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Editorial: Understanding sibling relationships in developmental disabilities. K. Cebula^a & H. Kovshoff^b

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Much of the work published in Research in Developmental Disabilities focuses on individuals with developmental disabilities themselves – those whose life-course differs from 'typical pathways' in diverse and numerous ways. Often overlooked is that this diversity of developmental experience exists within the even more diverse context of 'families'. In particular, relationships between siblings play a unique and powerful role in the lives of children and adults, offering reciprocal opportunities for learning, as well as challenges, joy and support throughout the lifespan.

Accordingly, there is a long history of sibling research in developmental disabilities; though often the focus of this has been on understanding the 'impact' (both positive and negative) of the child with the disability on the 'neurotypical' sibling. Understanding the experiences and support needs of neurotypical siblings within the family, and how these change over time, is valuable. However, family systems frameworks (e.g. Cridland, Jones, Magee & Caputi, 2014) remind us that no single member of the family shapes the system in isolation; each influences the others in dynamic and bidirectional ways. Further, all family members, including children and young people with disabilities and their siblings, are influenced by the wider cultural and societal systems in which they are raised. Using these family systems frameworks, researchers have contributed to a dynamic and productive research discipline. Nevertheless, there have been a number of calls for theoretical and methodological advancements to this field (e.g. Kovshoff, Cebula, Tsai & Hastings, 2017; McHale, Updegraff & Feinberg, 2016; Stoneman, 2005). In particular, there is a need for theoretically-driven research that seeks to capture and account for interaction between variables; greater diversity in study participants; the use of population-wide data to better understand the factors that impact on sibling relationships; and greater involvement of individuals with developmental disabilities themselves.

The need to better understand sibling relationships in developmental disabilities in a systemic context led to the conceptualisation of this special issue. We aimed to collate manuscripts that reflect the current state of the art research in this field, and which consider the experiences and interactions of siblings in childhood and adulthood. Crucially, we invited submissions designed to further our understanding of sibling *relationships* — which makes explicit our position that both siblings - with and without developmental disabilities — are participants in this relationship, and there is a need to understand the perspectives of both parties.

This special issue is made up of nine original research papers that responded to the call for manuscripts which advance our knowledge of sibling relationships through a focus on innovative methods, novel research contexts, and participant groups not previously included in research. In so doing, we hoped to further understanding of how sibling relationships can be supported and valued across the lifespan. Collectively, the papers draw on data representing around 46,000 individuals with developmental disabilities and their siblings, from six different countries, and cover four broad areas of sibling research.

The first of these research topics includes a paper which reports data on the perspectives of individuals with developmental disabilities, something which has often been neglected in sibling research, despite the evident value in considering both parties in the relationship. Rossetti, Lee, Burke and Hall (2019) explored the views of autistic adults and adults with Down syndrome on their sibling relationship, with findings highlighting the importance of considering reciprocity in the relationship, something which has implications for not only support of sibling relationships, but also for approaches to research.

The second group of papers responds to the need to explore a wider range of outcomes and a broader group of siblings than has been considered to date. Shrivers (2019) explored the possible impact of growing up with a child with developmental disabilities on siblings' empathy and understanding of others. She found significantly higher levels of perspectivetaking amongst siblings of autistic children, compared to siblings of typically developing children, with perspective-taking significantly associated with greater positive feelings towards siblings. This leads the way towards exploring how interactions within the family might contribute to such outcomes. Gregory, Hastings, and Kovshoff (2019) examined school-related outcomes, a context which has often been omitted from research in sibling groups. They reported poorer academic self-concept and sense of school belonging amongst siblings of autistic children compared to siblings of neurotypical children, highlighting the importance of schools considering whether they can take steps to ensure that children with developmental disabilities and their siblings feel valued members of the school community. Finally, Cebula, Gillooly, Coulthard, Riby, and Hastings (2019) conducted the first study to explore psychosocial adjustment of neurotypical siblings of children with Williams syndrome, finding that behavioural and emotional adjustment was similar to population norms, but importantly that siblings themselves reported somewhat greater difficulties than caregivers perceived them to have. Indeed, all three of these papers highlight the importance of including the perspectives of siblings via self-report, rather than relying solely on the views of parents/carers.

The third group of papers use systematic review or 'big data' to respond to the concern that it may be difficult to draw firm conclusions about sibling experiences or influential demographic or social factors solely through single studies or small datasets. Using systematic review, Leedham, Thompson & Freeth (2019) synthesised qualitative research on the lived experiences of siblings of autistic individuals and report a broad range of experiences, including feelings of being 'unseen' by professionals, a theme which was present across several of the papers in this issue. Marquis, McGrail, and Hayes (2019) use administrative health data to explore variables associated with the mental health of siblings of children with a developmental disability. They found that the odds of a diagnosis of mental health problems in siblings was associated with the specific developmental disability, as well as family income. Such larger-scale studies have the potential to develop our understanding of the role of macro-system factors in sibling outcomes. They also highlight that 'support' for siblings should also focus on addressing the societal inequalities which have been shown to be associated with sibling outcomes, rather than narrowly directing resources only to sibling group support programmes.

The final group of papers developed new methodological approaches or implemented methods less commonly used in this field to develop a more comprehensive understanding of sibling interactions and experiences. O'Brien, Cuskelly, and Slaughter (2019) developed a new questionnaire to measure parents' perceptions of play interactions between autistic children and their siblings. They found that autistic children in some families displayed more positive interactions during play with younger siblings than with older siblings or parents. The development of such measures is an important addition to the literature on play observations, with great potential for future developments, such as child self-report versions. Zaidman-Zait, Yechezkiely, and Regevb's (2019) paper includes an exploration of the extent to which children's drawings are a useful additional tool through which to understand sibling relationships. They reported that indicators of supportive relationships were present to a significantly greater degree in the drawings of siblings of children with intellectual disabilities compared to the drawings of control group siblings. Potential future directions

were also considered, such as the greater involvement of the children themselves in the interpretation of their drawings. Finally, Pavlopoulou and Dimitriou (2019) used a community-based participatory research approach, involving a modified Photovoice methodology, to allow adolescent siblings of autistic children to explore and share their experiences. The sisters identified key messages, including the need for greater opportunities for their autistic siblings in their local communities, and they also designed Photovoice exhibitions to share these messages with their communities. This method emphasises that siblings are not simply passively influenced by macro-system factors, but can contribute to shaping their own environments, for example by influencing the development of more positive cultural attitudes towards disability (for example, see the Sibling Leadership Network¹).

Collectively, the papers included in this special issue are reflective of the ways in which the field is building on classic sibling research, by continuing to ask new questions and develop insightful methods. In particular, there is welcome attention to the views of the individual with developmental disabilities, the more active research participation of the sibling, and a more nuanced approach to understanding sibling experiences, beyond simply 'positive' and 'negative' outcomes. These papers also enable us to reflect on the journey that the sibling research field is on, and we are excited about the potential for further development in the future, particularly in terms of longitudinal research, increased cultural and socio-economic diversity of participants, and the greater inclusion of individuals with developmental disabilities themselves, both as participants and as co-researchers (for a more thorough exploration of this latter point, see Meltzer & Kramer, 2016). Capturing the experiences and views of non-verbal individuals and those with more severe intellectual disabilities is particularly important if we are to develop ways to support all sibling relationships, and the onus is on us as researchers to develop new methodologies to achieve these aims.

Consistently, the papers included in this special issue raise the potential for future study, and point the way to a range of important questions yet to be fully explored within sibling research. Some of these questions have a very practical focus and aim to understand how our schools and communities can better create a feeling of belonging for individuals with developmental disabilities and their siblings. They also highlight the need for the development of concrete plans to help ensure that participatory sibling research leads to sustained change within communities. Other questions focus on methodological advances, including the further development of assessments of sibling interaction and perspective-taking. A third issue raised by the papers, albeit more indirectly, calls on the academic community to reflect on the extent to which current sibling theories enable high-quality research which will ultimately lead to positive outcomes in terms of sibling relationship support. While there are a number of theories and models drawn upon in the papers included in this issue, there is a continued need for reflection and further development as required. Ouestions in all three areas are, of course, intertwined.

As with all peer reviewed pieces of work, this has been a labour of love and we would be remiss to not extend our gratitude to all those who contributed to the end product. All of the manuscripts included in this special issue were evaluated by at least two reviewers, and we would like to thank these numerous individuals, not only for their rigorous reviews, but also for their enthusiastic support of this special issue. We would also like to thank the RIDD editorial team for the assistance they provided. Our thanks are also extended to Sibs, the UK charity for brothers and sisters of disabled children and adults, who will host summaries of the included articles on their website². Finally, we would like to thank the authors for their

contributions. Collectively the articles provide evidence of a thoughtful, exciting and dynamic field - one which we hope will inspire researchers to conduct family studies, focusing on sibling *relationships* in particular, in the future.

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¹ https://siblingleadership.org/

² https://www.sibs.org.uk/

³ Articles submitted to the special issue by the co-editors or by the editor-in-chief were handled by a different editor and submitted to the peer-review process.