



# The effect of a disability on siblings

Gráinne Collins, Cliona Doherty  
National Disability Authority



- **We are from the National Disability Authority (NDA), which is the independent statutory body that provides information and advice to the Government on policy and practice relevant to the lives of persons with disabilities.**

**Our functions include research, developing and collaborating on the development of relevant statistics**

- **Definition of disability is often elastic (and here it includes a chronic illness).**



# Background

- There is an increased recognition of the need to provide supportive interventions to protect families, and in particular siblings, when a child has a complex disability
- The HSE Programme ‘Progressing Disability Services for Children and Young People’ aims to develop a network of early-intervention and school- age disability teams which are community-based, multi-disciplinary, holistic including family orientated
- With this background we were interested in examining ‘what are the effects of having a child with a disability on the family?’



# Literature review

- **Early literature points in two opposing directions:**
- **Having a sibling with a disability is positive:**
  - Labay and Walco 2004
  - Pilowsky et al 2004
  - Macks and Reeve 2007
  - Mulroy et al 2008
- **Having a sibling with a disability is negative:**
  - Hastings 2003
  - Barrera et al 2004
  - Giallo and Gavidia-Paynes 2006
  - Gamble and McHale 1989



# Literature Review

- **Why such diametrically opposed results?**
  - Lots of confounding factors (Golics et al (2013) In a review of 157 papers found that illness can affect families emotional, financial, familial relationships, education and work, leisure time, and social activities)
  - Many studies based on small numbers often self-selected
  - Many on adults
  - Many are disability specific (or not specific enough)
- **More recent work has started to control for problems, for example**
  - O'Brien et al (2009) in a examination of 17 other studies concluded that siblings of children with Down's syndrome were well adjusted but there were more conflicting results for siblings of a child with Autism or cancer.



# GUI

- **The GUI has several very useful questions:**
  - Range of questions on health, disability (including depression), severity of impact of the child, primary care giver and secondary caregiver AND whether they affected the ability to look after study child.
- **Child09 also asks E7: Does anyone in your household CURRENTLY have any chronic illness or disability which adversely affects the Study Child**
- **[if yes] E8: What is the relationship of that person to the Study Child? (Parent /Sibling/Other relative/Non relative)**



# GUI

- **This is excellent because we can see if the child at 9 has a sibling with a chronic illness or a disability and track the child through time**
- **However:**
  - We don't know the nature of the chronic illness or a disability
  - We don't know of past illnesses (or if ongoing at 13 years of age)
  - We don't know if the sibling is older or younger or gender-matched
  - This requires a very high level of honesty/insight from the mother (Hasting 2007)
- **Therefore this variable probably misses some children who are affected**



# How many disabled siblings?

- **We don't know how many children have a disabled sibling.**
- **To estimate we need:**
  - Number of siblings
  - Probability of having a disability
  - Overlap random
  - Overlap because of clustering of disabilities (e.g. Autism may have a genetic link and therefore cluster among siblings)





# Probability of having a disability

- NDA used GUI13 to estimate no. of children likely to need input from specialist multi-disciplinary disability therapy team
  - all with ASD that are hampered by their disability
  - all with multi disabilities that are hampered
  - all with one disability if severely hampered by their disability
- Approximately 3% of the child population meet this definition in GUI13



# How many disabled siblings?

Number of siblings	8,568 (GUI09)
Prob of disability	0.03
Overlap	GUI
Overlap cluster	?
	Approx 200 (300 if you take $p=0.04$ )



# How many disabled siblings?

- In GUI09 157 mothers answered that there is a sibling in the household with a chronic illness or disability which adversely affects the Study Child
- Therefore even when we look at the most complex and severely affected children with disabilities and illnesses at least a quarter will not have a negative effect on a sibling (according to the mother)



# Family stressors matter

- **McAuley and Layte (2012) examined the relative influence of family stressors and the family's socioeconomic circumstances on children's happiness.**
- **Using GUI 9 year old cohort they looked at:**
  - conflictual parent–child relationship;
  - children with emotional and social problems;
  - parental depression;
  - low parental self-efficacy and
  - child isolation.
  - They found 16% of families and children were experiencing a higher level of these stressors.
  - “Although socioeconomic disadvantage contributed significantly to the vulnerability of this group, it was by no means the sole or dominant issue.”
  - family stressors were found to explain more than twice the variance in the children's happiness than explained by the measures of socioeconomic status.



# Confounding factors

	Parents of a child with a disability GUI09	Other GUI9	Parents of a child with a disability GUI13	Other GUI13
Male primary carer	0.9	2.3	2.1	3.5
Employee	39.3	47.8	53.4	59
Home duties	45.9	38.1	39.8	33.7
Partner in the home	75.7	82.6	75.0	81.4
Third level	14.6	17.6	18.8	21.8
Equivalised HH income	€17,245	€19,214	€14,948	€16,102
Mother depressed			16.8%	11%



# The effect of a disability on siblings?

- **GUI 13**
- **Cross-sectional**
- **7,033 GUI cases**
- **Weighted data**
- **OLS1: Dependent variable Piers Harris Children's Self-concept scale (that the child reports)**
- **Piers Harris measures the attitudes and beliefs the child has about themselves**
  
- **6 subscales make up the total scale**



# Piers Harris Scale

- 1. **Behavioural Adjustment** (e.g. “I am well behaved in school” and “I do many bad things”)
- 2. **Intellectual and School Status** (e.g. “I am smart” and “In school I am a dreamer”)
- 3. **Physical Appearance and Attributes** (e.g. “I have nice hair”)
- 4. **Freedom from Anxiety** (e.g. “I get worried when we have tests in school” and “I am often afraid”)
- 5. **Popularity** (e.g., “ “I am popular with boys/girls”)
- 6. **Happiness and Satisfaction** (e.g. “I am a happy person” and “I am cheerful”)



# Independent variables


Variables	
Income variables	Equivalised income (40%*, 30%*)
	Ability to make ends meet*
	% of income from social welfare
	Basic needs
	Receipt of Domiciliary care allowance*
Disability variables	Disability* - child/mother/father
	Hampered* - child/mother/father
	Depression of mother/father*
	Mother was unable at some point to look after study child*
	Sibling had disability or chronic illness that affected study child* FROM GUI 9
*=dummy variable	Mother of a disabled sibling is depressed*





# Independent variables

Variables	
Disability of child	ASD*, physical*, EB*, LD*, MH*, disability dum* and number of disabilities
	Very Healthy*
Weight	BMI
	BMI cut-offs* (bmi30+, bmi40+)
	Think overweight*/too thin*
Education of mother	High*/medium*
Social class	ProfManag*/ OthnonmanSkilledMan* /semiUnskilledMan*
Girl*	Also sister of disabled sibling*
Adverse life events	* Plus number of adverse life events

 \* = dummy variable



# Independent variables

Variables	
Size of family	Continuous and dummy
Drumcondra test results	Overall
friends	3 or more friends*
Parenting styles	Both score and dummy*
SDQ	Strengths and difficulties (the mother's answers)
* = dummy variable	



# Results 1

- **What predicts the child having positive attitudes and belief about themselves?**
- **R squared adjusted =0.152**
- **All 99% except if marked \*\*then 95%**
- **Protective factors**
  - Partner in the household
  - Positive relationship with SCG
  - Positive relationship with PCG
  - 3 or more friends
  - Good test results
  - Being healthy



# Results 2

- **Negative factors**

- Mother was so unwell she couldn't look after child at some point
- High education of mother
- Girl
- BMI 30+
- Think you are overweight\*\*
- Being bullied in the last 3 months
- Conflict with SCG
- Conflict with PCG\*\*
- A mental health disability
- Lots of bad things have happened to you
- Having a disabled sibling especially if your mother is also depressed



# Results 3

- **No effect**

- Income (but important if slight in GUI 9) (recession effect?)
- Poverty
- Social class
- Individual life events
- Broader measures of disability
- Dad's disability (loads on mother's ability to cope).
- Study child's disability (other than mental health and healthy)
- Family size
- Sister of a disabled sibling
- Strengths and difficulties score (but loads onto MH)



# Conclusion

- Having a sibling with a disability is a stressor in some circumstances
- One of the circumstances is where the mother is also depressed
- Effect lasts (variable was collected at age 9 and shown to have effect at 13)
- Important that HSE multidisciplinary disability teams include a family support worker
- It would be useful if further waves of GUI asked more detailed questions about the disability and illnesses of siblings.



# References

- Barrera Felming Khan (2004) The role of emotional social support in the psychological adjustment of siblings of children with cancer Child Care Health development 30(2) 103-11
- Gamble and McHale 1989 Coping with stress in sibling relationships: A comparison of children with a disabled and non-disabled sibling J of Applied Developmental Psychology 10 353-373
- Giallo and Gavidia-Paynes (2006) child parent and family factors in the adjustment for siblings of children with a disability J of Intellectual Disabilities research 50(12) 937-48
- Golics Basra Finlay Salek (2013) The impact of disease on family members: a critical aspect of medical care J R Soc Med October 2013 106: 399-407
- Hastings B (2003) Brief report: Behavioural Adjustment of sibling of siblings with autism J of Autism Dev Disorders
- Hastings B (2007) Longitudinal relationships between sibling behavioural adjustment and behavioural problems of children with developmental disabilities J of Autism Development Disorders 37:1485-1492



# References

- Labay and Walco (2004) Brief report: empathy and psychological adjustment of children with cancer J of Paediatric Psychology 29(4) PP 309-14
- Macks and Reeve (2007) The adjustment of non-disabled siblings of children with autism Journal of autism Development Disorders 37 pp 1060-7
- McAuley and Layte (2012) Exploring the Relative Influence of Family Stressors and Socio-Economic Context on Children's Happiness and Well-Being Child Indicators Research, 5(3), pp 523-545
- Mulroy Tobertson Aiberti Leonard Bower (2008) The impact of having a sibling with an intellectual disability: parental perspectives in two disorders Journal of Intellectual Disability research 52(3) 216-29
- O'Brien Duffy and Nicholl (2009) Impact of childhood chronic illnesses on siblings: a literature review British Journal of Nursing 18(22) pp1358-1365
- Pilowsky Yirmiya Doppelt Gross-Tsur (2004) Social and emotional adjustment of siblings of children with autism J Child Psychology & Psychiatry 45(4) 855-65
- Ross and Cuskelly (2006) Adjustment, sibling problems and coping strategies of brothers and sisters of children with Austic Spectrum Disorder J of Intellectual & Developmental Disability 31(2) 77-86
- Wittenberg E, Ritter G, Prosser L (2013) Evidence of Spillover of Illness among Household Members: EQ-5D Scores from a US Sample Med Decision Making February 2013 33: 235-243