The effect of a disability on siblings

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www.growingup.ie
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?’
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 Gavida-Paynes 2006
  - Gamble and McHale 1989
• **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.
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)
• 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?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Number of siblings</td>
<td>8,568 (GUI09)</td>
</tr>
<tr>
<td>Prob of disability</td>
<td>0.03</td>
</tr>
<tr>
<td>Overlap</td>
<td>GUI</td>
</tr>
<tr>
<td>Overlap cluster</td>
<td>?</td>
</tr>
<tr>
<td></td>
<td>Approx 200 (300 if you take p=0.04)</td>
</tr>
</tbody>
</table>
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).
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

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

<table>
<thead>
<tr>
<th>Variables</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Income variables</strong></td>
<td>Equivalised income (40%<em>, 30%</em>)</td>
</tr>
<tr>
<td></td>
<td>Ability to make ends meet*</td>
</tr>
<tr>
<td></td>
<td>% of income from social welfare</td>
</tr>
<tr>
<td></td>
<td>Basic needs</td>
</tr>
<tr>
<td></td>
<td>Receipt of Domiciliary care allowance*</td>
</tr>
<tr>
<td><strong>Disability variables</strong></td>
<td>Disability* - child/mother/father</td>
</tr>
<tr>
<td></td>
<td>Hampered* - child/mother/father</td>
</tr>
<tr>
<td></td>
<td>Depression of mother/father*</td>
</tr>
<tr>
<td></td>
<td>Mother was unable at some point to look after study child*</td>
</tr>
<tr>
<td></td>
<td>Sibling had disability or chronic illness that affected study child* FROM GUI 9</td>
</tr>
<tr>
<td>*=dummy variable</td>
<td>Mother of a disabled sibling is depressed*</td>
</tr>
<tr>
<td>Variables</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Disability of child</td>
<td>ASD*, physical*, EB*, LD*, MH*, disability dum* and number of disabilities</td>
</tr>
<tr>
<td>Weight</td>
<td>BMI</td>
</tr>
<tr>
<td></td>
<td>BMI cut-offs* (bmi30+, bmi40+)</td>
</tr>
<tr>
<td></td>
<td>Think overweight*/too thin*</td>
</tr>
<tr>
<td>Education of mother</td>
<td>High*/medium*</td>
</tr>
<tr>
<td>Social class</td>
<td>ProfManag*/ OthnonmanSkilledMan*/semiUnskilledMan*</td>
</tr>
<tr>
<td>Girl*</td>
<td>Also sister of disabled sibling*</td>
</tr>
<tr>
<td>Adverse life events</td>
<td>* Plus number of adverse life events</td>
</tr>
</tbody>
</table>

* = dummy variable
## Independent variables

<table>
<thead>
<tr>
<th>Variables</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Size of family</td>
<td>Continuous and dummy</td>
</tr>
<tr>
<td>Drumcondra test results</td>
<td>Overall</td>
</tr>
<tr>
<td>friends</td>
<td>3 or more friends*</td>
</tr>
<tr>
<td>Parenting styles</td>
<td>Both score and dummy*</td>
</tr>
<tr>
<td>SDQ</td>
<td>Strengths and difficulties (the mother’s answers)</td>
</tr>
</tbody>
</table>

* = dummy variable
• 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 measurers 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.
• 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
References