectual disability similarly decreased less than those with mild intellectual disability. In fact, for girls with severe or pro-

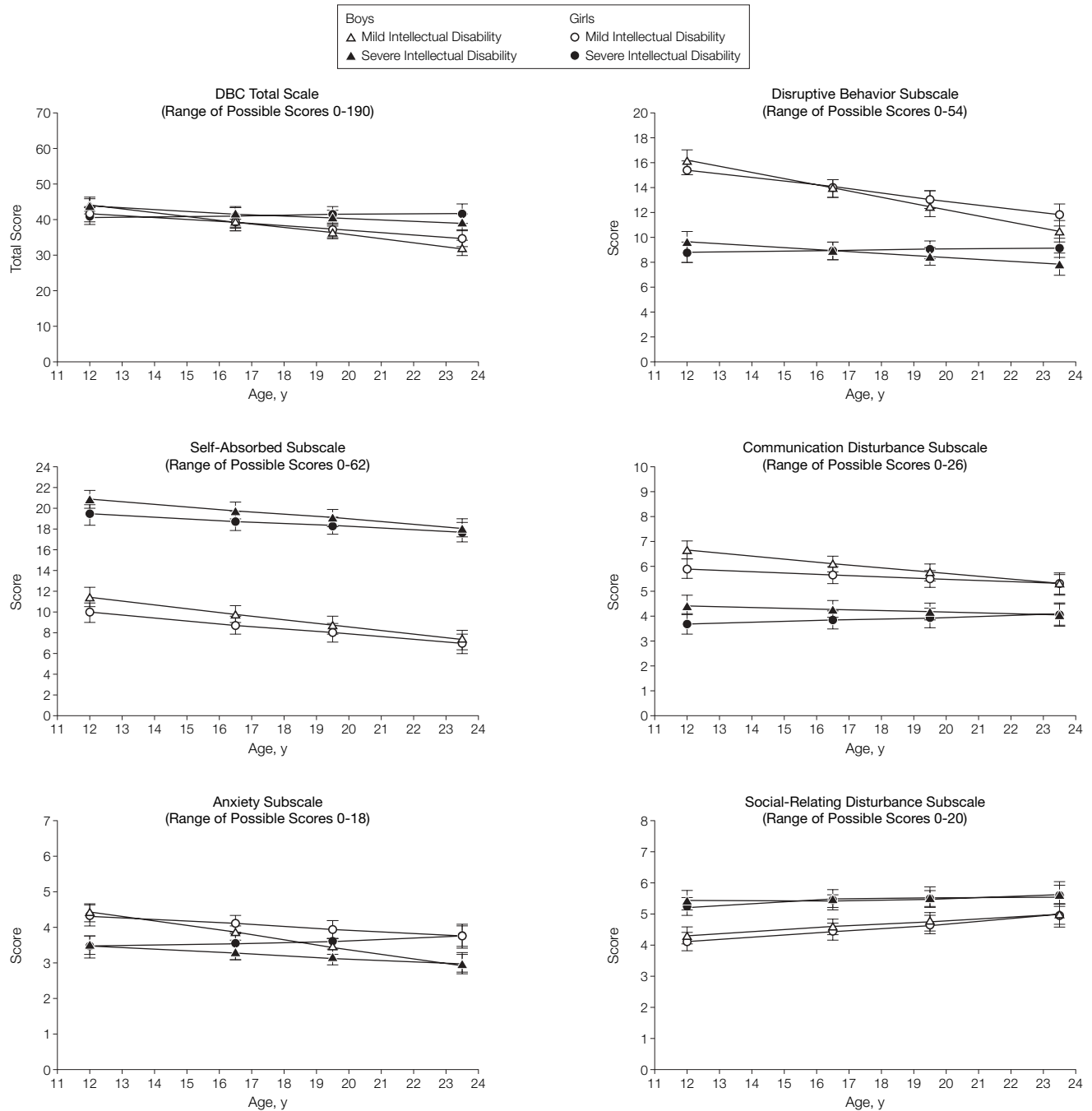
Table. Growth Curve Model Estimates for DBC Total Score (Full Sample and Mother Raters Subgroup) and 5 Social Subscales*

	Initial Estimate (SE)						
	DBC	DBC, Mother Rating	Disruptive	Self-absorbed	Communication Disturbance	Anxiety	Social-Relating Disturbance
Fixed effects							
Intercept†	44.14 (2.07)‡	40.59 (2.39)‡	16.16 (0.80)‡	11.40 (0.82)‡	6.63 (0.36)‡	4.40 (0.26)‡	4.32 (0.29)‡
Age	−0.27 (0.28)	−0.37 (0.35)	0.03 (0.11)	−0.43 (0.11)‡	0.02 (0.05)	−0.07 (0.04)§	0.11 (0.04)‡
Girls	−2.61 (2.14)	1.28 (2.71)	−0.86 (0.83)	−1.49 (0.85)	−0.75 (0.38)§	−0.07 (0.27)	−0.14 (0.30)
Intellectual disability							
Moderate	−0.24 (2.49)	−0.61 (2.92)	−1.51 (0.97)	2.07 (0.99)§	0.06 (0.44)	−0.15 (0.32)	−0.26 (0.34)
Severe or profound	−0.53 (2.77)	−0.90 (3.93)	−6.56 (1.08)‡	9.48 (1.10)‡	−2.20 (0.49)‡	−0.90 (0.35)§	1.18 (0.38)‡
Rate of change							
Intercept†	−1.05 (0.20)‡	−0.60 (0.24)§	−0.50 (0.07)‡	−0.36 (0.07)‡	−0.12 (0.04)‡	−0.13 (0.03)‡	0.06 (0.03)§
Age	0.001 (0.03)	−0.01 (0.03)	0.001 (0.01)	0.02 (0.01)§	−0.01 (0.005)‡	0.01 (0.004)§	−0.01 (0.004)§
Girls	0.45 (0.21)§	0.19 (0.26)	0.19 (0.08)§	0.10 (0.08)	0.07 (0.04)	0.07 (0.03)§	0.01 (0.03)
Intellectual disability							
Moderate	0.21 (0.25)	0.16 (0.28)	0.14 (0.09)	−0.04 (0.09)	0.04 (0.05)	0.03 (0.03)	0.01 (0.04)
Severe or profound	0.65 (0.28)§	0.31 (0.40)	0.34 (0.10)‡	0.11 (0.10)	0.08 (0.05)	0.08 (0.04)§	−0.04 (0.04)
Variance components							
Intercept	445.83 (36.47)‡	435.43 (43.77)‡	69.01 (5.52)‡	73.64 (5.76)‡	12.63 (1.14)‡	6.28 (0.60)‡	7.12 (0.71)‡
Slope	2.40 (0.35)‡	2.51 (0.40)‡	0.29 (0.05)‡	0.29 (0.05)‡	0.07 (0.01)‡	0.04 (0.01)‡	0.03 (0.01)‡
Residual	154.16 (7.99)‡	109.68 (7.40)‡	21.51 (1.10)‡	20.77 (1.08)‡	6.23 (0.33)‡	3.78 (0.20)‡	4.62 (0.24)‡

Abbreviation: DBC, Developmental Behaviour Checklist.
 *Relative to mild intellectual disability group; n = 507, except for mother-only analysis (n = 296).
 †The reference group is 12-year-old boys with mild intellectual disability.
 ‡ $P < .01$.
 § $P < .05$.

found intellectual disability, there was an increase in anxiety, particularly at older ages (0.07 points per year). Communication disturbance was more prominent in the mild compared with the severe or profound intellectual disability group. More rapid decreases in scores were observed in the older individuals. The social-relating disturbance subscale was higher for older individuals and those with severe or profound intellectual

Figure 2. Model-Based Expected Trajectories of Total DBC and Subscale Scores for Boys and Girls With Mild and Severe or Profound Intellectual Disability Aged 12 Years at First Visit



DBC indicates Developmental Behaviour Checklist. Standard error bars are shown.

disability; and, in contrast with the other scales, increased over time, although at a slower rate for older individuals.

Children With Changes in Raters

During the course of the study, some participants moved from home to residential care. Many of these participants continued to be rated on the DBC by their parents by virtue of their close, ongoing involvement with their children. However, in an average of 13% of participants across the 4 time waves, staff of the facility completed the instrument.

To address any effects of change in rater, a subsidiary analysis including only data from those participants who were rated consistently by their mothers ($n=296$) was undertaken. The Table shows that this subgroup had a 3-point lower intercept (40.59) and a smaller (by close to half) but still statistically significant decrease in problem behaviors over time (-0.60).

Prevalence of Definite Psychiatric Disorder

At wave 1, 41% of participants met criteria for major psychopathology, or definite psychiatric disorder. At wave 4, this prevalence had decreased to 31%.

Mental Health Interventions

Only 10% of those participants with definite psychiatric disorder received specialist mental health interventions.

COMMENT

The analyses presented use an individual differences approach to the investigation of changing patterns of psychopathology and behavioral disturbance over time. The overarching finding was one of a small, albeit significant, decline in severity of overall psychopathology over the 14 years in which the young participants with intellectual disability were followed up. Coupled with the absence of any relationship with age in the TBPS, the small size of this decline demonstrates that psychopathology and behavioral disturbance in young people

with intellectual disability is a phenomenon that largely persists through to young adulthood.

Only 10% of the children in this study who had clinically significant levels of psychopathology received specialist mental health services.^{3,22} Therefore, the findings are likely to reflect the natural history of psychopathology in young people with intellectual disability independent of any specific mental health intervention. Consequently, the findings present a basis for planning to address the public health problem of psychopathology complicating intellectual disability.

First, the application of established cutoff scores for psychiatric disorder on the DBC TBPS^{3,24} make it clear that major behavioral and emotional disturbance is an added burden for approximately 40% of parents of children and adolescents with intellectual disability. Consequently, programs providing support for such parents need to include mental health interventions effective in altering the trajectories we have identified. Second, the small degree of improvement during the school years means that educational settings for young individuals with intellectual disability will be required to contain high rates of psychopathology in their student groups, while attempting to maximize learning of independence skills. Third, in the postschool period, the critical task of establishing maximum vocational independence will also be threatened by mental health problems. Consequently, if the number of young persons requiring disability support pensions, and the community cost thereof, is to be minimized, effective mental health interventions and vocational flexibility will be required.

The prevalence of TBPS scores higher than 45, indicating definite psychiatric disorder, declined from approximately 41% to 31%. This decrease seems large in comparison with the small estimated overall decline in TBPS, but this may be accounted for by the cutoff being very close to the mean score at wave 1, so that a small decline

in severity leads to a large number of participants at below the cutoff.

In common with other studies, these estimates of prevalence are subject to both measurement and sampling error. Nevertheless, the indicative prevalence rates are higher than the rates found in a review of 52 studies of prevalence of psychopathology in children and adolescents without intellectual disability, which used a range of different methodologies.³⁶ In that review, the median rates were 12% for preadolescents and 15% for adolescents. We did not identify a comparable review of prevalence studies of psychopathology in young adults without intellectual disability, so comparison with this age group is more difficult. Although not identical in methods, 1 study that may provide some comparison is the study by the Australian Bureau of Statistics.³⁷ This study also used a cutoff score on a continuous measure to estimate a prevalence of psychiatric illness in adults. A 1-month prevalence of high or very high psychological distress of 13% was found.³⁷

Notwithstanding the overall change, there was statistically significant variance between individuals both in terms of initial levels of disturbance and subsequent change during the course of the study. From the clinical perspective, it is desirable to explain observed individual differences. These differences in level or change between individuals were in part explained by sex and severity of intellectual disability. The finding of a difference between boys and girls in the course of overall psychopathology to some extent corresponds with findings of male predominance prepuberty and the reversal to female predominance postpuberty in normally developing children. However, this is also modified by levels of intellectual disability, with those individuals with the most severe or profound intellectual disability declining less than those with milder intellectual disability. One explanation for this could be that those individuals with more severe congenital brain impairment are less affected by any rehabilitative or en-

environmental influences on development.

The decreases in the disruptive, self-absorbed, communication disturbance, and anxiety subscales for the overall group parallel that of the TBPS values. Given the general trend for scores to decline, the findings of increases in scores are intriguing. At this stage, the reasons for this are unknown. Perhaps the increase in anxiety for the girls with severe or profound intellectual disability and the increase in social-relating disturbance may reflect the increased demands on social skills experienced by young people with intellectual disability once they leave the protective school environment. This finding warrants further exploration, particularly in terms of examining other variables, such as the transitions experienced by young people as they leave school or move out of the family home.

That sex and severity of intellectual disability only partly explain individual differences justifies the need to search more widely for possible predictors of change or to examine at a more detailed level the nature of the changes by disaggregating the DBC total score. It may also warrant investigating the characteristics of individuals with particular types of trajectories. This exploratory approach would seek to define classes of individuals on the basis of patterns of initial status and change, and then compare the attributes of these classes. In contrast with these individual-centered analyses, it may also warrant examining individual items from the DBC to determine whether individual components of the DBC exhibit differential change, and whether these changes are influenced by different factors. Such differential change patterns may be obscured in the total score. In addition, we plan in future studies to explore the range of biopsychosocial variables assessed in the ACAD study in an attempt to delineate predictors of individual mental health trajectories.

The possibility of differences in DBC scores that are partly ascribable to rat-

ers must be acknowledged. However, differences between raters may be confounded with child characteristics, as those participants with behavioral problems may be more likely to move into residential care. Our findings point to the likelihood that the reduction in psychopathology over time is not an artifact due to any change in the caregivers who observe the young person's behavior.

These findings are robust yet available internationally, given the representativeness of the sample especially with respect to those participants with moderate and severe or profound levels of intellectual disability, the high participation rate over time, the validity of the psychopathology assessment, and the approach to data analysis. The observation that severe psychopathology was already present in a high proportion of the cohort at commencement of the study, and the persistence of these symptoms, suggest the need for effective mental health interventions. This should include support, education, and skills training for their parents who are likely to be stressed by the burden of care.³⁸ Without effective interventions, these data could lead to the prediction that this sizable and neglected public health problem will also continue to be a burden on families, communities, and governments.

Author Contributions: Drs Einfeld and Tonge had full access to all of the data in the study and take responsibility for the integrity of the data. Drs Piccinin, Hofer, Hoffman, and Mackinnon, and Mr Bontempo take responsibility for the accuracy of the data analysis.

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Analysis and interpretation of data: Einfeld, Piccinin, Mackinnon, Hofer, Taffe, Gray, Bontempo, Hoffman, Parmenter, Tonge.

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Art is a human product, a human secretion; it is our
body that sweats the beauty of our works.
—Émile Zola (1840-1902)