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The longitudinal relationship between behavior and emotional disturbance in young people with intellectual disability and maternal mental health

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Abstract

Although elevated rates of parent psychosocial distress have been associated with child behavior and emotional problems, little is known about the nature of this relationship over time. This study followed an epidemiological cohort of children and adolescents over 11 years with 4 waves of data collection. Within this cohort, complete data were available on 238 mothers and their children. Behavior and emotional problems were assessed using the DBC, maternal mental health with the GHQ. Multivariate growth curve modelling was used to evaluate the commonality of individual change patterns. High levels of mental health problems were reported, which were stable over time. Higher scores on the DBC were associated with higher rates of mental health problems. Increases in child social relating problems were associated with increases mental health symptoms, particularly depression and anxiety.

Keywords

Behavior and emotional problems; maternal mental health

1. Introduction

For many years, research in the field of intellectual disability (ID) has considered parent well being. Studies have demonstrated that mothers and fathers of children with ID suffer from significantly elevated levels of stress (Dyson, 1993; Dyson, 1997; Khamis, 2007; White & Hastings, 2004), and psychopathology (usually depression or anxiety), compared to the parents of children without ID (Beck, Hastings, Daley, & Stevenson, 2004; Emerson, 2003; Feldman et al., 2007; Olsson & Hwang, 2001; White & Hastings, 2004).

It has been reported that these elevated rates of parent psychosocial distress are not related to severity of ID *per se*, but rather to the extent of child behavior problems. This has been demonstrated for the parents of preschool children with developmental delay (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker, Blacher, & Olsson, 2005; Herring et al., 2006), and for parents of school age children and adolescents with autism (Lecavalier, Leone, &

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Wiltz, 2006). Similar findings have also been reported for the parents of children, adolescents, and adults with ID (Abbeduto et al., 2004; Beck et al., 2004; Feldman et al., 2007; Hassall, Rose, & McDonald, 2005; Maes, Broekman, Dosen, & Nauts, 2003; McIntyre, Blacher, & Baker, 2002; Nachshen, Garcin, & Minnes, 2005; Orr, Cameron, Dobson, & Day, 1993; Seltzer, Greenberg, & Krauss, 1995).

Researchers have consistently demonstrated that children and adolescents with ID present with behavior and emotional problems three to four times higher than typically developing children (Dekker, Nunn, Einfeld, Tonge, & Koot, 2002; Einfeld & Tonge, 1996b; Linna et al., 1999; Richardson & Koller, 1996; Rutter, Tizard, & Whitmore, 1970; Wallander, Dekker, & Koot, 2003). Whilst these problems have been shown to persist into adolescence and adulthood (de Ruiter, Dekker, Verhulst, & Koot, 2007; Einfeld et al., 2006; Richardson & Koller, 1996), little research has examined the nature of the relationship between child behavior and emotional problems and parent psychosocial stress over time.

Some longitudinal research has suggested that parent psychological well-being improves over time, with a decline in depressive symptomatology (Flaherty & Glidden, 2000; Glidden & Schoolcraft, 2003; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). However, in adolescents and adults with autism elevated maternal anxiety was found to be stable over an 18 month period of time (Lounds, Seltzer, Greenberg, & Shattuck, 2007). In cases where child behavior problems decreased, associated decreases in maternal anxiety and depression were reported. Longitudinal research has shown that increased behavior and mental health problems in adult children with ID are associated with maternal depressive symptomatology and pessimism (Esbensen, Seltzer, & Greenberg, 2003; Essex, Seltzer, & Krauss, 1999; Orsmond, Seltzer, Krauss, & Hong, 2003).

Although it has been proposed that child behavior problems lead to parental stress (Hastings, 2002), studies suggest that this may be bidirectional relationship (Baker et al., 2003; Lecavalier et al., 2006; Orsmond et al., 2003). In preschool children it has been noted that this relationship is mediated by parental optimism (Baker et al., 2005) and in adults by a parental problem-focussed coping style (Essex et al., 1999).

Although acknowledging that there is a relationship between parent well-being and child behavior and emotional problems, research suffers from a number of inconsistencies and shortcomings. In contrast to the majority of research in this area, some studies have suggested good outcomes in terms of psychological well-being for parents over time (Flaherty & Glidden, 2000; Glidden & Schoolcraft, 2003; Seltzer et al., 2001). However, a significant proportion (50%–100%) of samples studied consisted of children with Down syndrome (Flaherty & Glidden, 2000; Glidden & Schoolcraft, 2003), retrospectively collected parent mental health data (Flaherty & Glidden, 2000), or did not consider child behavior problems (Glidden & Schoolcraft, 2003; Seltzer et al., 2001). As lower rates of behavior problems are seen in children and adolescents with Down syndrome (Einfeld, Tonge, Gray, & Taffe, 2007), reported positive outcomes may be a function of this bias. Longitudinal research focussing on psychological stress and child behavior problems to date has consisted of varying follow-up periods of 12–24 months in children and 1.5–6 years in adults. In order to more fully understand the relationship between behavior and emotional problems and parental psychological distress, research in large, non-syndrome specific samples, over longer periods of time is needed.

Current study

Material previously published by the authors established high levels of behavior and emotional problems in children and adolescents with ID, which were largely persistent over a follow-up period of 11 years (Einfeld et al., 2006). Although persistently high over time,

statistically significant decreases in overall behavior and emotional problems were observed, although this change was impacted by age, degree of ID, and gender. In general, the more severe the degree of ID, the slower the rate of change. In contrast, social relating problem behaviors increased over time for the entire sample, whilst anxiety increased for girls with severe-profound ID. This study aimed to build upon these findings by exploring the relationship between child behaviour problems and maternal mental health over time.

The study therefore aimed to (1) investigate whether there are elevated levels of mental health symptoms in the parents of young people with ID, (2) whether parental mental health is associated with child behavior and emotional problems, and (3) investigate how child behaviour and emotional problems and maternal mental health relate to each other over time. It was hypothesised that parent reported mental health symptoms would be higher than normative rates, and would decrease over time. Having previously reported both decreases and increases in terms of child behavior problems from childhood to early adulthood (Einfeld et al., 2006), it was anticipated that decreases in child behavior problems would be associated with decreases in parent reported mental health symptoms. Similarly, it was hypothesised that increases in child behavior problems over time would be associated with increases in parent mental health symptoms.

In this report, we evaluate the associations among initial status and rates of change in the Developmental Behaviour Checklist (DBC) subscales from childhood through adolescence and into early adulthood and indicators of mental health of parents using multivariate growth curve modelling (Sayer & Willett, 1998; Sliwinski, Hofer, & Hall, 2003). These models permit direct evaluation of covariation among individual differences in initial status, rates of linear change, and time-specific deviations (i.e., within-person correlation) across the five DBC subscales and parental outcomes (total score, plus four subscales). Correlations among the initial levels (i.e., intercepts) indicate similarity in the relative ordering of individuals at their initial time point across outcomes (i.e., relations among individual differences in initial status). Correlations among the slopes indicate the extent to which individual differences in change in one outcome are related to individual differences in change in another (i.e., correlated change). Correlations among residuals—often neglected in the modelling of associations between trajectories—provide an estimate of systematic time-specific fluctuation in emotional and behavior disturbance measured three to four years apart after accounting for an individual's growth trajectory. Residuals in these models are a combination of reliable and error variance so that correlations between them represent a lower bound of strength of association. These outcomes provide distinct and complementary evidence regarding the structure or commonality of change by examining correlated rates of change and coupling of temporal dynamics of psychopathology outcomes with indicators of parental mental health (Snijders & Bosker, 1999).

2. Method

2.1 Sample

The ACAD study epidemiological cohort (n=578) was recruited in 1991 from every health, education, and family agency that provided services to children with ID of all levels, whose families lived in six census districts of the states of New South Wales and Victoria, Australia. The first wave was composed of individuals aged 4 to 19 years whose families lived in the six census districts. These districts were selected as representative of the Australian population in terms of social class, ethnicity, and urban/rural distribution (Einfeld & Tonge, 1996a). The response rate at Wave 1 was 80.2% for individuals with IQ less than 50, and 78.5% for individuals with IQ above 50. A selection of parents of nonparticipants were contacted by telephone and asked the last question in the DBC regarding whether their child had any major or minor problems with his or her emotions or behavior (Einfeld &

Tonge, 1996a). There was no difference between the participants and nonparticipants on this question. The most common reason for non participation was an inability to contact or locate the caregivers, presumably because they had moved. Full details about recruitment and participant demographics are provided in Einfeld and Tonge (1996a) and Tonge and Einfeld (2003).

For those with moderate, severe, and profound ID, the ascertainment process is likely to be virtually complete. However, as in other studies, some young people with the mildest forms of ID blend in to the normal population and were not identified because they may not have impairments in adaptive behavior that require services. Those in the cohort with mild ID may therefore be biased towards higher levels of disturbance. The mean age of the entire epidemiological cohort at Wave 1 was 12.1 years (SD 4.4), at Wave 2 16.5 (*sd* 4.5), at Wave 3 19.5 (*sd* 4.5) and at Wave 4 23.5 (*sd* 4.5).

Participation has been consistently high throughout the study. The response rate (excluding the 31 participants who have died since Wave 1) was 82.5% at Wave 2 (n=477), 78.5% (n=448) at Wave 3, and 84% (n=438) at Wave 4. Ethics approval for the study was obtained from the ethics committees of Monash University, University of New South Wales, University of Sydney, and South Eastern Sydney Area Health Service. Informed consent was provided by caregivers/guardians, and the young people themselves wherever possible.

Analyses were limited to mothers with children aged 5–19.5 years at the first Wave who were consistently the respondents for both the DBC and the GHQ. In addition, we included only individuals with complete data on the DBC for the first two waves (n=238). Of these, 223 young people had three waves of data and 204 had four waves. We used General Health Questionnaire (GHQ) (Goldberg & Williams, 1988) data from Waves 2 through 4 because GHQ was obtained on only a small, non-representative subset of parents at Wave 1 (n=39). For this subset of the children, 131 were male, 94 Mild, 105 Moderate, and 39 Severe or Profound ID.

2.2 Measures

2.2.1 Developmental Behaviour Checklist (DBC)—The DBC (Einfeld & Tonge, 1995, 2002) was used to measure behavior and emotional problems. The DBC consists of 96 items and is completed by parents or other primary caregivers. It has been designed specifically for measuring behavior and emotional problems in young people with ID. The DBC provides measures of overall behavioral / emotional disturbance, (the *Total Behavior Problems Score* or TBPS) and 5 subscale scores derived from factor analysis (Disruptive, Self-absorbed, Anxiety, Communication disturbance, and *Social relating problems*). For the purposes of this longitudinal analysis, the DBC was scored according to the factor-analytically derived subscales allowing for a description of 5 dimensions of disturbance (see Einfeld et al., 2006 for a description of the subscale items). The DBC has been shown to be both a reliable and valid measure of behavior and emotional problems in young people with ID, including reported Cronbach alphas ranging from .66 – .95 (Dekker, Nunn, & Koot, 2002; Einfeld & Tonge, 1995, 2002; Hastings, Brown, Mount, & Cormack, 2001).

Beginning at age 19 in Wave 4, behavior problems were measured using an adapted form of the DBC, the DBC-Adult (DBC-A) (Mohr, Tonge, & Einfeld, 2005). 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, in order 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 pro-rated.

2.2.2 General Health Questionnaire-28 (GHQ-28)—The GHQ-28 is a self-administered adult screening test designed to detect psychiatric disorder in the community settings (Goldberg & Williams, 1988). The 28 item version provides a total score, along with four subscale scores, namely *Somatic Symptoms* (e.g. Have you recently felt that you are ill?, Have you recently been feeling run down and out of sorts?), *Anxiety and Insomnia Symptoms* (e.g. Have you recently had difficulty staying asleep once you are off?, Have you recently been getting scared or panicky for no good reason?), *Social Dysfunction* (e.g. Have you recently felt on the whole that you were doing things well?, Have you recently been managing to keep yourself busy and occupied?), *and Severe Depression* (e.g. Have you recently felt that life is entirely hopeless?, Have you recently found yourself wishing you were dead and away from it all?). Likert scoring was used (0-1-2-3), with higher scores indicating greater difficulties. The GHQ-28 has been shown to be a reliable instrument (Cronbach alpha range = 0.82 – 0.93) with good sensitivity and specificity with median values measured over 16 studies of 0.79 and 0.87 (Goldberg & Williams, 1988).

2.2.3 Degree of ID—Children were categorised as having a mild, moderate, or severe/profound degree of ID. Categorisation was based upon the results of cognitive assessments, according to the ranges of ID specified by the DSM-IV (American Psychiatric Association, 1994). Cognitive assessments were only administered by the project when testing had not been undertaken.

2.3 Procedure

Data collection has taken place at four time points: Wave 1 (1991–1992), Wave 2 (1995–1996), Wave 3 (1999), and Wave 4 (2002–2003) through a mail survey of a questionnaire booklet to the parents and caregivers. Scores on the GHQ-28 were compared to an Australian normative sample (Purcell, Pathé, & Mullen, 2005).

2.4 Statistical analysis

Growth curve models (also known as mixed-effects, random effects, or hierarchical linear models) were used to identify average and individual patterns of growth and change over time in problem behaviors. A multivariate extension of these growth curve models was used to evaluate the commonality of the individual change patterns between parental mental health and distinct features of behavior and emotional problems.

Conceptually, the growth models involve estimating individual regressions of the dependent variable on time and adding, at the next level, predictors of the regression parameters of individual trajectories (i.e., each participant's intercept and slope). A Level 1 model summarizes individual values on the dependent variable at each occasion of measurement in terms of “true” initial level of disturbance (intercept), slope (rate of change), and time-specific residual variance (composed of both systematic and random deviation from an individual's predicted trajectory) parameters. A Level 2 model estimates average (fixed) effects and variance components (random effects) representing individual variation about these fixed effects. The Level 2 component of a model can include predictors of individual and/or group differences in Level 1 intercept and slope parameters. Maximum likelihood estimation methods can account for incomplete data (missing values; attrition) and provide unbiased population estimates under the assumption that the data are “missing at random” (i.e., missingness is accounted for by covariates and prior values in a longitudinal study) (Little & Rubin, 1987).

In the case of multivariate growth models, growth curves are estimated simultaneously for multiple variables. It is then possible to estimate the covariation between intercepts, slopes and residuals of the growth models for the variables of interest. The estimation of correlated

growth curves permits questions such as whether growth in one characteristic is correlated with growth in another. Focus on the time-specific covariation among the residuals is known as the analysis of coupled change, and provides information regarding systematic occasion-specific fluctuation across the growth curves, in this case among aspects of parental mental health and the different types of psychopathology indicated by the DBC subscales. This is a novel departure from typical models of correlated age-conditional slopes at the between-person level which are typically based on smoothed (e.g., linear) individual trajectories over time, and which usually consider the time-to-time dynamics to be unmodelled error components. The multivariate model produces covariance matrices for between-person variance components (i.e., random intercepts and random age slopes) and within-person variance components. Conceptually, the covariation of slopes represents the extent to which child behavior and parent stress `travel together' in the long term while the covariation of residuals indicates the common effect of `shocks' to the parent-child system (or their mutual influence) around the time of each wave of measurement.

As a single multivariate model with 10 or even 6 scales would be overly complex, separate bivariate models for each DBC-GHQ subscale pair were fitted using Mplus (version 4.21, (Muthén & Muthén, 1998–2007) based on a time-in-study data structure allowing individually-varying intervals between occasions of measurement. These bivariate analyses were based on DBC outcomes at all four occasions but on GHQ outcomes for Wave 2 to Wave 4 data only. To maintain consistency across previous analyses of the ACAD study, the intercept was specified to be at the first occasion of measurement, with both the intercept and linear slope conditional on age at Wave 1, centered near the mean age (M=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 (effect of girls, with boys as the reference group) and ID (mild, moderate, or severe, with mild as the reference). Corresponding time-specific residual variances and covariances were constrained to equality across the four measurement occasions. The within-person variance component reflects the variability of individuals from their predicted values at each measurement occasion. Statistical significance of these cross-variable associations was based on the unstandardized estimates. We report multivariate results from a model that conditions time-in-study change on age, sex, IQ status and all two-way interactions.

3. Results

Tables 1 and 2 provide the means and standard deviations for the GHQ and DBC Totals and subscales for the children and families consistently rated by the mother. Australian GHQ-28 normative data (n=1216, aged 18–65+ years) (Purcell et al., 2005) reported a mean Total GHQ score of 16.30 (sd 9.42), mean *Somatic Symptoms* score of 4.10 (sd 3.47), mean *Anxiety and Insomnia* of 4.88 (sd 3.99), mean *Social Dysfunction* of 6.25 (sd 2.01), and mean *Severe Depression* of 1.06 (sd 2.41). Comparison with this GHQ-28 normative sample indicates significantly higher total and subscale scores for the mothers of ID children, across all time points (p<.001).

Again looking cross-sectionally, for descriptive purposes, Table 3 presents the correlations among the GHQ and DBC assessed at Wave 2. The overall pattern of association between GHQ and DBC is one of statistically significant modest positive association. Higher GHQ scores are associated with higher DBC scores. The strongest relationships among the subscales are between GHQ *Anxiety / Insomnia* and DBC *Disruptive* and *Self-Absorbed*. The weakest correlations are with GHQ *Social Dysfunction* (all non significant) and with DBC *Social Relating*.

Table 4 provides the coefficients and standard errors for the univariate growth curve analyses of the GHQ and GHQ subscales, conditional on baseline age, sex, degree of ID and all two-way interactions. Intercept and residual variances in the unconditional models (baseline age included to separate cross-sectional and longitudinal effects of age) were all statistically significant. Slope variances were significant for the *GHQ Total*, *Anxiety / Insomnia*, and *Severe Depression* scales, but not for *Somatic* or *Social Dysfunction*. Although this means that we cannot look at correlated change in these two subscales, we can still consider correlated intercepts and correlated within occasion residuals, and there are a few significant associations. Detailed descriptions of the results for the DBC subscales are available elsewhere (Einfeld et al., 2006). For convenience, they are summarized here.

The majority of age, sex, and IQ main effects and interactions for the GHQ models were not statistically significant. The GHQ *Severe Depression* subscale was 1.63 points lower for mothers of girls. GHQ *Somatic* scores were 2.66 points higher for mothers of children with severe ID than for mothers of children with mild ID.

Two interaction terms suggest more maternal distress when children are younger. The interaction of age with moderate ID was significant for the initial level of *GHQ Total* score (−1.43, $p<0.05$). The meaning of this interaction was clarified using a cut-point of 12 years in the Wave 2 data: at younger ages mothers of children with moderate ID had significantly higher GHQ scores than mothers of children with mild ID, whereas above 12 years of age the mothers of children with mild ID had higher GHQ scores. This interaction was not reflected in the longitudinal rate of change, for which the age by moderate ID interaction was not significant. An age by moderate interaction for GHQ *Somatic* (−0.45), and age by moderate (−0.47) and by severe (−0.62) ID interactions with similar patterns were found for the GHQ *Severe Depression* subscale, with mothers of younger children with mild ID reporting being less distressed, whilst the mothers of older children with mild ID report being more distressed.

Statistically significant individual variation was found for the initial status (intercept) variance for *GHQ Total* and subscale scores, meaning that some mothers were more distressed than others. The average slope was not significantly different than zero, indicating that there is no general trend for mothers to become more or less distressed over time, although there is a trend for mothers to report more social dysfunction over time. Slope variance in the unconditional models was significant for total GHQ and for the *Anxiety / Insomnia* and *Severe Depression* subscales, meaning that different mothers were changing at different rates. Lack of significant slope variance on the *Somatic* and *Social Dysfunction* subscales limits the extent to which correlated slopes can be found in the bivariate models. All time-specific residual variance estimates were significant however, meaning that there was individual variability in self-reported mental health symptomatology at each occasion that was not explained by the individual trajectories or covariates in the model.

Table 5 contains the univariate DBC model estimates. Total problem behaviors show statistically significant decreases over time, as do Anxious and Disruptive behaviors. Communication Disturbance does not show significant change, and Self-absorbed behaviors show only a trend toward declining ($p=0.08$). Social Relating problems, in contrast, increase over time. At age 12, on average, the children with severe ID were rated as exhibiting significantly fewer *Disruptive* and more *Self-absorbed* behaviors. The age by moderate ID interaction for *Disruptive* indicates that although the mild ID group were on average rated as less disruptive, the younger children with mild ID were rated lower, whereas for the children with moderate ID the older ones were rated lower. Girls and children with moderate ID did not decrease in anxious behaviors. Older girls showed faster decreases in *Disruptive* and

Total Behavior Problem Score. All variance components were significant in both the unconditional and conditional models.

Table 6 shows the degree of covariation, expressed as correlation, between the GHQ and DBC intercept, slope, and time-specific random coefficients based on models conditional on age at study entry, sex, IQ and all two-way interactions described above. Covariances, and their significance, are estimated in the models. For ease of interpretation, we have computed correlations based on these covariances and the variances of their corresponding variables, but the statistical significance must remain based on the value of the covariance. The intercept correlations are based on model-predicted intercepts at the initiation of this study. All DBC subscales except *Communication Disturbance* and *Social Relating* were associated with *GHQ Total* score. In addition, correlations of the DBC subscales and GHQ subscales permit further interpretation of particular aspects of maternal mental health related to the child's emotional and behavior disturbance. Higher scores on the child's DBC *Anxiety* subscale were related to GHQ *Somatic* (.36) and *Anxiety / Insomnia* (.31) subscales. Higher DBC *Disruptive* behavior scores corresponded with maternal GHQ *Severe Depression* (.35) scale. Child's DBC *Self-Absorbed* and *Social Relating* subscales were also related to mother's GHQ *Anxiety / Insomnia*.

The slope correlations represent the extent to which change in child problem behavior is related to change in maternal mental health over the 11.5 year period, controlling for age at study entry, sex, and IQ differences. Only changes in child *Social Relating* ratings were found to be associated with changes in maternal outcomes. Child *Social Relating* problems were positively correlated with maternal *GHQ Total* score (.47), *Anxiety / Insomnia* (.54), *Social Dysfunction* (.54), and *Severe Depression* (.46).

The residual covariation represents the association between the deviations of the observed scores at any particular occasion from those expected based on the overall trajectory (in this case of linear change). Residuals have an expected value of zero at any particular occasion and so higher covariances would be expected if individual differences in child behavior and emotional problems and maternal mental health scales exhibited systematic patterns of fluctuation at each occasion (e.g., both observed scores were farther from their predicted values). *GHQ Total* score residuals covaried with each of the DBC subscale residuals except *Social Relating*. The estimated residual covariances were significant for the DBC *Communication Disturbance* subscale and all of the GHQ scores. Maternal GHQ *Anxiety / Insomnia* score were associated with child DBC *Anxiety* and Self-Absorbed behaviors. Maternal GHQ *Somatic Symptoms* were associated with child DBC *Anxiety* and *Disruptive* behaviors.

4. Discussion

The present study addressed questions regarding the interdependence of developmental changes in behavior and emotional problems and maternal mental health in a population of young people with ID. As hypothesized, compared to a normative sample, consistently higher levels of mental health problems were reported by mothers of young people with ID. The observation that the mothers of younger children with mild ID reported less distress, whilst the mothers of older children (above 12 years of age) with mild ID reported more distress, may be an indication of the increased burden experienced by parents of adolescents and young adults. Fewer services are available to young adults compared to young children, behavior problems may be harder to manage to due the young person's increased size, a lack of post school options, and concerns regarding current and future living arrangements. In contrast to those with a more severe degree of ID, unmet maternal expectations in terms of employment and housing opportunities may be a particular cause of distress.

Contrary to what was hypothesised, no decrease over time in maternal reported mental health symptomatology was observed; GHQ scores remained stable over time despite overall decreases in child behavior problems. This finding is in contrast to research suggesting that parent psychological well-being improves over time (Flaherty & Glidden, 2000). This may be due to sample differences, with a large proportion of children with Down Syndrome in other reports (Flaherty & Glidden, 2000; Glidden & Schoolcraft, 2003). The lower levels of behavior problems reported in children with Down Syndrome (Einfeld et al., 2007), may be associated with improved parent well-being.

Associations were found between various aspects of maternal reported overall mental health problems, and child behavior problems. Higher levels of child anxiety were associated with higher parent scores on GHQ *Somatic* and *Anxiety / Insomnia* subscales. Higher child disruptive behavior was associated with higher maternal *Severe Depression* scores, whilst child *Self-absorbed* and *Social Relating* problems were specifically associated with maternal *Anxiety / Insomnia*.

Although, on average, there is evidence for decline in severity of overall behavior and emotional problems over the course of the study (Einfeld et al., 2006), this decline is less evident in the children rated consistently by their mothers, and there is substantial heterogeneity in this change. At least some of this heterogeneity is related to maternal mental health, as indexed by the GHQ subscales. The multivariate analysis of the distinct dimensions of emotional and behavioral disturbance in children and the mental health of their mothers indicates moderate interdependence in level of behavior and emotional problems, with some evidence for associations among change in child behavior and emotional problems and the mental health of the mother. Importantly, this effect was specific and differential: change in the DBC subscales of *Anxiety*, *Communication Disturbance*, *Disruptive*, and *Self-absorbed* was not correlated with change in maternal mental health symptomatology, while increases in child *Social Relating* problems were related to increases in maternal anxiety, social dysfunction and severe depression over time.

Whilst the focus of this paper is on the impact of behavior problems on parental mental health, the direction of this association necessarily remains ambiguous given the quasi-experimental longitudinal design and long interval between occasions of measurement. It is important to acknowledge that parents provided the reports of both their own mental health and their child's behavior problems. It could be argued that their own symptomatology influenced the way in which they rated their child's behavior. Although little research has examined the ways in which parent psychological distress impacts the completion of ratings of child behavior, some studies have suggested that it should be taken into account when interpreting child behavior checklists (Sanger, MacLean, & Van Syke, 1992), and that personality, specifically neuroticism, may account for some variance in parent ratings of child behavior (Kurdek, 2003). In contrast however, Kroes et al. (2005) reported that neuroticism in professional raters, but not mothers, was related to higher rates of reported child behavior problems.

Relative to our previous published results of the overall sample (including all respondents) (Einfeld et al., 2006), the mother only sample reported somewhat lower levels of child behavior problems, with the exception of *Anxiety*. Mothers reported the same rate of decline in child *Anxiety*, lower rates of decline in *Total Behavior Problems Score*, *Disruptive*, *Self-absorbed* behaviors, and *Communication Disturbance*, but reported almost twice the increase in *Social Relating* problems. Further research exploring child behavior problems and parental mental health should therefore ideally involve both mothers and other caregivers.

The large intervals between occasions, typical of many longitudinal studies, limits the extent to which cross-occasion effects may be found, unless the underlying developmental progression is stronger than the momentary shocks to the system. Individually relevant, idiosyncratic events, such as accidents, a death in the family, some of which directly impact both mother and child, rather than affecting one directly and one indirectly through the other, may be the driving force in the relations among some of the DBC and GHQ scales.

These data build upon previous research demonstrating high levels of psychosocial distress in the parents of children and adolescents with ID. Whilst the correlation of initial status and of slopes between parent mental health problems and child behavior and emotional problems does not, in itself, resolve causal direction, that long term change in child behavior is associated with change in parent mental health, particularly parent anxiety and depression, both cross-sectionally and over time is a substantial advance over previous studies. There are several possible reasons for this association. It is possible that the more socially complex world of the young adult is a more demanding one for young people with ID, resulting in the increase in behaviors indicating some degree of social withdrawal (as described by the Social Relating subscale of the DBC). Parents of young people with ID often report feelings of concern regarding their child's living arrangements and future during the transition to adulthood. As parents themselves age, caring for their child with ID into adulthood may also become an increasing burden. These stressors may contribute to their symptoms of depression and anxiety. It is also possible that parental anxiety and depression may contribute to the increasing withdrawal in the young person with ID. Further work is needed to elucidate the nature of the relationship between increases in specific behavior problems and parent anxiety and depression.

5. Conclusion

As research in this field is demonstrating the high rate of behavior and emotional problems in young people with ID coupled with relative stability or slow decline over time (de Ruiter et al., 2007; Einfeld et al., 2006), services need to ensure treatment and support for children and families, throughout childhood and adulthood. Professionals in this field need to be alert to the mental health needs of parents, particularly for signs of anxiety and depression. As research indicates that treatment of parent depression can result in reduced behavior and emotional problems in children (Gunlicks & Weissman, 2008), and that problem focussed coping style and optimism can have a buffering effect on parental distress (Baker et al., 2005; Essex et al., 1999; Seltzer et al., 1995), there needs to be a focus on incorporating adequate support and treatment for families. There is a need to include parent-based interventions and skills training, along with programmes to support and improve the social skill development of adolescents and young adults as they leave the relative protection of the school environment.

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Table 1

Means and Standard Deviations for GHQ-28 Total and Subscale Scores, Mother Respondents Only

Wave 2	N	Mean (SD)
Total	232	20.56** (11.35)
Somatic Symptoms	232	5.60** (3.95)
Anxiety/Insomnia	233	5.94** (4.51)
Social Dysfunction	233	7.14** (2.45)
Severe Depression	233	1.85** (3.17)
Wave 3		
Total	216	19.97** (11.06)
Somatic Symptoms	217	5.39** (3.86)
Anxiety/Insomnia	217	5.87** (4.43)
Social Dysfunction	216	7.07** (2.71)
Severe Depression	216	1.67** (2.88)
Wave 4		
Total	195	21.41** (12.26)
Somatic Symptoms	196	5.83** (4.24)
Anxiety/Insomnia	196	6.19** (4.38)
Social Dysfunction	196	7.48** (2.71)
Severe Depression	196	1.90** (3.47)

Note:

** $p<0.001$ relative to Australian GHQ-28 normative data (n=1216, aged 18–65+ years) (Purcell et al., 2005): mean Total GHQ score of 16.30 (*sd* 9.42), mean *Somatic Symptoms* score of 4.10 (*sd* 3.47), mean *Anxiety and Insomnia* of 4.88 (*sd* 3.99), mean *Social Dysfunction* of 6.25 (*sd* 2.01), and mean *Severe Depression* of 1.06 (*sd* 2.41).

Table 2

Means and Standard Deviations for DBC Total and Subscale Scores, Mother Respondents Only

Wave 1	N	Mean (SD)
Total	238	40.63 (23.01)
Anxiety	237	4.00 (3.22)
Communication Disturbance	238	5.70 (4.14)
Disruptive	238	13.26 (9.33)
Self-Absorbed	238	12.71 (9.07)
Social Relating	236	3.79 (3.04)
Wave 2		
Total	237	38.88 (22.32)
Anxiety	238	3.81 (2.91)
Communication Disturbance	237	5.73 (4.15)
Disruptive	237	12.31 (8.91)
Self-Absorbed	237	11.17 (9.09)
Social Relating	238	4.43 (3.43)
Wave 3		
Total	219	36.71 (23.03)
Anxiety	219	3.52 (2.93)
Communication Disturbance	220	6.01 (4.35)
Disruptive	219	11.41 (9.04)
Self-Absorbed	219	9.88 (8.55)
Social Relating	220	4.66 (3.56)
Wave 4		
Total	203	36.45 (21.95)
Anxiety	205	3.57 (2.78)
Communication Disturbance	203	5.65 (3.99)
Disruptive	203	11.28 (8.40)
Self-Absorbed	205	9.57 (7.89)
Social Relating	205	4.87 (3.49)

Table 3

Wave 2 Correlations Among GHQ and DBC Scores, Mother Respondents Only

	GHQ				
DBC	**Total**	**Somatic**	**Anxiety/Insomnia**	**Social Dysfunction**	**Severe Depression**
Total	.30**	.30**	.32**	.08	.20**
Anxiety	.24**	.24**	.22**	.08	.19**
Communication Disturbance	.20*	.22**	.18**	.09	.11
Disruptive	.26**	.23**	.25**	.04	.24**
Self Absorbed	.24**	.22**	.29**	.07	.11
Social Relating	.14	.18*	.19*	−.03	.03
GHQ					
Somatic Symptoms	.83**				
Anxiety/Insomnia	.91**	.70**			
Social Dysfunction	.68**	.45**	.50**		
Severe Depression	.73**	.37**	.60**	.41**	

* $p<0.01$

** $p<0.001$

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Table 4

Fixed and Random Effects Estimates and Standard Errors for GHQ Scores, Mother Respondents Only.

	GHQ Total		GHQ Somatic		GHQ Anxiety/Insomnia		GHQ Social Dysfunction		GHQ Severe Depression	
Fixed Effects										
Initial status	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**
Intercept (12 yr mild ID boys)	**19.97** **	2.72	**4.65** **	0.91	**6.22** **	1.01	**6.62** **	0.58	**2.36** *	0.85
Age	0.39	0.49	0.03	0.18	0.11	0.19	−0.07	0.12	0.37	0.17
Girls	−3.49	3.64	0.90	1.34	−1.65	1.44	−0.69	0.76	−1.86	0.96
Moderate ID	1.33	3.77	0.48	1.19	−0.29	1.42	0.29	0.85	0.61	1.18
Severe ID	3.97	4.12	2.23	1.52	1.81	1.56	0.93	1.00	−0.99	1.02
Age × Girls	−0.01	0.456	0.06	0.19	0.00	0.23	0.00	0.13	−0.08	0.15
Age × Moderate	**− 1.43** *	0.61	**− 0.40** *	0.21	−0.47	0.25	−0.12	0.13	**− 0.47** **	0.17
Age × Severe	−1.06	0.68	−0.05	0.27	−0.27	0.28	−0.14	0.18	**− 0.62** **	0.18
Girls × Moderate	−0.46	5.00	−1.08	1.74	0.36	2.00	0.38	1.10	0.10	1.36
Girls × Severe	−5.98	7.15	−4.31	2.39	−2.59	3.07	−0.25	1.62	0.99	1.55
Rate of Change										
Slope: (12 yr mild ID boys)	0.25	0.36	0.15	0.12	−0.02	0.12	0.15	0.08	−0.02	0.10
Age	0.01	0.06	0.01	0.02	0.01	0.02	0.02	0.01	−0.04	0.02
Girls	0.34	0.49	−0.12	0.17	0.22	0.18	−0.01	0.11	0.22	0.13
Moderate ID	−0.32	0.46	−0.12	0.15	0.08	0.16	−0.11	0.11	−0.13	0.14
Severe ID	−0.63	0.50	−0.27	0.18	−0.24	0.16	−0.14	0.13	0.04	0.13
Age × Girls	−0.03	0.07	−0.01	0.02	−0.02	0.02	−0.01	0.02	0.023	0.02
Age × Moderate	0.09	0.07	0.03	0.03	0.03	0.03	−0.00	0.02	0.04	0.02
Age × Severe	0.02	0.09	−0.01	0.04	−0.00	0.03	−0.01	0.02	0.05	0.03
Girls × Moderate	−0.06	0.61	0.14	0.21	−0.18	0.23	0.02	0.14	−0.07	0.17
Girls × Severe	1.24	0.94	0.56	0.30	0.40	0.37	0.18	0.20	0.13	0.24
Intercept Variance	**138.58** **	36.84	**9.36** *	3.88	**22.97** **	5.69	2.73	2.16	**10.65** **	4.54
Slope Variance	**1.56** *	0.47	0.09	0.06	**0.20** **	0.07	0.04	0.04	**0.13** *	0.04
Residual Variance	**50.99** **	6.0	**8.64** **	1.00	**7.99** **	0.89	**4.03** **	0.54	**3.37** **	0.61

Note:

Age = child's age at entry into study

* $p<0.05$

** $p<0.01$

[a] relative to Mild ID group; N=238.

Table 5

Fixed and Random Effects Estimates and Standard Errors for DBC Scores, – Mother Respondents Only

	Total		Anxiety		Communication Disturbance		Disruptive		Self-Absorbed		Social Relating	
Fixed Effects												
Initial status	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**	**Est**	**SE**
Intercept (12 yr mild ID boys)	**40.24**	3.04	**4.45** **	0.45	**6.11** **	0.56	**14.65** **	1.12	**9.79** **	0.93	**3.93** **	0.47
Age	−0.21	0.69	−0.00	0.11	−0.08	0.13	0.15	.026	−0.36	0.23	0.02	0.10
Girls	0.70	4.25	−0.06	0.64	0.12	0.82	−0.28	1.73	0.50	1.37	−0.11	0.61
Moderate ID[a]	−3.29	4.18	−0.95	0.61	0.16	0.80	−2.83	1.60	1.40	1.35	−0.70	0.58
Severe ID[a]	2.41	5.77	−1.06	0.69	−1.75	0.92	**− 4.92** **	1.84	**10.87** **	2.69	0.85	0.82
Age × Girls	1.35	0.70	0.15	0.11	0.19	0.12	0.51	0.29	0.32	0.25	0.18	0.10
Age × Moderate	−1.06	0.76	−0.21	0.12	0.02	0.14	**− 0.71** *	0.31	−0.16	0.25	0.01	0.11
Age × Severe	−1.13	1.11	−0.18	0.13	0.00	0.18	−0.56	0.41	−0.37	0.51	−0.06	0.16
Girls × Moderate	5.59	6.06	0.69	0.88	−0.70	1.12	3.50	2.47	0.70	2.02	1.06	0.84
Girls × Severe	−3.47	9.28	−0.40	1.09	−0.44	1.53	−0.55	3.56	−2.67	4.01	0.53	1.27
Rate of Change												
Slope: (12 yr mild ID boys)	−0.55*	0.27	−0.13**	0.03	−0.03	0.06	−0.30**	.010	−0.17	0.09	0.11**	0.04
Age	0.06	0.07	0.01	0.01	0.00	0.01	0.02	0.02	0.03	0.02	0.01	0.01
Girls	0.27	0.48	0.12*	0.06	0.01	0.09	0.15	0.18	−0.05	0.15	0.01	0.07
Moderate ID[a]	0.24	0.38	0.12*	0.05	0.05	0.08	0.15	.014	−0.11	0.13	−0.01	0.05
Severe ID[a]	0.24	0.44	0.07	0.06	0.06	0.07	0.18	0.16	−0.17	0.21	−0.05	0.06
Age × Girls	−0.14*	0.07	−0.01	0.01	−0.03	0.01	−0.05*	0.03	−0.04	0.02	−0.02	0.01
Age × Moderate	−0.01	0.08	0.00	0.01	−0.00	0.02	0.01	0.03	−0.01	0.03	−0.02	0.01
Age × Severe	−0.06	0.09	−0.00	0.01	−0.02	0.02	−0.01	0.03	−0.02	0.04	−0.01	0.01
Girls × Moderate	−0.46	0.61	−0.12	0.09	−0.05	0.12	−0.22	0.23	0.01	0.19	−0.04	0.09
Girls × Severe	−0.34	0.84	0.02	0.12	−0.05	0.15	−0.08	0.30	−0.05	0.35	−0.09	0.11
Intercept Variance	**408.88** **	51.47	**7.32** **	0.98	**11.20** **	1.37	**63.55** **	7.99	**54.60** **	6.55	**6.66** **	1.06
Slope Variance	**2.28** **	0.50	**0.04** **	0.01	**0.05** **	0.02	**0.27** **	0.06	**0.24** **	0.05	**0.03** **	0.01
Residual Variance	**110.65** **	12.80	**2.66** **	0.23	**5.50** **	0.45	**17.45** **	1.85	**14.73** **	1.65	**3.48** **	0.34

Note:

Age = child's age at entry into study

* $p<0.05$

** $p<0.01$

[a] relative to Mild ID group; N=238.

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Table 6

Correlations Based on the Estimated Covariances Between the DBC and GHQ Subscales – Mother Respondents Only

	Correlations Conditional on Age, Sex and IQ		
DBC Subscales	**Initial Status**	**Linear Slope**	**Time-Specific Residual**
Anxiety			
GHQ Total	0.29*	0.20	0.24**
GHQ Somatic Symptoms	0.36*	0.21	0.28**
GHQ Anxiety/Insomnia	0.31*	0.18	0.19**
GHQ Social Dysfunction	0.13	0.24	0.09
GHQ Severe Depression	0.14	0.17	0.13
Communication Disturbance			
GHQ Total	0.12	0.16	0.21**
GHQ Somatic Symptoms	0.28	0.06	0.13**
GHQ Anxiety/Insomnia	0.17	0.24	0.19**
GHQ Social Dysfunction	0.02	0.04	0.14*
GHQ Severe Depression	−0.06	0.18	0.16**
Disruptive			
GHQ Total	0.27*	0.11	0.15*
GHQ Somatic Symptoms	0.23	0.10	0.17**
GHQ Anxiety/Insomnia	0.27	0.14	0.14
GHQ Social Dysfunction	0.02	−0.03	0.09
GHQ Severe Depression	0.35**	0.15	0.02
Self-Absorbed			
GHQ Total	0.24*	0.13	0.12*
GHQ Somatic Symptoms	0.28	−0.01	0.10
GHQ Anxiety/Insomnia	0.35**	0.19	0.15*
GHQ Social Dysfunction	−0.09	−0.07	0.07
GHQ Severe Depression	0.15	0.33	0.01
Social Relating			
GHQ Total	0.19	0.47*	0.01
GHQ Somatic Symptoms	0.27	0.26	0.01
GHQ Anxiety/Insomnia	0.29*	0.54*	0.05
GHQ Social Dysfunction	−0.15	0.54*	−0.01
GHQ Severe Depression	0.09	0.46**	−0.10

Note:

* $p<0.05$

** $p<0.01$