

Do siblings matter too?

What it is like to be a sibling
of a child with a disability?

Jenny Peddar



What is it like to be a sibling of a child with a disability? A study involving photo-elicitation.

- This was a joint research project between the University of Portsmouth and the Family Fund.
- It was a 2 strand project
 1. the analysis of a data download of the assessments undertaken over a 2 month period by the Family Fund using the answers to the question- 'What is the impact on siblings?'
 2. A photo- elicitation study involving families who had been given a sibling grant by the Family Fund

Rationale for this research

- Professional experience
 - As an assessor there are times when the issues for siblings are pronounced.
 - Family Fund support has to be for the child with a disability – leading to times when it can appear that for children with behavioural issues you are ‘rewarding bad behaviour’. This is evident to many siblings.
- There appeared to be a research gap on issues for siblings and in particular research from the ‘Voice of the child’ rather than the views of parents or other adults.
- Given that at the start of the research project, the young carer role had a higher profile from previous research, this project aimed to focus on the wider issues of the sibling experiences.

What is photo-elicitation?

- Photo-elicitation is one of a series of visual methodologies.
- In photo-elicitation, the design was to send disposable cameras to siblings of a child with a disability for them to take pictures of what being a sibling meant to them. The cameras were returned for developing and the photos taken to an interview with the sibling.

Jenny Peddar - Young Carers conference 2017

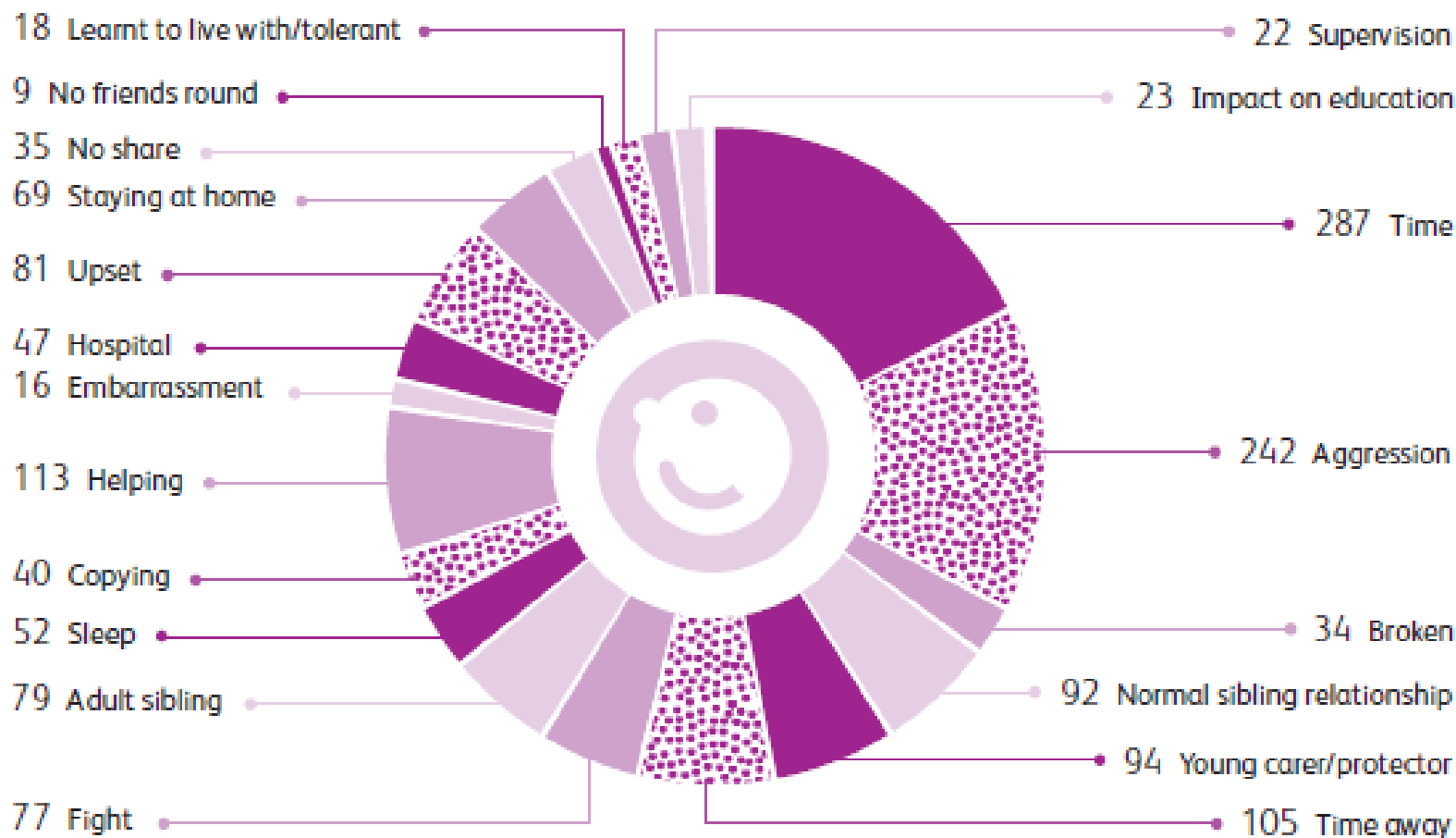
Rationale for this study

We are required as a profession to 'hear the voice of the child' but most previous studies asked the views of the parent or a professional rather than the sibling. (Taylor, Fuggle and Sharman 2001; Burton 2010)

It is known that children will hide elements in order not to worry the adults in their family. (Hames and Appleton, 2009; Stalker and Connors, 2004)

'There is a need for further research on the needs of young siblings who currently have a disabled brother or sister... From our experience it would seem that being a sibling today is harder now than it was 20 or even 10 years ago.....' (Sibs 2012)

Findings from the data download



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Photo-elicitation findings

- 10 children/young people completed this part of the study – families were invited to participate when provided with a ‘Siblings Matter Too’ grant.
- 100 photos taken – ranging from 1-18
 - Interviews focussed on
 - Why each image was chosen – what they meant to the individual
 - Were there any images they would have wanted to take but could not
 - Anything else the child felt they wanted people to know about their experiences

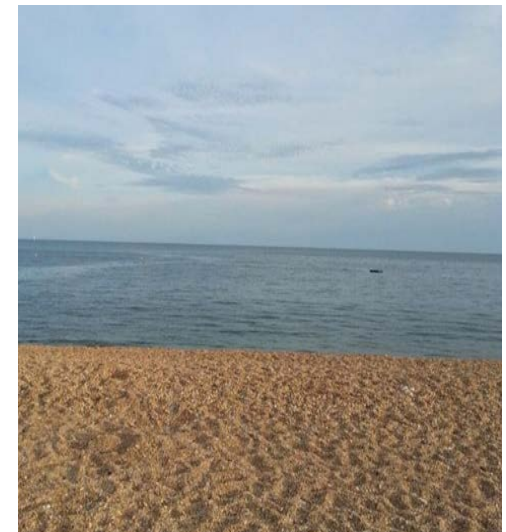
Major themes

- Helping
- Time available to the sibling
- Aggression/violence
- Impact on sleep
- Impact on education
- Restrictions to family life/staying at home
- Emotional needs/wellbeing
- Positive impacts
- Impact on adult siblings



Young Carer issues

- Data download findings
 - 9.4% mentioned specific young caring/protecting roles
 - 11.3% mentioned helping
 - 2.2% mentioned protecting role
 - Of the 79 adult siblings there was a split between those heavily involved in caring and those that had moved to avoid violent situations etc.
- Photo elicitation findings – all mentioned their caring role in some way



Helping

Summary of interview about B's birthday outing to Disney on Ice

'it (*the show*) was about an hour and a half but they put us right at the back where the bar was high and so... we weren't supposed to be there we were supposed to be at the front.. and we were supposed to have power access and power sockets and all that.... but we didn't so...

I so how much extra stuff do you need to take on a trip like that?

B you have to take all of her medicines, all of her milks, juices, syringes, stuff, button replacement, so you can put the button back in, oxygen, monitors, feed, feed pumps, push chair... loads....

B aged 16



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Adult siblings

- Issues for adult siblings mirrored those for the younger siblings but there were 2 main groupings of those involved in caring and those who missed out on family contact

When I asked how X was with his siblings, A (an adult sibling) said “Oh dear!” and got up and left the room (25)

X’s older brother moved into independence as he was struggling to cope. Carers are saddened that A no longer lives at home (635)

Mum said X’s sister and 2 brothers are very helpful, they work as a team to keep X safe (787).



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Aggression

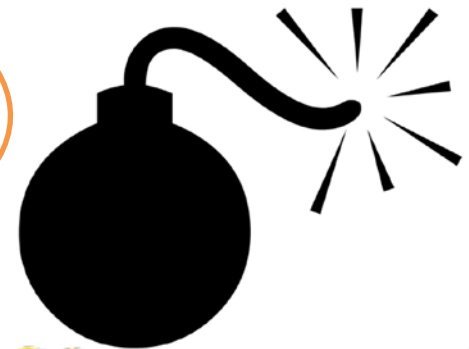


'.....well..... it was really like a safety thing really so he couldn't just come into my room and like, hurt me and stuff, so that my room didn't get like, trashed or anything...'

R aged 9

B has been thrown across the room

Sibs have to accommodate his needs as his angry outbursts can be directed at them,including attempts at strangling and stabbing with knives



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Time/impact on family life



- 'Then the ant I chose because sometimes you can feel so small'
- C aged 16

A's opportunities are limited By X's poor health and frequent hospital appointments

A aged 12 is a weekly boarder due to X's aggression and Mum being unable to provide sufficient attention



Sleep

A's sleep is disturbed at night when Mum gets up to change X's clothes and head position (509)

A tries to ignore his brother, but this can be difficult when he pees on him when he is asleep (158)



'..every time, even when he goes down to our Mum at night, in the middle of the night.....' (*he makes his bed like this*) T aged 10



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Education



A helps Mum to cope and care for X, although she had a place at University she decided not to go but instead to stay and support her mother (944)

A is very tired as her sleep is interrupted and academically she has fallen behind at school

A (6) has missed a lot of school as she has had to attend appointments with her brother



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Advantages

There were only 3 comments from the data download covering advantages

All the siblings in the photo-elicitation study mentioned positives including

- More activities as a family (some funded by the Family Fund)
- Additional maturity and understanding
- Closeness to siblings
- 'Queue jumping' at theme parks



What it feels like - 1

'stairs is like.... a never ending uphill battle..... never ending uphill battle....'

Ch aged 12



Findings

What it is like - 2



‘I play airsoft to try and release any frustration I have with my disabled siblings have most of the attention and I fade into the background, so airsoft is my way of coming forward and it gives me something to talk to my parents about this makes me feel happier...’

A aged 14

Expect the unexpected in research!!

Further photos



Contact - jenny.peddar@port.ac.uk

**Further
information**

For full report see
www.familyfund.org.uk/news/new-siblings-report



Further images taken by siblings

References

- Burton, M. (2010). Supporting adolescents who have a sibling with a life-threatening illness: An exploratory study. *Counselling and psychotherapy research*, 10(4), 316-321
- Hames, A., & Appleton, R. (2009). Living with a brother and sister with epilepsy: Siblings' experiences. *Seizure*, 18(10), 699-701.
- Sibs. (2012). The needs of siblings. Retrieved March, 3, 2012, from <http://www.sibs.org.uk/professionals/supporting-young-siblings/needs-siblings>
- Stalker, K., & Connors, C. (2004). Children's perceptions of their disabled siblings: 'She's different but it's normal for us'. *Children and Society*, 18(3), 218-230.
- Taylor, V., Fuggle, P., & Charman, T. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *Journal child psychology and psychiatry*, 42(7), 953-962.