



Exploring the views and perspectives of siblings of autistic students in residential school

Executive Summary

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Background

Family research in the autism field often focuses on the autistic child and their parents. Few studies consider sibling perspectives to explore the unique implications that having an autistic sibling might have on the non-autistic child (McHale, Updegraff & Whiteman, 2012). Even fewer studies consider the siblings of children in residential special schools, yet these children are keen to have their voices heard (Naylor & Prescott, 2004). Within these sibling dyads, the non-autistic child often assumes roles of responsibility, protection and nurturing towards their autistic sibling (Knott, Lewis & Williams, 1995; Stoneman, 2001). A greater understanding of their sibling's behaviours positively correlates with the quality of relationship between them (Roeyers & Mycke, 1995). However, the opportunity to build and maintain this relationship may be disrupted if the autistic child requires educational and medical provision which can only be optimally accessed within a residential school, and little is known about how siblings experience and navigate this relationship when their sibling lives away from home. Consequently, this research project aimed to broaden existing knowledge by collating data on siblings' views and experiences of having an autistic sibling in residential provision, as well as exploring the ways in which the residential special school can provide support and inclusive events for siblings.

Research Questions

1. What are siblings' experiences before and during the residential placement of their autistic sibling?
2. In what ways would siblings like to be supported by, and involved with, the residential school?

Method

Nine participants aged 9-19 years (3 male, 6 female) were recruited as siblings of autistic students at a residential special school in the south of England. The three male participants had a sister aged 16-18 at the school; five of the female participants had a brother aged 13-18, and one female participant had a 15-year-old sister at the school.

Data were collected via a structured series of questions, deployed flexibly depending on preference: via online questionnaires, postal questionnaires and in-person interviews. Four participants responded via post, four via interview and one via the online survey. The questions were proposed by staff at the school and comprised a short demographic section, followed by a mix of open and closed questions about participants' experiences of having their sibling at home, experiences since their siblings' residential placement, and types of activities and support they would be interested in at the school. This research was reviewed and approved by the Faculty of Social Sciences Research Ethics Committee (Ref # 47934.A1).

Key Findings

Thematic analysis was conducted to identify, compare and summarise responses. Overall the findings showed:

- the **strong emotional bond continued between siblings** as well as their immediate family members; even after the autistic sibling had moved into residential placement, there was still much love, care and desire for closeness reported by siblings and they often missed their sibling and felt lonely without them;
- the siblings who remained at home continued to hold a **sense of responsibility** in making sure their autistic sibling was happy, safe and still reminded of how valued they are in their family;
- positive impacts of residential placement on the sibling at home included **greater parental attention**;
- participants reported having **more free time** for themselves and their parents due to not needing to constantly watch their autistic sibling once they started residential placement and, in some cases, freedom from **disruptive behaviours** which could be distressing for all family members.;
- due to residential school placement, the **needs of the child remaining at home could be better prioritised** by parents without concern over how this may cause distress and reduced attention for their autistic sibling;
- **distance from the home** and consequent **lack of opportunity to spend time together** were identified as challenging by many siblings. However, the distance created between family members was considered by the siblings as a necessary sacrifice, enabling a better quality of life for the autistic child within residential provision;
- indeed, siblings noted how much **happier their brother or sister was** since starting at the school and felt that they were receiving much better support and teaching;
- siblings often expressed **interest in receiving more information** from the school about autism in general, and about their siblings' educational and recreational activities;
- many siblings were also interested in **attending family events** at the school and **sharing experiences with other siblings**.

Conclusions

Participants' were clear about the positive impacts of residential placement for their siblings and themselves, and these positive feelings outweighed a sense of loneliness due to the distance between family members. There was a desire for greater support and education for siblings of autistic children in residential special schools (Arnold, Heller & Kramer, 2012). Schools could implement sibling specific support, information and on-site events to support siblings to work through any potential worries or concerns, improve their sense of value within the school community and maintain strong bonds with their brother or sister (Li & Ping, 2006). The methodology of this study could be replicated by other residential special schools to better understand the experiences and optimal provision for siblings of students attending that particular setting.

References

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