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## A strengths-based approach to autism research with siblings

Sibling relationships are some of the most enduring connections throughout the lifespan, in most cases characterised by the familiarity that underpins the emotional intensity of these relationships. Research has tended to focus on the negative outcomes for neurotypical siblings of autistic children, focusing on stress and coping when exploring siblinghood in families.

An autism deficit focus?

The medical model is applied to autistic children and their family members from the moment they are diagnosed. Parents are introduced into the socially constructed ideology that autism is bad, abnormal and unexpected (Jaarsma & Welin, 2012). Metaphors have often been used in published material to describe autism, all which view autistic people as having deficits which require intervention:

'hidden behind walls or within fortresses; as aliens; as animals or savages; as robots or other machines; as mind-blind; or as puzzles'  
(Cascio 2015, p. 236).

Such descriptions of autism are associated with a medical view of disability which dominated disability research and policy until the middle of the 20th century, assuming there is always a conflict in family life between neurotypical and autistic family members. ([see Meltzer and Kramer, 2016](#), for how

siblinghood experiences in families raising a child with a disability are framed negatively).

Although more recent sibling studies have portrayed a more balanced picture of their experience - for example their acceptance and understanding of autism (Petalas 2012) - news, campaigns and other media output still focus on deficits and difficult family experiences.

Siblings as experts of their own experiences

The preoccupation with the behavioural or emotional outcomes of children growing up with an autistic sibling has led to other pivotal aspects of their lives, such as their experiences at home and school, being neglected in siblings' research. The purpose of this research was to explore siblinghood experiences, perspectives and needs of neurotypical and autistic brothers and sisters.

The idea and methodology design for this research was developed in consultation with communities and siblings in order to gain insights into their experiences: how everyday interactions affected siblings' wellbeing as well as the struggles they face. Siblings were co-researchers as it was felt that a co-production approach would identify more authentic sibling experiences and needs - siblings were trained and supported to carry out their data collection and analysis.

What did we learn?

The language used and narratives shared by siblings revealed how they experience concepts of disability in the community, and also highlighted how they experience disability through their sibling relationship.

The results showed the feelings, needs and thoughts of the children's experiences as siblings, friends and carers, but also as students and citizens with a passion for advocacy, albeit it with limited support in the community. Their experience is a continuation of their human experience - rather than just negative or positive influences - in their interactions with their local and wider communities.

The research highlighted opportunities for wellbeing within the sibling relationship, for example by:

- creating flexible environments to accommodate siblings' needs
- feeling defined by things siblings are able to do together and not by disability
- feeling connected to their siblings by things they share and enjoy together.

It also identified the struggles experienced by siblings:

- trying to fit to others' expectations during lunch/dinner time
- feeling different during community outings

Finally, the research uncovered the challenges related to being autistic:

- sensory needs that are not always met
- sleep difficulties that may have an impact on both neurotypical and autistic siblings.

Neurotypical siblings seemed to be a dominant force in autistic siblings' lives by helping them practise new skills, or by boosting their own confidence when teaching autistic siblings new skills.

Additionally, autistic siblings indicated that the sibling relationship provides a safe space to be themselves, to experiment and to enjoy social communication. In contrast, other relationships with peers lacked coherence or predictability and may be a source of anxiety and confusion for autistic siblings.

Most importantly, the themes capture the warmth and importance of siblinghood relationships in the lives of autistic children as well as the difficulties dealing with the expectations of the typical world.

### Educating local communities

Informed by community priorities and siblings themselves, the research looked at ways to involve neurotypical and autistic siblings in educating their local communities around disability issues - challenging communities' sense of 'normalcy' - as well as to provide a framework for future research and practice.

Through the research, siblings collaborated in order to:

- train and engage international audiences in siblings' related issues
- promote autism acceptance in local communities

- share both neurotypical and autistic peoples' experiences of siblinghood and opportunities for wellbeing.

Neurotypical siblings led multimedia presentations of their experiences, needs and priorities for a week at their local community centre. Local schools, policy makers and healthcare professionals attended.

The research project collaborated with parents in order to empower autistic children and their families to take social action in ways they felt comfortable with, in order to inform their local community - for example exhibitions and talks in local cafes and family cooking workshops.

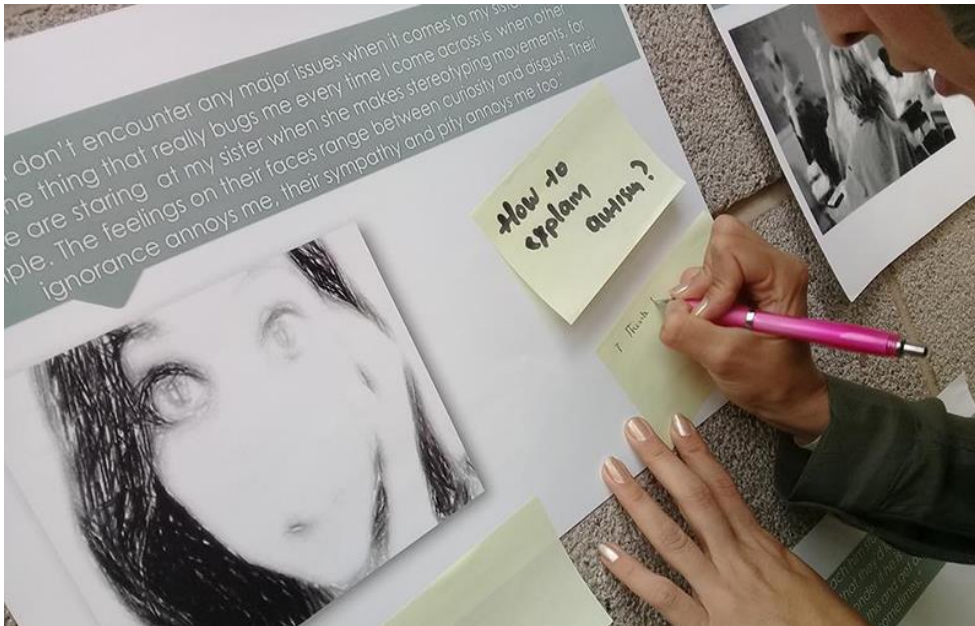
This way, siblings, rather than being viewed as passively influenced by society, were seen as agents of their own wider environment, by contributing to cultural attitudes towards disability.

#### Benefits of siblings' involvement

People with supportive family and good social experiences and relationships generally have better mental and physical health than those who lack these networks. The same is true for autistic and neurotypical siblings growing up together. The way siblings interact, think and feel about each other extends across the lifespan and across a range of social relationships.

It is only by analysing autistic and neurotypical siblings' lives over time within a structural, social and cultural context that we can establish the ways siblings' relationships may contribute to better mental health and increased wellbeing for both autistic and neurotypical siblings.

Understanding well-being as experienced by autistic individuals and their family members allows for a whole new endeavour: that of promoting wellbeing which in turn builds on the work of the positive psychology movement (Csikszentmihalyi 2004).



We still know very little about the way(s) family members try to accommodate the disability-specific needs of the family's disabled child. Siblings of autistic people may use the knowledge they have learnt at home from their brother and sister to promote inclusion or challenge ideas of what is 'normal' in society and build local capacity in their communities.

The co-production method used in Dr Pavlopoulou's study co-generated research findings with family members and engaged local communities. This is crucial in shifting the balance between vulnerability and resilience in families raising an autistic child. Furthermore, when knowledge about the lived experience is drawn directly from the perspective of the actual people (siblings) involved in the research (siblinghood and autism), a more appropriate, responsive and need-fulfilling strategy of supportive and proactive interventions can be initiated in areas such as sleep and sensory management.

“What is autism for me...?  
For me, autism is an integral part of my life. I grew up with autism and that's probably why I don't consider it as a problem in my life... And by the way I don't live with autism, I live with my sister”



### Further information

In the coming months we will be publishing more siblings research results from the authors:

- sibs' school experiences
- sisters' experiences of caretaking
- sibs' sleep difficulties

To find out more about how Dr Pavlopoulou can support you to run a siblings' event in your local community/charity or school email at:  
[georgia.pavlopoulou@ucl.ac.uk](mailto:georgia.pavlopoulou@ucl.ac.uk)

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