The family as a context for the behavioural and emotional health of young children with intellectual and developmental disabilities

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Today’s presentation

1. Mental health problems in children with intellectual and developmental disabilities (IDD)
2. Psychological well-being among parents of children with IDD
3. Family variables in early developmental pathways for behaviour problems in IDD
   - Longitudinal analysis of relationships between maternal well-being and child behaviour in the early years
   - Parenting and child behaviour in the early years
Limitations of existing research

• Case-control studies typically include referred and self-referred (volunteer) children and families

*Population-based samples are needed*

• Diagnosis of ID not always confirmed clinically or by a recognised diagnostic assessment

*Need samples that include clear method for identification of ID*
ONS child mental health surveys  
[Emerson & Hatton, 2007 - secondary analysis]

- N= 18,415 children age 5-16 years; population based sample across the UK with high response rate (80% across both surveys – 1999 and 2004)
- Structured clinical interview used with all children leading to ICD-10 diagnoses (carer interview, plus child interview 11+ and able to participate)
- Emerson identified a sub-sample with likely ID (N= 641), 3.5% of total sample
- Compared prevalence of childhood psychiatric disorders in ID and non-ID groups. Found increased risk of comorbidity
Psychiatric disorders
Emotional disorders
Anxiety disorders
Depressive disorders
Hyperkinesis
Conduct disorders

Emerson & Hatton, 2007

ID=641
non-ID=17,774
Behavioural and emotional problems in 5-year-olds
[Totsika, Hastings et al., 2011 JAbCP]

- N = 15,246 from the Millennium Cohort Study Wave 3
- ASD: parental report 0.92% (n = 143†)
- ID: British Ability Scales 3.07% (n = 479)
- Child outcomes: hyperactivity, emotional symptoms, conduct problems (SDQ)

† sample weighted
Group differences child behavioural and emotional problems - MCS
The family system

- Family systems theory suggests that family members are inter-dependent. Well-being of one member will impact across the system on other individuals/sub-systems.

- Therefore, an interest in the families of children with IDD and how they might be affected.

- **Also**, well-being and actions of other family members will affect children with IDD…
Mothers of five year old children

[Totsika, Hastings et al., 2011 *JAbCP*]
Correlates of child emotional problems

[Totsika, Hastings et al., 2011, *JAbCP*]

Adjusted Odds Ratios (controlling child age, gender)

- Child emotional problems
- Maternal serious mental illness: 4.98
- Intellectual Disability: 2.33
- Adversity - family: 2.28
- ASD: 5.68
MCS modelling of bidirectionality
[Totsika, Hastings et al., 2013, Autism Research]

• N = 132 from the Millennium Cohort Study identified with ASD by parent report at age 5
• Child behaviour problems and maternal well-being in first three waves of MCS (9 months, 3 years, 5 years)
• Three wave cross-lagged path models fitted using AMOS
• Conceptual model fitted reflecting the reciprocal relationships between child behaviour problems and maternal well-being…
Results – maternal Kessler 6
Results – maternal physical health
Results – Life satisfaction

Diagram showing relationships between life satisfaction at 9 months, life satisfaction at 3 years, life satisfaction at 5 years, cumulative deprivation, infant temperament at 9 months, child behavior problems at 3 years, and child behavior problems at 5 years. The diagram includes coefficients and R-squared values for each relationship.

- Life satisfaction at 9 months: R² = 0.176
- Life satisfaction at 3 years: R² = 0.209
- Life satisfaction at 5 years: R² = 0.308
- Cumulative deprivation: R² = 0.118

Significance levels indicated by * for p < 0.05 and ** for p < 0.01.
MCS modelling of bidirectionality 2

[Totsika, Hastings et al., under review]

• Same methods/design and analysis approach
• Focus on child prosocial behaviour in the early years
  – also measured using the SDQ
Maternal psychological distress

Model fit: Chi-sq.=7.38, p=.496; CMIN/DF=.923; CFI:1.000; RMSEA:.000 (90% CIs:.000,.110)
Maternal life satisfaction

Life satisfaction @ 9 mth $\rightarrow$ Life satisfaction @ 3 yrs $\rightarrow$ Life satisfaction @ 5 yrs

Infant temperament @ 9 mth $\rightarrow$ Child prosocial behavior @ 3 yrs $\rightarrow$ Child prosocial behavior @ 5 yrs

$R^2=.212$ $R^2=.233$ $R^2=.005$ $R^2=.379$

**p<.001; *: p<.05

Model fit: Chi-sq.=7.02, p=.535; CMIN/DF=.877; CFI: 1.000; RMSEA: .000 (90% CIs: .000, .094)
Parenting and child behavioural and emotional problems over time

[Totsika, Hastings et al. 2014, AJIDD]

• N = 516 from the MCS identified with ID by a g score 70 or below on BAS II at age 5
• Parenting measured when the children were age 3 years: Harsh discipline, Chaotic home environment, Parent child conflict, Close relationship
• SEM using data from three waves of MCS - concurrent associations at age 3, longitudinal associations with age 5 behavioural and emotional problems
Child gender

Calm/organized home @3 yrs

Inappropriate discipline @3 yrs

Temperament @9m

Conflict @3 yrs

Closeness @3 yrs

Cumulative deprivation 9m to 3 yrs

Behavior Problems @3 yrs

Behavior Problems @5 yrs

R² = .234

R² = .278

**: p<.001; *: p<.05
Model fit: 17.46, p = .357; CMIN/DF = 1.091; CFI = .995; RMSEA = .01 (90% CIs: .00, .04)
Theoretical/Research Implications

- Bring together key variables – parental well-being, parenting behaviours, deprivation

- Family Stress Model suggests deprivation results in family stress that in turn impacts on parenting and then child outcomes

- Family Investment Model suggests deprivation affects parental investments in the child (educational, other activities, learning in the home), that affect child outcomes

- Both models need to be explored in the early years for children with IDD – results will make a difference to support models for families
Implications for family support

- Young children with IDD at increased risk for behavioural and emotional problems, their parents are at risk for psychological problems
- Intervention must be proactive and early
- *Developmental sequencing* based on evidence is needed?
  - Earliest intervention needs to focus on: directly reducing behavioural and emotional problems; but also on parents, parent-child relationship, and building child pro-social behaviour
- Significance of family members other than parents, especially siblings?
Sibling well-being affects child with disability over time
[Hastings et al., 2014 RASD]

60 Families

- Behavioural and emotional problems – child with ASD
- Sibling behavioural and emotional problems
- Maternal depression

Behavioural and emotional problems – child with ASD

2.5 to 3 years later
Family support 2

- Parenting interventions needed – behavioural parent training has positive effects on behaviour problems in young IDD children
  
  [RCT Triple P Stepping Stones - Roberts et al., 2006; RCT IY adapted – McIntyre, 2008; Pilot RCT brief SSTP – Tellegen & Sanders, in press]

- Adaptations to include more on parent-child relationship or parent well-being?
  
  [RCT Positive Family Intervention (PBS + optimism training) vs. PBS – Durand et al., 2013; RCT autism parent education + either counselling or BPT - Tonge et al., 2014]

- Attachment-informed approaches? Increasing parental sensitivity, and attachment security
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Why more psychological problems?

• Socio-economic status (poverty) is a big factor
• The child’s behaviour problems
• Lack of support from/access to health, social care, and education services
• The nature of caring – more hours of “care” per week, more daily physical and personal care
• Other people’s attitude - affiliate stigma
• Worry about future care
• Less social support available