**Supplementary Table 1:**  *Candidate predictor variables for parental well-being in UK ONS (1999) Survey and IMAGINE-ID*

|  |  |  |  |
| --- | --- | --- | --- |
| Study | | UK ONS (1999) Survey, secondary analysis  Emerson, 2003. J Intellect Disabil Res. 47(Pt 4-5): 385-99. | IMAGINE-ID |
| Key to highlighting of measures | | **Significant predictor of maternal well-being (GHQ-12 category)**  **Significant predictor of social or psychological impact** | **Significant predictor of parent / caregiver distress (EFQ score)**  **Significant predictor of total impact score** |
| *Candidate predictor variable* | | **Measure** (N/A = not available) | **Measure** (N/A = not available) |
| Socio-economic circumstances | *Educational level of mother* | None or GCSE D–F versus higher | N/A |
| *Home owner* | Yes/no | N/A |
| *Housing type* | Detached or semi-detached versus terraced or ﬂat | N/A |
| *Neighbourhood deprivation* | Jarman quintile | Index of Multiple Deprivation Decile |
| *Income poverty* | **Weekly household income <60% of national median** | N/A |
| *Receipt of family credit* | **Yes**/no | N/A |
| Household composition | *Lone parent* | Yes/no | Yes / no |
| *Number of adults in the household* | 1–2 versus ≥3 | 1–2 versus ≥3 |
| *Number of children in household* | 1–2 versus ≥3 | 1–2 versus ≥3 |
| Characteristics of the sampled child | *Age group* | 5–10 or 11–15 years | **Age as continuous variable** |
| *Gender* | **Boy**/girl | Boy/girl |
| *ID* | Operational definition yes/no | Developmental quotient |
| *Physical disability* | **Yes**/no | **DAWBA checklist** **summed score** |
| *Any ICD-10 diagnosis\** | Yes/no | **Yes** / no (any diagnosis other than ASD or conduct disorder) |
| *More than one ICD-10 diagnosis\** | **Yes**/no | N/A |
| *ICD-10 conduct disorder\** | **Yes**/no | **Yes yes** / no |
| *ICD-10 emotional disorder\** | Yes/no | Yes / no |
| *ICD-10 pervasive developmental disorder\** | **Yes**/no | **Yes** / no |
| Family functioning | *Use of reward-based or punishment-based child management practices1* | Y-score >10 | N/A |
| *‘Healthy’ family functioning2* | **Y-score >2** | N/A |
| Life events | *Number of potentially stressful life events experienced in past 12 months* | None versus **one or more** | **Total score (7 item checklist)** |
| Caregiver’s appraisal of impact of sampled child’s difﬁculties | *Psychological* | Mother’s Self-Assessed Psychological Impact Scale: Y-score>3 | Impact Supplement of the Strengths and Difficulties Questionnaire3  **Total impact score** |
| *Social* | Mother’s Self-Assessed Social Impact Scale: **Y-score >4** |
| Genetic diagnosis | *Broadly categorised genetic diagnoses* | N/A | Clinical genetics laboratory reports: Aneuploidy/**copy number variant**/single nucleotide variant/other chromosomal |

\* For the ONS (1999) Survey, theDevelopment and Well Being Assessment (DAWBA) was conducted by face-to-face interview with carer and child (>11 years), and teacher questionnaire. In IMAGINE-ID, the Development and Well Being Assessment (DAWBA) was completed by the parent / carer only, via online completion or telephone interview or face-to-face interview. Both studies utilised computer algorithm scoring.

1. Meltzer H., Gatward R., Goodman R. & Ford T. (2000) Mental Health of Children and Adolescents in Great Britain. The Stationery Ofﬁce, London.
2. Miller I. W., Epstein N. B., Bishop D. S. & Keitner G. I. (1985) The MacMaster Family Assessment Device: reliability and validity. Journal of Marital and Family Therapy 11, 345–56.
3. Goodman R (1999) The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden. J Child Psychol Psychiatry. 1999 Jul;40(5):791-9.

**Supplementary Table 2:** *Socioeconomic distribution of children with ID in the UK ONS Survey (1999)\* and IMAGINE-ID cohorts*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Index of Multiple Deprivation / Jarman Quintile | | | | |
|  | Quintile 1  (Most Deprived) | Quintile 2 | Quintile 3 | Quintile 4 | Quintile 5  (Most Affluent) |
| ONS-ID  (N=245) | 66 (27%) | 61 (25%) | 41 (17%) | 40 (16%) | 37 (15%) |
| Imagine ID  (N=802) | 115 (14.3%) | 142 (17.8%) | 195 (24.3%) | 180 (22.4%) | 170 (21.2%) |

The ONS-ID group differed significantly from the Imagine-ID group in SES, χ2 (4) = 33.89, p < .0001, Cramer’s V = 0.1799. We compared the proportions of children in each Decile across the two groups and adjusted the p-value to account for multiple comparisons (p < .01). The proportions of children in each decile differed significantly across the two samples (all ps < .00001).

*\*Emerson (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child’s difﬁculties. J Intellect Disabil Res. 47(Pt 4-5): 385-99*

**Supplementary Table 3:** *Correlation Matrix*

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 |
| 1 | Age |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 2 | Gender | .05 |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 3 | DQ | **-.11** | -.01 |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 4 | Disability | .03 | .03 | **-.53** |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 5 | Diagnosis | .01 | -.01 | .01 | -.02 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 6 | ASD | -.06 | **-.15** | **-.28** | **.26** | **.13** |  |  |  |  |  |  |  |  |  |  |  |  |
| 7 | CD | .01 | **-.09** | .01 | .02 | **.30** | **.13** |  |  |  |  |  |  |  |  |  |  |  |
| 8 | Impact | **.09** | **-.08** | -.06 | **.12** | **.33** | **.26** | **.41** |  |  |  |  |  |  |  |  |  |  |
| 9 | SNV | **.20** | .05 | **-.24** | **.25** | -.03 | .03 | -.03 | -.04 |  |  |  |  |  |  |  |  |  |
| 10 | Multiple | -.01 | .02 | .02 | -.02 | -.02 | -.003 | .04 | -.02 | **-.18** |  |  |  |  |  |  |  |  |
| 11 | Chromo | -.02 | .06 | -.04 | .008 | -.05 | -.04 | **-.08** | **-.09** | **-.11** | **-.09** |  |  |  |  |  |  |  |
| 12 | Aneuploidy | -.05 | .05 | **.10** | -.06 | -.03 | -.04 | **.07** | -.02 | **-.09** | **-.08** | -.05 |  |  |  |  |  |  |
| 13 | Inherited | -.03 | -.04 | .05 | -.07 | .02 | -.004 | -.02 | .02 | **-.20** | **.20** | **-.09** | **-.11** |  |  |  |  |  |
| 14 | Unknown | -.03 | -.05 | **.12** | **-.09** | **.07** | .01 | .05 | .02 | **-.13** | .01 | **-.09** | **-.16** | **-.47** |  |  |  |  |
| 15 | IMD | .07 | .05 | -.01 | .004 | -.04 | -.06 | .01 | -.04 | **.08** | .008 | .04 | -.008 | **-.07** | -.007 |  |  |  |
| 16 | Life Events | **.13** | .004 | -.07 | **.10** | **.12** | .04 | **.12** | **.11** | -.03 | .06 | -.03 | -.04 | .05 | -.02 | **-.09** |  |  |
| 17 | Caregiver EFQ | **.08** | .01 | -.04 | **.08** | **.14** | **.12** | **.23** | **.35** | -.03 | .02 | -.04 | .02 | .04 | -.02 | .007 | **.19** |  |

*Note.* **Bold** = *p* < .05. Disability = Physical disability score. Diagnosis = Number of DAWBA diagnoses. SDQ Impact = Perceived impact of difficulties on school and home life. SNV = CNV *vs.* SNV. Multiple = CNV *vs.* Multiple. Chromo = CNV *vs.* Chromosomal. Aneuploidy = CNV *vs.* Aneuploidy. Inherited = De novo *vs.* Inherited. Unknown = De novo *vs.* unknown. Life Events = Total negative life events in past 12 months. IMD = Index of Multiple Deprivation score. Caregiver EFQ = Respondent EFQ Total (Distress).

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