

What Impact can a School Have on Siblings of Children with SEND and why is this Important?

Family systems theory identifies the importance of considering the family as a whole rather than focussing on an individual – something which affects one member will affect the rest of the family (Cox and Paley 1997). Families are made up of a number of interconnected 'sub systems' including the sibling subsystem (Langley et al 2021), which Cicerelli (1994) noted are likely to be the longest lasting of all family relationships. Sibling relationship change over time, with adolescence often a time when young people report there is least satisfaction with the sibling relationship and peer relationships are seen as more important (Orsmond et al 2009).

Raising a child with a disability affects all members in the family subsystems (Lovell and Wetherell 2016) as well as impacting the functioning of the family as a whole. Research concerning the effect on children of having a sibling with complex needs or disability has identified mixed results (Havill et al 2019) with some researchers suggesting an elevated risk of adjustment problems and worse outcomes than those seen in children who do not have siblings with complex needs or disabilities, while others found that having a sibling with complex needs / disability makes a positive contribution to a child's development (Rum et al 2022, Conway & Meyer 2008, Emerson & Giallo 2014, Jones et al 2019).

Siblings of children with a disability cannot be seen as a homogenous group (Woodgate et al 2016). The challenges faced by siblings of children with complex needs or disabilities may be different to those faced by children of siblings with an intellectual disability such as autism, who are not physically impacted by their disability. Given that the parents may need to spend more time with their child with the disability, they may have less time and attention available for the other children in the family (Curran et al 2001). Severity and type of need can also affect the way that siblings interact with each other. Families of children with complex care needs often need to tailor their activities to take into account their needs () which can limit the opportunities for the rest of the family. Murphy et al (2021) noted the benefits afforded by respite care for children with complex needs and disabilities in allowing their siblings to spend quality one to one time with their parents. Luijckx et al (2016) identified that children who have a sibling with complex needs may be negatively impacted in several ways including reduced academic achievement, careers and ongoing feelings of guilt which can lead to feelings of exclusion or isolation, and these may have long term negative effects. However, for many children their sibling relationship is a priority, and they feel that they have a particular role in their brother's or sister's life which makes them feel special. Prchal and Lando (2012) Found that spending time with their peers talking about the challenges help children to deal with life. Roberts et al (2015) also discussed the importance of children sharing experiences with fellow siblings of children who have a disability in helping children to understand and accept their siblings' needs.

Needs of children who attend special schools will typically be more significant than those with additional needs who are able to attend mainstream schools with additional support the and the support needs of siblings may also be different. There is a dearth of literature which considers how special schools can support siblings of

their pupils and help to identify their importance in the life of a child with additional needs and build their relationships. Willow Dene is an outstanding (Ofsted 2022) 2 to 19 special school in Plumstead SE London. It is part of the Compass Partnership of schools. The school is on two sites which are in proximity and caters for 292 children with complex needs and autism.

Each academic year school core priorities are set for the year and form the basis for our school development plan. Set for the academic year 2022/23, one of these was to extend links with the community and encourage growing relationships, participation and involvement with a particular focus on siblings. The school takes a whole family approach to its work and has a number of measures in place to support families beyond the child's educational needs. The addition of siblings into a core priority was in response to Willow Dene parents' reports that siblings of children with additional needs often take on greater caring roles (Rum et al 2022) which can make them more empathetic towards and concerned about their sibling. Parents also reported the anxiety felt by their child concerning what school looks like for their sibling with SEND and if they were safe. Some children however, expressed that they found having a sibling with SEN embarrassing due to the potential perceptions of their friends in mainstream school, which research suggests is more prevalent in siblings of children with ASD than complex needs (Roeyers and Mycke 1995). Research by Sibs has identified that siblings of children with additional needs reported a lack of understanding from their mainstream school of the impact of having a brother or sister with SEN/D (Kassa and Pavolopoulou 2024).

The core priority aimed to:

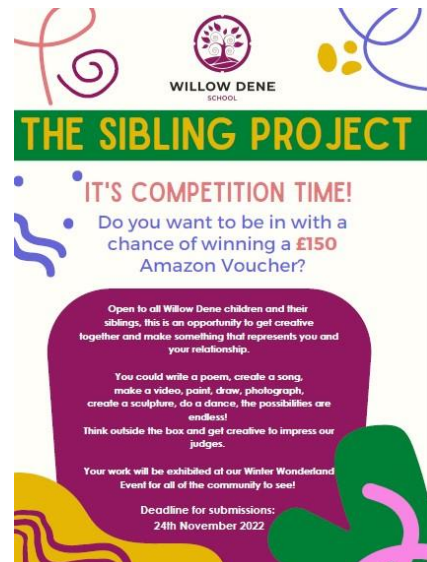
- build relationships between Willow Dene and siblings of the children who attend the school.
- celebrating sibling relationships in the home.
- encourage a network of peer-to-peer support.

Each core priority is led by members of the senior leadership team, in this case a deputy head teacher and an assistant head teacher. Events were planned throughout the academic year to focus on the siblings of children at the school and the development of their relationships as well as to support the needs of the siblings and the possible development of relationships between siblings of children in the school, and this report will consider some of these.

Projects & Competitions

The school's work with siblings began in Autumn 2022, with the launch of a competition, 'The Sibling Project'. It was considered this was a good way for children from Willow Dene to engage in a creative process with their sibling to work towards an end product.

It was decided to leave the brief for the project relatively open, asking children and their siblings to create something that was representative of them and their relationship or something they like to do together. Suggestions of the mediums in which this could be presented such as visual art, poetry, photography, a dance, a song etc were given, and a brief description of the work and what it represented was requested within a submission form. The competition was shared with children and their siblings via a flyer home and a launch video. Advertisement of the project also took place via Willow Dene's social media, school newsletters, emails, and text messages to parents, as well as via class teachers in their daily communications with families which helped to ensure that all families had the information and opportunities to take part.



The deadline for submissions coincided with the week of a whole school event. It was planned that there would be an exhibition of submissions on display, for children, staff, families, and local communities to view. The submissions were varied in medium, with several digital submissions of dances, and montages of videos and photographs, artwork, poetry, painted jumpers, photography and more. All the entries created an impactful exhibition which was enjoyed by all who attended the event. The competition was judged by the Chair of Governors, who had a challenging job to decide and announce the winner. The winning entry was presented with a voucher, kindly donated by a local business. The winning submission was a multi-medium piece consisting of two painted school jumpers and a video montage of photos and videos of how the pieces were created.



In the Spring term, it was decided to continue to create opportunities for the children and their siblings to work towards something together. The idea of 'Super Sibling Selfie Competition' was born. It was hoped that this would encourage more families to get involved, as it was as simple as snapping a selfie and sending to the school via email. This aimed to bring siblings together whilst focusing on identity, togetherness and a sense of

belonging. This was advertised once again with a flyer, through school social media channels and through schools-based newsletters. There were once again great prizes on offer, including an instant Kodak camera.

Following a similar format to the Autumn project, a deadline was set to coincide with a whole school and community Spring event. This allowed the creation of an

exhibition of the submissions to be enjoyed by visitors to the event. There was a variety of submissions from across the school, from EYFS to Key Stage 4.

Work from both competitions were kept, forming a more permanent exhibition within the school reception area, demonstrating commitment to the children and their siblings and allowing the work to be seen by a wider number of people, raising the profile of the work across the school and community.

Sibling Activity Events

In the Spring term, teenage siblings were invited to come together for an evening of wellbeing-based activities, which were considered to be a good opportunity for children and young people to meet others of a similar age, who also had siblings with SEND who attend the school, allowing development of a supportive network (Jones et al 2019). The event was once again advertised via a flyer, social media channels and the school newsletter, as well as follow up calls from a member of the admin team to encourage participation.

The evening consisted of a choice of activities which included cooking, an art-based activity using clay, a manicure, foot massage and hair styling. Siblings were able to choose between the activities, as well as have time to chat to other siblings and staff at the school. Refreshments were provided and an opportunity for children to tour the school site and see their sibling's school was offered.

The evening was run by staff within Willow Dene, who had a specialist skill set which they were keen to share. Some parents stayed with the children and others attended alone. One sibling attended with her brother who attends Willow Dene. Following the evening, a feedback form was sent out to gather views from the siblings who attended and to gauge interest for further events. Feedback forms were returned and used to create ideas for the next teenage siblings' event.

In the Summer term, a further sibling evening was organised. This event was an evening, with a focus on a fitness activity and an opportunity to swim in the school pool. These activities were then followed by a movie night and pizzas which took place in the summer term. This was attended by nine siblings. Feedback from the event was sought from the attendees and this was used in the planning of future events.

"I love spending time with different teenagers and they understand what it is like to have an autistic sibling. Very cool." J – Age 14



Sibling Communication and Website

One of the main challenges around the sibling focus has been how to communicate directly with siblings and find ways to engage them, without the need to go through parents. One of the initiatives has been to design an area on the school website, specifically for siblings. This area of the website contains useful links to charities and support networks, an area to find out about upcoming events and projects within school for siblings, as well as an area to ask questions directly to the school. There is also a gallery, in which photographs from events are shared with permission from the siblings and families. The hope is that this will become a space in which siblings visit regularly. During the sibling events, members of staff shared the website details with attendees, and this was also advertised within the school newsletter for parents to pass on to siblings. Our bi-weekly school newsletter also features a sibling section.

Engaging the wider school community

To ensure that engagement was high across the school community, every class team had the opportunity to participate in sibling focused projects, through Team Development Plans. These were designed as a mechanism for all members of class teams to actively engage with school core priorities. Teachers and class teams thought creatively about how they could research, engage with and plan events for the siblings of children within their classrooms. The impact of this meant that staff were more aware of the demographic of siblings within their class community, they were able to build positive relationships with those siblings who engaged and open up conversations about what school looks like for their sibling with SEND.

Scope for extending and ongoing impact

The school recognises that work with siblings is vital and there is still opportunity for development. The leadership team has therefore extended this as a school core priority for the academic year 23/24. The two key members of the leadership team leading in this area have accessed and made links with local and national charities, through attending conferences and training. The school has continued to offer opportunities for sibling engagement through offsite activities this term, as well as opportunities for siblings to work with their brother or sister with SEND, through further projects and competitions. The leaders continue to gain feedback from the siblings which support future planning. To date studies related to siblings of children with additional needs have shown a wide variation in outcomes (Emmerson and Giallo 2014, Kovshoff et al 2017) and there is a dearth of studies evaluating support work (Roberts et al 2015). Thus, it is hoped that work undertaken at Willow Dene can feed into the evidence base.

Whilst work continues to be in place, the school has begun to focus on other demographics of siblings, such as adult siblings, and those who have moved away for further education. This is an iterative process, and whilst the school will continue to maintain their regular events, projects, and competitions which the sibling community have grown to embrace and enjoy, they are also keen to branch out and develop new opportunities for a wider demographic of siblings as well as developing staff knowledge in the area.

Although there is clearly a need for special schools to support the siblings of their children to develop and celebrate their relationships, Sibs identified that the needs of siblings of children with SEND also needs to be considered in the mainstream education settings that they attend (Kassa and Pavlopolou 2024) to reduce the negative impacts and improve the understanding of teachers and peers. As part of a partnership of schools that includes 12 mainstream schools, Willow Dene is well placed to emphasise this and support colleagues in mainstream schools.

School governors receive regular feedback regarding the progress of all the school core priorities. Parent governors reported that their own children had joined the sibling activities, and the Chair of Governors has a particular interest in the impacts of having a sibling with additional health care or educational needs through her own professional work. This support has further encouraged and supported the school's work.

There has been a significant amount of research related to the experiences and needs of siblings of children with complex needs and disabilities. What has not been considered in the literature is how special schools can support the brothers and sisters of their pupils and support the development of positive relationships.

This article has presented work undertaken with siblings at Willow Dene School. Senior staff leading the core priority have not only developed the offer for siblings, but have also enhanced their own knowledge, skills and understanding of working with the siblings of children with SEND. This has been a significant piece of work which has received very positive feedback from pupils at the school, siblings, and their wider families as well as others involved with the school such as governors and a national charity who focus their work on siblings. Moving forward the aim is to continue to expand and share the work done so far with interested parties.

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References

Cicirelli, V. G. (1994). The longest bond: The sibling life cycle. In L. L'Abate (Ed.), *Handbook of developmental family psychology and psychopathology* (pp. 44–59)

Conway S, Meyer D. (2008) Developing support for siblings of young people with disabilities. *Support for Learning* 23(3) 113-117

Cox MJ, Paley B. (1997) Families as systems. *Annu Rev Psychol.*48:243-67.

[https://doi: 10.1146/annurev.psych.48.1.243](https://doi.org/10.1146/annurev.psych.48.1.243)

Curran A L, Sharples P M, White C, Knapp M (2001) Time costs of caring for children with severe disabilities compared with caring for children without disabilities. *Developmental Disabilities and Child Neurology* 43 529-533

Emerson E, Giallo R. (2014) The wellbeing of siblings of children with disabilities. *Res Dev Disabil.* 35(9):2085-92. doi: 10.1016/j.ridd.2014.05.001.

Havill N, Fleming L K, Knafel K. (2019) Well siblings of children with chronic illness: A synthesis research study. *Res Nurs Health* 42: 334-348

Jones, E.A., Fiani, T., Stewart, J.L. et al. (2019) When One Sibling has Autism: Adjustment and Sibling Relationship. *J Child Fam Stud* **28**, 1272–1282. <https://doi.org/10.1007/s10826-019-01374-z>

Kassa C, Pavlopoulou G. (2024) 'If only you knew' The school experiences of siblings of disabled children. Available <https://www.sibs.org.uk/supporting-young-siblings/ifonly/> Last accessed 24.5.24

Kovshoff H, Cebula K, Tsai HJ, Hastings RP. (2017) Siblings of Children with Autism: the Siblings Embedded Systems Framework. *Curr Dev Disord Rep.* 2017;4(2):37-45. doi: 10.1007/s40474-017-0110-5

Langley E, Totsika V, Hastings R P, Bailey T; Family Relationships and Their Associations with Perceptions of Family Functioning in Mothers of Children with Intellectual Disability. *Am J Intellect Dev Disabil* 1 May 2021; 126 (3): 187–202. doi: <https://doi.org/10.1352/1944-7558-126.3.187>

Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*, 49-50, 226–234. <https://doi.org/10.1016/j.ridd.2015.11.023>

Luijckx J, van der Putten A J, Vlaskamp C. (2016) 'I love my sister, but sometimes I don't': A qualitative study into the experiences of a siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual and Developmental Disability* 41:4 279-288 <https://doi.org/10.2109/13668250.2016.1224333>

Murphy M, Hill K, Begley T, Brenner M, Doyle C. (2021) Respite Care for Children with Complex Care Needs: A Literature Review. *Compr Child Adolesc Nurs.* 23:1-10. doi: 10.1080/24694193.2021.1885523

Orsmond G, Kuo H-Y, Seltzer MM, (2009) Siblings of individuals with an autism spectrum disorder *Autism* 13(1) 59-80

OFSTED (2022) Inspection of Willow Dene School. Available <https://files.ofsted.gov.uk/v1/file/50202233> Last access 24.5.24

Prchal A, Landolt MA. (2012) How siblings of pediatric cancer patients experience the first time after diagnosis: a qualitative study. *Cancer Nurs.* 35(2):133-40. doi: 10.1097/NCC.0b013e31821e0c59. PMID: 21760484.

Roberts R M, Ejova A, Giallo R, Strohm K, Lillie M, Fuss B, (2015) A controlled trial of the SibworkS group program for siblings of children with special needs, *Research in Developmental Disabilities*, Volumes 43–44, 21-31, doi.org/10.1016/j.ridd.2015.06.00

Roeyers, H., & Mycke, K. (1995). Siblings of a child with autism, with mental retardation and with a normal development. *Child: Care, Health and Development*, 21 (5), 305–319. <https://doi.org/10.1111/j.1365-2214.1995.tb00760.x>

Rum Y, Genzer S, Markovitch N, Jenkins J, Perry A, Knafo-Noam A. (2022) Are there positive effects of having a sibling with special needs? Empathy and prosociality of twins of children with non-typical development. *Child Development* 93(4) 1121-1128

Woodgate R L, Edwards M, Ripat J D, Rempel G, Johnson S F.(2016) Siblings of children with complex care needs: their perspectives and experiences of participating in everyday life. *Child: Care, Health and Development* 42(4) 504-512